WELCOME TO THE IHSS TRAINING ACADEMY CAC

The IHSS Training Academy provides courses that are designed to enhance the participant's skills in completing individual assessments and authorization of IHSS services.

This three-day training has been designed specifically for IHSS staff that have been newly hired, have limited IHSS experience, or require a refresher course. This course utilizes lecture, discussion, group, and individual activities to deliver course content.

Topics will include:

- Interview Challenges
    - Communication techniques
    - Blind/ Visually Impaired
    - Deaf and hard or hearing
    - Grief and loss
- Cultural Implications
- Supporting IHSS Providers
- Paramedical Services
- IHSS and Minors
    - Minor eligibility
    - Age Appropriate Guidelines
- Mental Disorders
- Protective Supervision
    - Adult
    - Minors
    - Removing PS

Objectives:

By the end of this training, participants will be able to:

1. Define uniformity in the IHSS program and how it can be accomplished utilizing Functional Index Ranking, IHSS regulations, Annotated Assessment Criteria, Hourly Task Guidelines, and individualized assessments.
2. Identify IHSS program rules that direct assessment and authorization of services.
3. Describe successful best practice techniques for interviewing and communicating with consumers, families, and IHSS providers in order to obtain an accurate individualized assessment.

4. Explain the importance of awareness and sensitivity to various cultures and how it impacts the assessment process.
5. Explain the importance of documentation in creating a clear picture of a consumer's needs and in substantiation of the authorization process, including exceptions.
6. Demonstrate the process of authorization of service hours using the Hourly Task Guidelines, including an ability to identify appropriate exceptions.
7. Have an understanding of the programs that interact with IHSS and how these programs affect the authorization of services.
8. Describe common mental illnesses and key things to consider when working with consumers with mental illness.
9. Identify protective supervision regulations and eligibility criteria for adults and minors.
10. Identify factors that affect the calculations of protective supervision hours.
11. Describe the process of authorizing paramedical services including the application of regulations, the social worker's role in completion of the SOC 321, and how to address issues that arise in authorizing services.
12. Accurately apply regulations that affect minor's eligibility for IHSS.
13. Identify how Age Appropriate Guidelines are used as a guideline to delineate between normal parental responsibilities and needs which exceed those responsibilities.
14. Define extraordinary need and how it affects the authorization of services for minors.

WELCOME TO THE IHSS TRAINING ACADEMY CAC

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Back Pocket

AGENDA CAC

DAY 1

Time	Topic	Notes
8:00 – 8:30	**Sign in**	• Continental breakfast & Networking
8:30 – 9:00	**Welcome/Introductions**	• Welcome & Housekeeping • Introductions • Pre-Evaluations
9:00 – 10:00	**IHSS 101 Review**	• Process flow • Apply it with Jason (30 min)
10:00 – 10:15	**Break**	**15 minutes**
10:15 – 11:30	**Interviewing Challenges**	• Interviewing Skills • Complex types of interviews
11:30 – 12:30	**Lunch**	**60 minutes**
12:30-1:30	**Interviewing Activity**	• Utilize scenarios with different challenges
1:30 – 2:10	**Cultural Implications**	• Activity using the *Culture and Clinical Care* book • Using an interpreter
2:10 – 2:25	**Break**	**15 minutes**
2:25 – 2:45	**Supporting IHSS Providers**	• Caregiver/provider issues and references • Provider modes • Provider orientation
2:45 – 3:15	**Paramedical**	• Review of regulations • Things to consider • Working with the MD
3:15 – 4:15	**Emily**	• Interview strategies for Emily
4:15 – 4:30	**Wrap-up**	

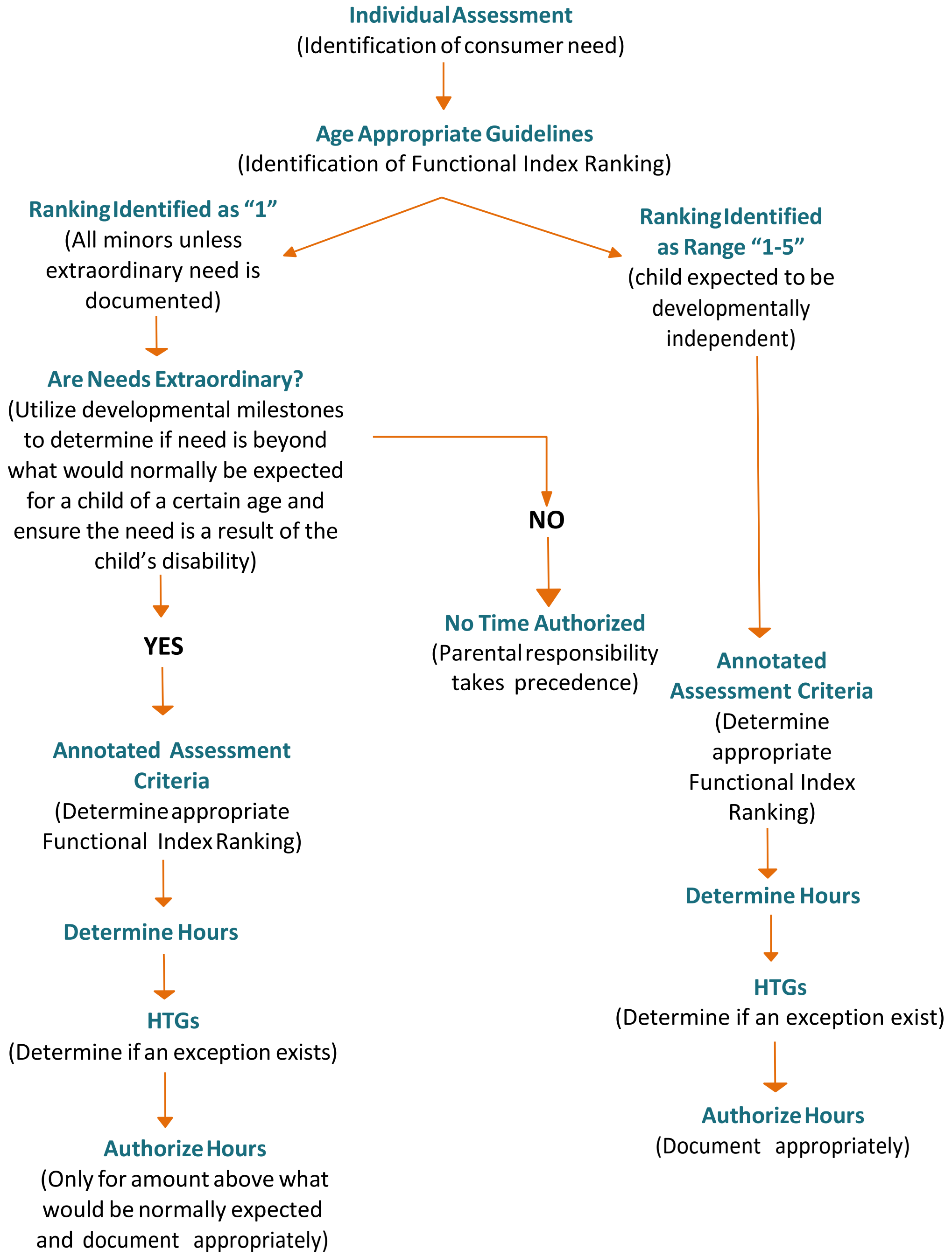
DAY 2

Time	Topic	Notes
8:00 – 8:30	**Sign in**	• Continental breakfast & Networking
8:30 – 9:00	**Welcome/Overview of Day 2**	• Learning objectives • Activity – Making a Difference
9:00 – 9:15	**Working with Minor Consumers**	• Activity
9:15 – 9:30	**Video - Autism**	• Autism Speaks video – context for the morning content
9:30 – 10:30	**Minor Eligibility - Determining Program Eligibility**	• Eligibility process • Things to consider • Regulations and policy clarification • Documentation
10:30 – 10:45	**Break**	**15 minutes**
10:45 – 11:45	**Age Appropriate Guidelines**	• Using the AAG tool • Extraordinary need
11:45 – 1:00	**Lunch**	**75 minutes**
1:00 – 1:15	**Working with Consumers with Mental Disorders**	• Activity
1:15 – 2:15	**Mental Disorder Diagnosis Information**	• Distinguishing characteristics
2:15 – 2:30	**Break**	**15 minutes**
2:30 pm	**Mental Disorder Teach back**	• Activity – teach back and report out • Scenarios – Borderline Personality, OCD, Depression, Hoarding, Schizophrenia • Utilize mental illness resources / apply to case
3:45 – 4:15	**Wrapping it up with George**	• Uniformity video – how can the SW best assess?
4:15 – 4:30	**Wrap-up**	

DAY 3

Time	Topic	Notes
8:00 – 8:30	**Sign in**	- Continental breakfast & Networking
8:30 – 9:00	**Welcome** **Overview of Day 3**	- Learning objectives
9:00 – 9:15	**Assessing for Protective Supervision**	- Activity
9:15 – 9:30	**Scenarios Activity – Adult PS**	- Scenario exercise – does this meet the standard?
9:30 – 10:30	**Protective Supervision**	- Form: Assessment of Need for PS - Utilize PS regulations
10:30 – 10:45	**Break**	**15 minutes**
10:45 – 11:00	**Protective Supervision Calculations**	- Components of PS calculations - PS Scenarios Activity
11:15 – 12:30	**Lunch**	**75 minutes**
12:30 – 1:30	**Activity – Documenting When Ineligible for PS**	- Use scenario – that are not eligible
1:30 – 2:30	**Removing PS**	- Scenario – Margaret
2:30 – 2:45	**Break**	**15 minutes**
2:45 – 3:00	**Scenarios: PS and Children**	- Scenario exercise – does this meet the standard?
3:00 – 4:15	**PS and Children**	- Assessment, interviewing, regulations and policy
4:15 – 4:30	**Wrap-up**	- Evaluations

USING THE AGE APPROPRIATE GUIDELINE TOOL FOR ASSESSMENT OF MINOR CHILDREN



Individual Assessment
(Identification of consumer need)

Age Appropriate Guidelines
(Identification of Functional Index Ranking)

Ranking Identified as "1"
(All minors unless extraordinary need is documented)

Are Needs Extraordinary?
(Utilize developmental milestones to determine if need is beyond what would normally be expected for a child of a certain age and ensure the need is a result of the child's disability)

YES

Annotated Assessment Criteria
(Determine appropriate Functional Index Ranking)

Determine Hours

HTGs
(Determine if an exception exists)

Authorize Hours
(Only for amount above what would be normally expected and document appropriately)

NO

No Time Authorized
(Parental responsibility takes precedence)

Ranking Identified as Range "1-5"
(child expected to be developmentally independent)

Annotated Assessment Criteria
(Determine appropriate Functional Index Ranking)

Determine Hours

HTGs
(Determine if an exception exist)

Authorize Hours
(Document appropriately)

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

DOMESTIC SERVICES

Includes sweeping, vacuuming, washing and waxing of floor surfaces. Washing kitchen counters and sinks. Cleaning the bathroom. Storing food and supplies. Taking out garbage. Dusting and picking up. Cleaning oven and stove. Cleaning and defrosting refrigerator. Bringing in fuel for heating or cooking purposes from a fuel bin in the yard. Changing bed linen. Miscellaneous domestic service (e.g. changing light bulbs, wheelchair cleaning, and changing and recharging wheelchair batteries), when authorized.

Rank		
1	Independent: Able to perform all domestic chores without a risk to health or safety. Recipient is able to do all chores though s/he might have to do a few things everyday so s/he doesn't overexert her/himself.	No HTG. Time Guideline - 6.0 hours total per month per household unless the recipient's need requires an exception.
2	Able to perform tasks but needs direction or encouragement from another person. Recipient is able to perform chores if someone makes him/her a list or reminds him/her.	
3	Requires physical assistance from another person for some chores (e.g., has a limited endurance or limitations in bending, stooping, reaching, etc.).	
4	Although able to perform a few chores (e.g., dust furniture or wipe counters) help from another person is needed for most chores.	
5	Totally dependent upon others for all domestic chores.	

LAUNDRY

Includes washing and drying laundry, mending, ironing, folding, and storing clothes on shelves or in drawers.

Rank		
1	Independent: Able to perform all chores.	No HTG. Time Guideline - for laundry within the home is 1.0 hour total per week and out of home facilities is 1.5 hours per week per household unless the recipient's need requires an exception.
4	Requires assistance with most tasks. May be able to do some laundry tasks (e.g., hand wash underwear, fold and/or store clothing by self or under supervision).	
5	Cannot perform any task, is totally dependent on assistance from another person.	

SHOPPING FOR FOOD AND OTHER SHOPPING/ERRANDS

Includes reasonable food shopping and other shopping/errands limited to the nearest available stores or other facilities consistent with the recipient's economy and needs. Food shopping includes the tasks of making a grocery list, travel to/from the store, shopping, loading, unloading, and storing food. Other shopping/errands includes the tasks of making a shopping list, travel to/from the store, shopping, loading, unloading, and storing supplies purchased, and/or performing reasonable errands such as delivering a delinquent payment to avert an imminent utility shut-off or picking up a prescription, etc.

Rank		
1	Independent: Can perform all tasks without assistance.	No HTG. Time Guideline - for food shopping is 1.0 hour per week and for Other shopping/errands is 0.5 hour per week per household unless the recipient's need requires an exception.
3	Requires the assistance of another person for some tasks (e.g., recipient needs help with major shopping needed but can go to a nearby store for small items, or the recipient needs direction or guidance).	
5	Unable to perform any tasks for self.	

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

PREPARATION OF MEALS / MEAL CLEAN-UP

Meal preparation includes planning menus; removing food from the refrigerator or pantry; washing/drying hands before and after meal prep; washing, peeling, and slicing vegetables; opening packages, cans and bags; measuring and mixing ingredients; lifting pots and pans; trimming meat; reheating food; cooking and safely operating the stove; setting the table; serving the meals; pureeing food; cutting the food into bite-sized pieces.

Meal clean-up includes loading and unloading dishwasher; washing, rinsing, and drying dishes, pots, pans, utensils, and culinary appliances, and putting them away; storing/putting away leftover foods/liquids; wiping up tables, counters, stoves/ovens, and sinks; and washing/drying hands.

			Hours			
			Meal Prep		Meal Clean-up	
Rank		Rank	Low	High	Low	High
2	Needs only reminding or guidance in menu planning, meal preparation, and/or cleanup.	2	3:01	7:00	1:10	3:30
3	Requires another person to prepare and cleanup main meal(s) on less than a daily basis (e.g., recipient can reheat food prepared by someone else, can prepare simple meals, and/or needs some help with cleanup but requires another person to prepare and cleanup with more complex meals which involve, peeling, cutting, etc. on less than a daily basis.	3	3:30	7:00	1:45	3:30
4	Requires another person to prepare meals and cleanup on a daily basis.	4	5:15	7:00	1:45	3:30
5	Totally dependent on another person to prepare and clean up all meals.	5	7:00	7:00	2:20	3:30
6	ALL services are exclusively provided under Paramedical Services.	6	No HTG. No Time Guideline.			

FEEDING

Includes assistance with consumption of food and assurance of adequate fluid intake consisting of feeding or related assistance to recipients who cannot feed themselves or who require other assistance with special devices in order to feed themselves or to drink adequate liquids. Tasks include assistance with reaching for, picking up, and grasping utensils and cup; cleaning recipient's face and hands; washing and drying hands; washing/drying hands before and after feeding.

			Hours	
			Feeding	
Rank		Rank	Low	High
2	Able to feed self, but needs verbal assistance such as reminding or encouragement to eat.	2	0:42	2:18
3	Assistance needed during the meal (e.g., to apply assistive device, fetch beverage or push more food within reach, etc.) but constant presence of another person is not required.	3	1:10	3:30
4	Able to feed self some foods, but cannot hold utensils, cups, glasses, etc., and requires constant presence of another person.	4	3:30	7:00
5	Unable to feed self at all and is totally dependent upon assistance from another person.	5	5:15	9:20
6	ALL services are exclusively provided under Paramedical Services.	6	No HTG. No Time Guideline.	

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

AMBULATION

Includes assisting the recipient with walking or moving from place to place inside the home, including to and from the bathroom; climbing or descending stairs; moving and retrieving assistive devices, such as a cane, walker, or wheelchair, etc. and washing/drying hands before and after performing these tasks. Also includes assistance to/from the front door to the car (including getting in and out of the car) for medical accompaniment and/or alternative resource travel.

			Hours	
		Rank	**Ambulation**	
Rank			Low	High
2	Can move independently with only reminding or encouragement (e.g., needs reminding to lock a brace, unlock a wheelchair or to use a cane or walker).	2	0:35	1:45
3	Requires physical assistance from another person for specific maneuvers (e.g., pushing wheelchair around sharp corner, negotiating stairs or moving on certain surfaces).	3	1	2:06
4	Requires assistance from another person most of the time. Is at risk if unassisted.	4	1:45	3:30
5	Totally dependent upon others for movement. Must be carried, lifted, or assisted into a wheelchair or gurney at all times.	5	1:45	3:30

TRANSFER

Transfer includes assisting from standing, sitting, or prone position to another position and/or from one piece of equipment or furniture to another. Includes transfer from a bed, chair, couch, wheelchair, walker, or other assistive device generally occurring within the same room.

			Hours	
		Rank	**Transfer**	
Rank			Low	High
2	Able to transfer and reposition, but needs encouragement or direction.	2	0:30	1:10
3	Requires some help from another person (e.g., routinely requires a boost or assistance with repositioning).	3	0:35	1:24
4	Unable to complete most transfers or reposition without physical assistance. Would be at risk if unassisted.	4	1:06	2:20
5	Totally dependent upon another person for all transfers. Must be lifted or mechanically transferred. Must be repositioned often and have skin rubbed daily.	5	1:10	3:30

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

BATHING, ORAL HYGIENE, AND GROOMING / ROUTINE BED BATHS

Bathing includes cleaning the body in a tub or shower; obtaining water/supplies and putting them away; turning on/off faucets and adjusting water temperature; assistance with getting in/out of tub or shower; assistance with reaching all parts of the body for washing, rinsing, drying and applying lotion, powder, deodorant; washing/drying hands. Oral hygiene includes applying toothpaste, brushing teeth, rinsing mouth, caring for dentures, flossing, and washing/drying hands. Grooming includes hair combing/brushing; hair trimming when the recipient cannot get to the barber/salon; shampooing, applying conditioner, and drying hair; shaving; fingernail/toenail care when these services are not assessed as "paramedical" services for the recipient; washing/drying hands.

Routine bed baths includes cleaning basin or other materials used for bed sponge baths and putting them away; obtaining water and supplies; washing, rinsing, and drying body; applying lotion, powder and deodorant; washing/drying hands before and after bathing.

Hours

Rank		**Rank**	**Bathing, Oral Hygiene & Grooming**		**Routine Bed Baths**	
			Low	High	Low	High
2	Able to bathe, brush teeth, and groom self with direction or intermittent monitoring. May need reminding to maintain personal hygiene.	2	0:30	1:55	0:30	1:45
3	Generally able to bathe and groom self, but needs assistance with some areas of body care (e.g., getting in and out of shower or tub, shampooing hair, or brushing teeth).	3	1:16	3:09	1:00	2:20
4	Requires direct assistance with most aspects of bathing, oral hygiene, and grooming. Would be at risk if left alone.	4	2:21	4:05	1:10	3:30
5	Totally dependent on others for bathing, oral hygiene, and grooming.	5	3:00	5:06	1:45	3:30

BOWEL & BLADDER / MENSTRUAL CARE

Bowl & bladder includes assistance with using, emptying, and cleaning bed pans/bedside commodes, urinals, ostomy, enema and/or catheter receptacles; application of diapers; positioning for diaper changes; managing clothing; changing disposable barrier pads; putting on/taking off disposable rubber gloves; wiping and cleaning recipient; assistance with getting on/off commode or toilet; and washing/drying recipient's and providers hands.

Menstrual care is limited to external application of sanitary napkins and external cleaning and positioning for sanitary napkin changes, using and/or disposing of barrier pads, managing clothing, wiping and cleaning, and washing/drying hands before and after performing these tasks.

Hours

Rank		**Rank**	**Bowel & Bladder**		**Menstrual**	
			Low	High	Low	High
2	Requires reminding or direction only.	2	0:35	2:00	All Ranks	
3	Requires minimal assistance with some activities but the constant presence of the provider is not necessary.	3	1:10	3:20	0:17	0:48
4	Unable to carry out most activities without assistance.	4	2:55	5:50		
5	Requires physical assistance in all areas of care.	5	4:05	8:00		
6	ALL services are exclusively provided under Paramedical Services.	6	No HTG. No Time Guideline.			

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

DRESSING / CARE & ASSISTANCE WITH PROSTHESIS

Dressing includes washing/drying of hands; putting on/taking off, fastening/unfastening, buttoning/unbuttoning, zipping/unzipping, and tying/untying of garments, undergarments, corsets, elastic stockings and braces; changing soiled clothing; bringing tools to the recipient to assist with independent dressing.

Care of and assistance with prosthetic devices and assistance with self-administration of medications, which includes assistance with taking off/putting on and maintaining and cleaning prosthetic devices, vision/hearing aids and washing/drying hands before and after performing these tasks. Assistance with self-administration of medications consists of reminding the recipient to take prescribed and/or over-the-counter medications when they are to be taken and setting up Medi-sets.

Hours

Rank		**Rank**	**Dressing**		**Care/Assistance w/Prosthetic Devices**	
			Low	High	Low	High
2	Able to dress self; put on, fasten, and remove all special/prosthetic devices and/or hearing aid; and self-administer medication but requires reminding or direction.	2	0:34	1:12	FI Ranking Does Not Apply	
3	Unable to dress self completely without the help of another person (e.g., tying shoes, buttoning, zipping, putting on hose, brace, hearing aid, etc.).	3	1:00	1:52	0:28	1:07
4	Unable to put on most clothing items, special/prosthetic devices, and/or hearing aid by self.	4	1:30	2:20		
5	Without assistance the recipient would be inappropriately or inadequately clothed.	5	1:30	2:20		

RESPIRATION

Limited to nonmedical services such as assistance with self-administration of oxygen and cleaning IPPB machines

Rank		
1	Does not use respirator or other oxygen equipment or is able to use and clean independently.	No HTG. No Time Guideline.
5	Needs help with self-administration and/or cleaning.	
6	ALL services are exclusively provided under Paramedical Services.	

FUNCTIONAL INDEX RANKINGS AND HOURLY TASK GUIDELINES

Memory

Recalling learned behaviors and information from distant and recent past.

Rank		
1	No problem. Memory is clear. Recipient is able to give you accurate information about his/her medical history; is able to talk appropriately about comments made earlier in the conversation; has good recall of past events. The recipient is able to give you detailed information in response to your questions.	No HTG. No Time Guideline.
2	Memory loss is moderate or intermittent: Recipient shows evidence of some memory impairment, but not to the extent where s/he is at risk. Recipient needs occasional reminding to do routine tasks or help recalling past events.	
5	Severe memory deficit: Recipient forgets to start or finish activities of daily living that are important to his/her health and/or safety. Recipient cannot maintain much continuity of thought in conversation with you.	

Orientation

Awareness of time, place, self, and other individuals in one's environment.

Rank		
1	No problem. Orientation is clear. Recipient is aware of where s/he is and can give you reliable information when questioned about activities of daily living, family, etc.; is aware of passage of time during the day.	No HTG. No Time Guideline.
2	Occasional disorientation and confusion is apparent but recipient does not put self at risk: Recipient has general awareness of time of day; is able to provide limited information about family, friends, age, daily routine, etc.	
5	Severe disorientation which puts recipient at risk: Recipient wanders off; lacks awareness or concern for safety or wellbeing; is unable to identify significant others or relate safely to environment or situation; has no sense of time of day.	

Judgment

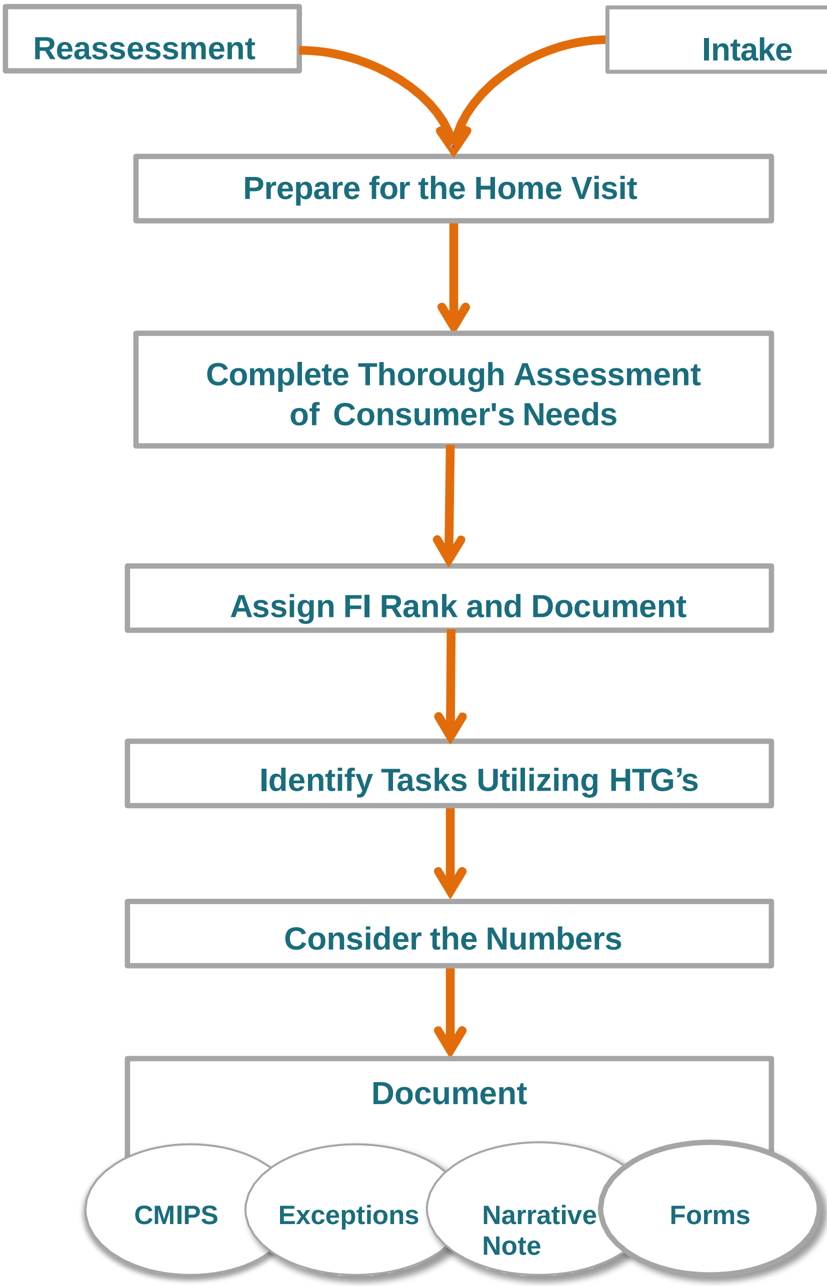
Making decisions so as not to put self or property in danger. Recipient demonstrates safety around stove. Recipient has capacity to respond to changes in the environment (e.g. fire, cold house). Recipient understands alternatives and risks involved and accepts consequences of decisions.

Rank		
1	Judgment unimpaired. Able to evaluate and respond appropriately.	No HTG. No Time Guideline.
2	Judgment mildly impaired: Shows lack of ability to plan for self; has difficulty deciding between alternatives, but is amenable to advice; social judgment is poor.	
5	Judgment severely impaired: Recipient fails to make decisions or makes decisions without regard to safety or well-being.	

IHSS
IN-HOME SUPPORTIVE SERVICES

CDSS

IHSS ASSESSMENT PROCESS



Reassessment

Intake

Prepare for the Home Visit

Complete Thorough Assessment of Consumer's Needs

Assign FI Rank and Document

Identify Tasks Utilizing HTG's

Consider the Numbers

Document

CMIPS

Exceptions

Narrative Note

Forms

PS and MINORS CAC

1. Is there a mental illness/mental impairment?
2. Is there a behavior that puts him/her at risk?
3. Is the behavior nonself-directed?
4. Is supervision protective in nature?
5. Is the supervision above and beyond what you would provide a child of the same age without mental impairment?
6. Is there a 24 hour need?
7. Are there any interventions in place?

QUESTIONS TO ASK MY COUNTY

IHSS
IN-HOME SUPPORTIVE SERVICES
TRAINING ACADEMY

Comprehensive Assessment

DAY 1

CDSS
CALIFORNIA
DEPARTMENT OF
SOCIAL SERVICES

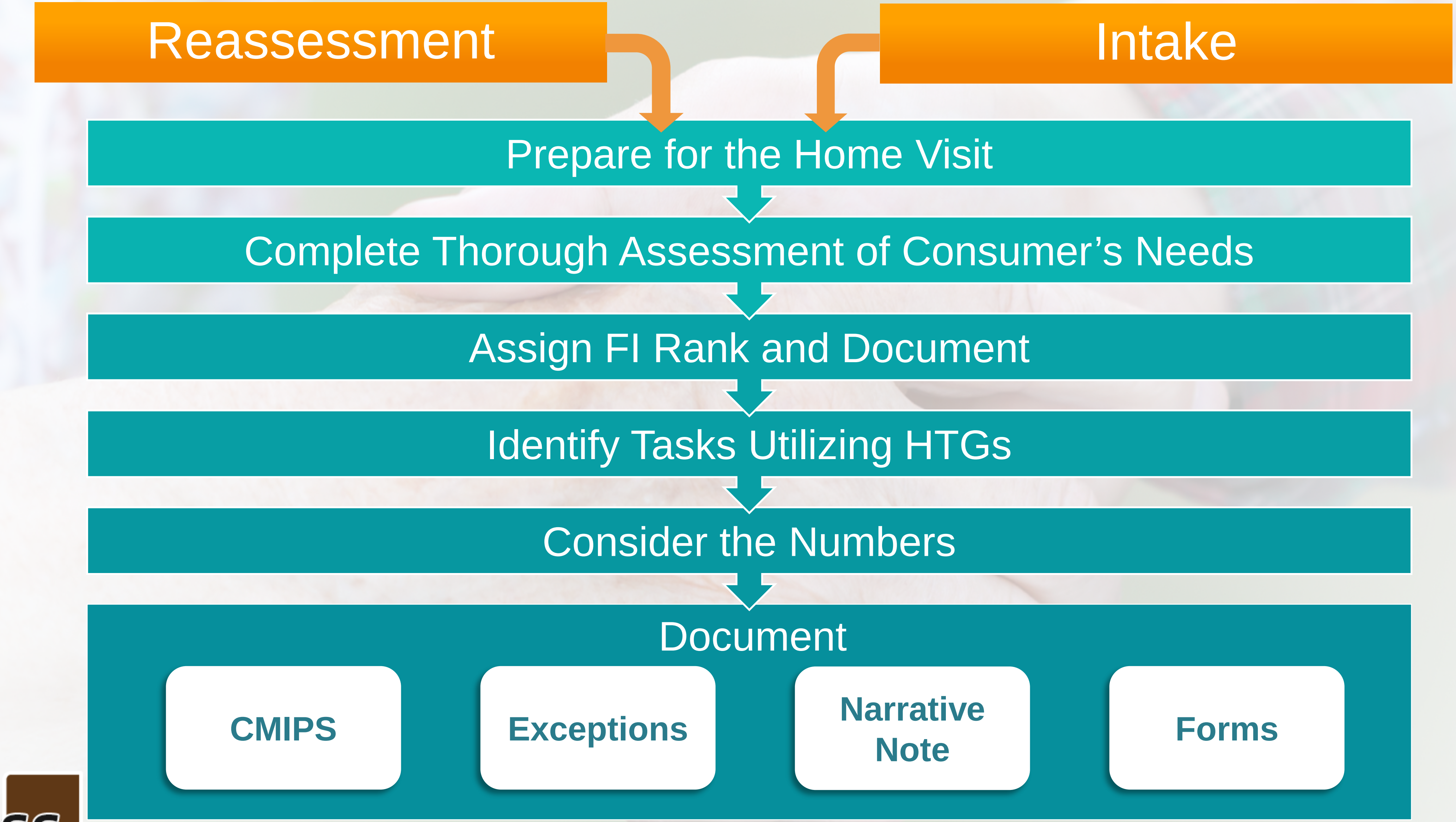
SAN DIEGO STATE
UNIVERSITY

AGENDA

- Orientation Review
- Interview Challenges
- Cultural Implications
- Supporting IHSS Providers
- Paramedical Services

Orientation Review

IHSS ASSESSMENT PROCESS



Reassessment

Intake

Prepare for the Home Visit

Complete Thorough Assessment of Consumer’s Needs

Assign FI Rank and Document

Identify Tasks Utilizing HTGs

Consider the Numbers

Document

- CMIPS
- Exceptions
- Narrative Note
- Forms

ACTIVITY: JASON

Interview Challenges

THE COMPREHENSIVE INTERVIEW

INTERVIEW SUCCESS IN A COMPLEX ASSIGNMENT

Avoiding Bias

- Don’t express your own opinions – consumers may change their answers to make you happy.
- Don’t suggest answers is consumer wants your help – repeat the question, pause and let them take a moment.
- Avoid leading probes that might suggest an answer.

From ***“Doing the Interview: How to Really Ask Those Question and Enjoy It”***

INTERVIEW SUCCESS IN A COMPLEX ASSIGNMENT

Use Probes for Clarity and Completeness

- *“You said…What do you mean by that?”*
- *“I’m not sure I understand. Could you give me more information?”*
- *“Could you explain, tell me more about that?”*

From ***“Doing the Interview: How to Really Ask Those Question and Enjoy It”***

INTERVIEW SUCCESS IN A COMPLEX ASSIGNMENT

Tread Carefully – But Don't Avoid Embarrassing Subjects

- Build rapport at beginning of interview.
- Reassure consumer you are not embarrassed.
- Ask questions straight-forwardly and without hesitation.
- Explain these are questions you ask everyone.

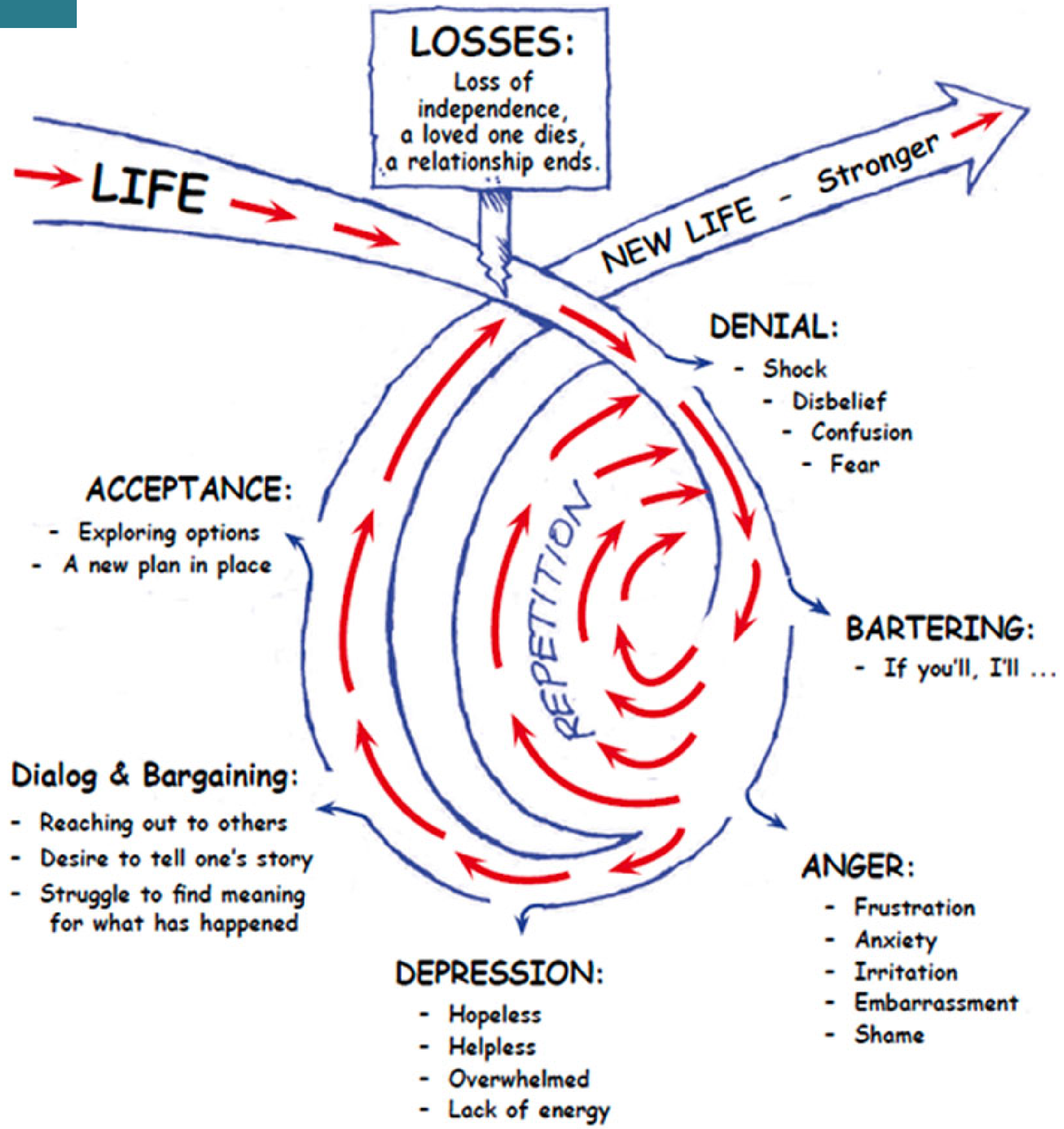
From ***"Doing the Interview: How to Really Ask Those Question and Enjoy It"***

INTERVIEW CHALLENGES

- People dealing with **grief/loss** issues
- Consumers dealing with impact of **chronic illness**

THE LOSS CYCLE

The normal cycle for all losses



INTERVIEW CHALLENGES

- Consumers who **understate** their need.
- Consumers who **overstate** their need.
- IHSS providers or family that want to speak for the consumer.

INTERVIEW CHALLENGES

- Communication challenges
- Angry consumers
- Hostile consumers
- Emotionally distraught consumers
- Distracted consumers
- Passive consumers
- Timid consumers

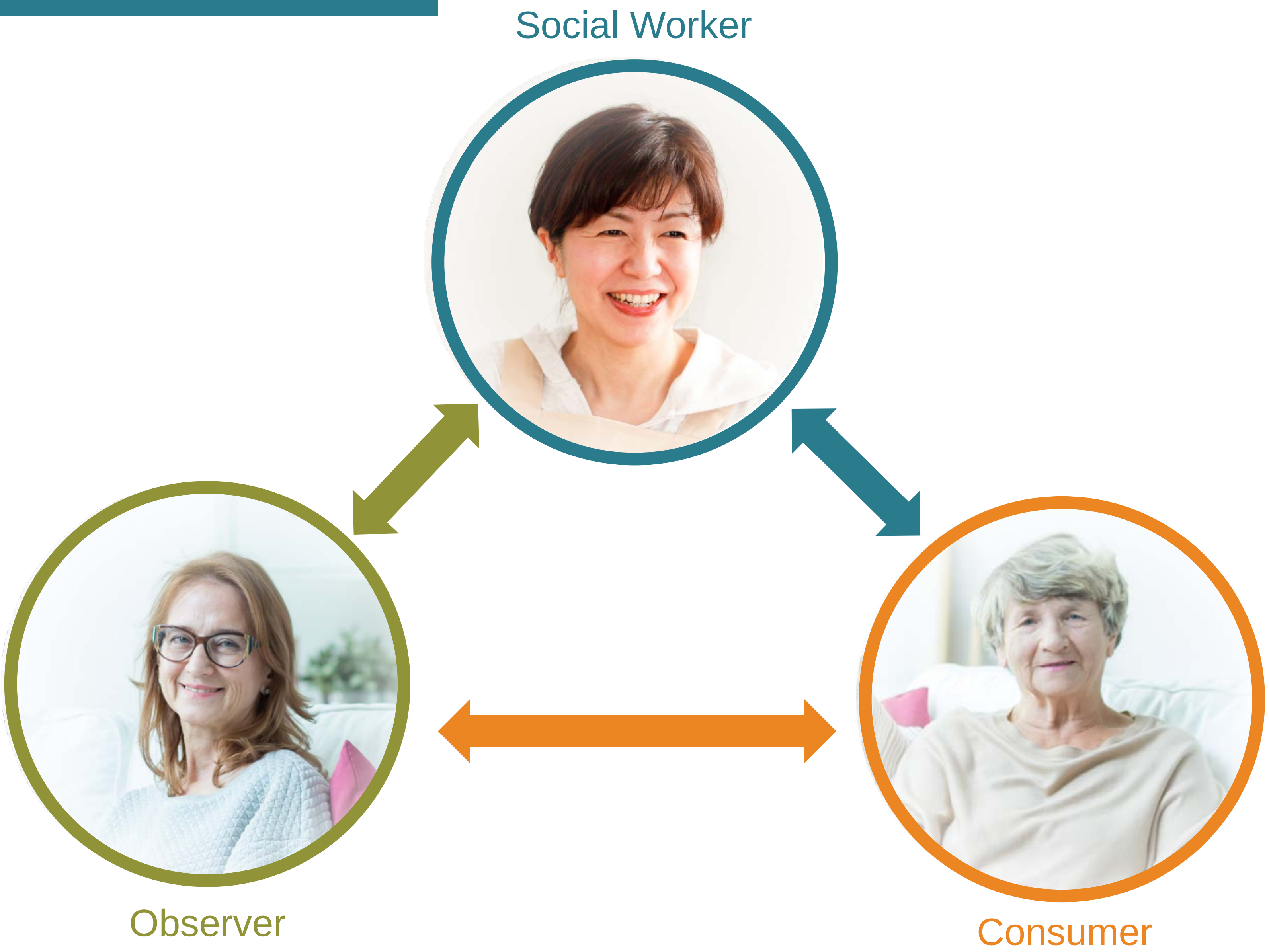
COMMUNICATING IN DIFFICULT SITUATIONS

- Handle the anger **up front** so the assessment can continue.
- Listen for **full understanding** to get a clear picture of the situation.
- Stay **focused** on the interview.
- Take the time to really **understand** the situation.
- Keep your body language **soft.**
- Respond to concerns in an **affirming** manner.
- **Restate** concerns to show you have heard their issues.
- Focus on the overall **goal** of the situation.
- Avoid **personalization** of the issues.
- Keep the conversation **professional.**

INTERVIEW CHALLENGES

- Hearing impairments
- Blind/visual impairments
- Speaking impairments

INTERVIEW ACTIVITY



Social Worker

Observer

Consumer

Cultural Implications

Cultural Implications

STEREOTYPING VS. GENERALIZING

THINGS TO CONSIDER

- Importance of individuality
- Influences on beliefs
- Importance of understanding own cultural context and influences
- Cultural understanding leads to greater sensitivity

VARIATIONS IN COMMUNICATION

- Conversational style and pacing
- Eye contact
- Personal space
- Touch
- Time orientation

EXERCISE: CULTURE AND CLINICAL CARE

USING AN INTERPRETER

- Must be 18 years of age
- Give instructions to interpreter
  - Consumer’s own words
  - Be thorough and accurate
- Focus conversation on the consumer
- Observe consumer’s non-verbal communication
- Use simple language – no slang
- Check for understanding

Care Providing

Care Providing

BEING AN IHSS PROVIDER

WHO PROVIDES IHSS SERVICES?

- Spouse
- Parents
- Other family members
- Nonrelated

Paramedical Services

(MPP §30-757.19)

RANK 6

- Paramedical services needed
- **ALL** functions in the task are met by Paramedical
  - Meal preparation/meal cleanup
  - Bowel, bladder, and menstrual care
  - Eating
  - Respiration

PARAMEDICAL SERVICES

Characteristics of Services

- Functional limitations prevent recipient from performing (self-care)
- Are necessary to maintain the recipient’s health due to their physical of mental condition
- Tasks include:
  - Administration of the medication
  - Puncturing the skin
  - Inserting a medical device into a body orifice
  - Activities requiring sterile procedures
  - Activities requiring judgement based on training given by a licensed health care professional

PARAMEDICAL SERVICES

- Services are provided **when ordered by** the licensed health care professional
- Services are provided **under the direction of** the licensed health care professional
- The SOC 321 should indicate the **time and frequency** necessary to perform the ordered services
- Services are provided by IHSS providers at the **IHSS hourly rate**

PARAMEDICAL SERVICES

- A signed and dated SOC 321 form must be obtained from the licensed health care professional.
- The Paramedical services order must be received prior to authorization of Paramedical services.
- Other IHSS services can/should be authorized without delay, even if there is a delay in obtaining the authorization for Paramedical services.

WHEN CONSIDERING NEED FOR PARAMEDICAL SERVICES

- Does the consumer require injections?
  - Are they able to **safely** self-administer them?
- Do they require a bowel program or other invasive medical type procedure?
- Is the consumer physically or mentally able to perform the function?

CONFIRM

- Nature of services approved
    - Are they paramedical?
- Time period for which the services are authorized
    - Services should be reassessed at the time of reassessment
- Time authorized on the form

WORKING WITH THE LHCP

Evaluating the ‘real’ functional need

- They don’t understand IHSS criteria or program limitations.
- May not understand services that he/she is asking for.
- May not understand the functional abilities of the consumer.
- They do not see consumer in the home.

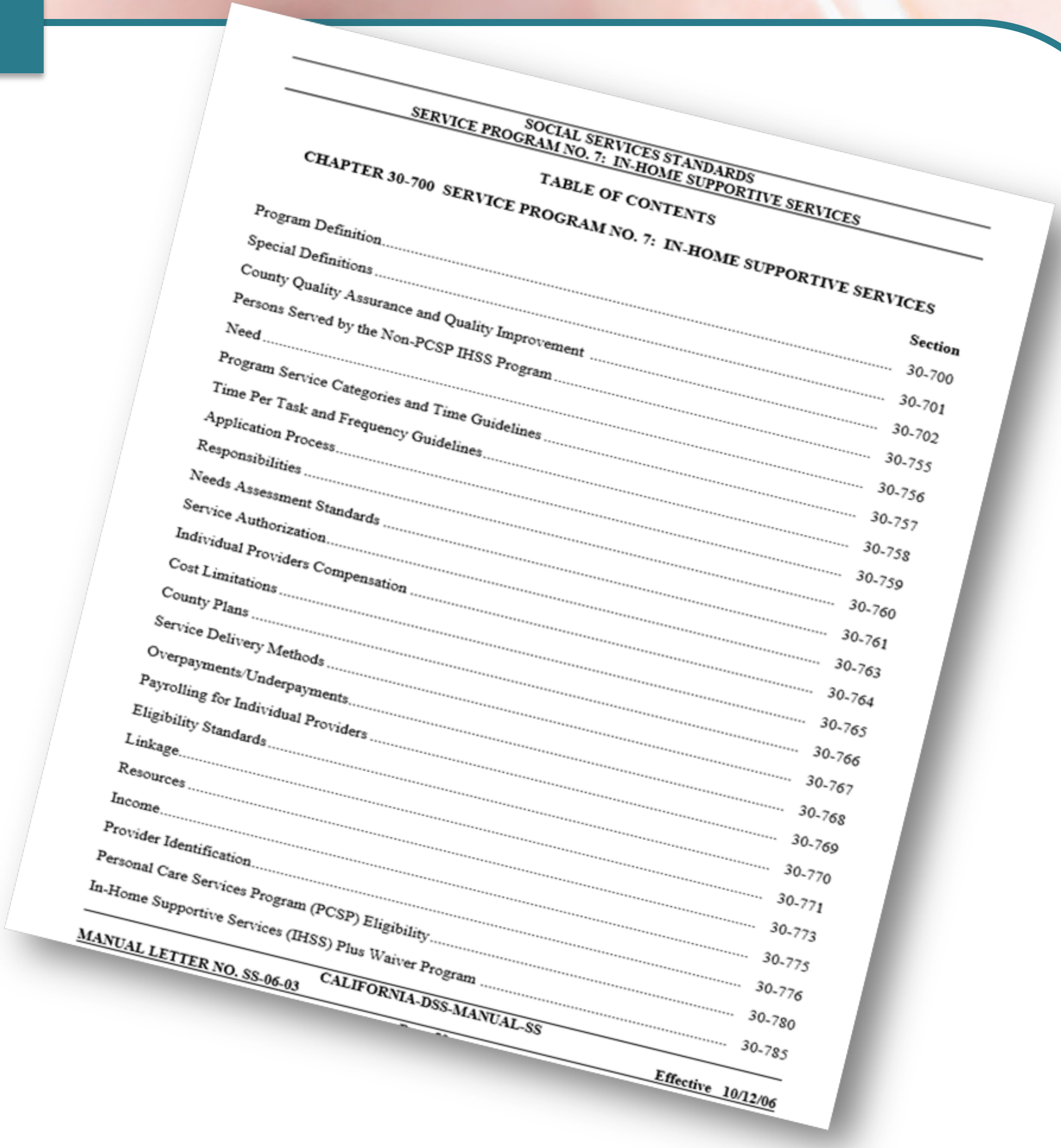
STRATEGIES FOR COMMUNICATING WITH LHCP

Strategies for communicating with the LHCP's office

- If county has IHSS nurses, discuss concerns with him/her first.
- Be prepared.
- Talk with the LHCP's back-office nurse first.
- Give the LHCP facts and let them know what you need.
- Be concise and respectful of their time, but be persistent.
- Be careful of taking offense or defense when approaching the LHCP.

DOCUMENTING YOUR CASE

- Data integrity
- Cite regulation section
- Use regulation language



SOCIAL SERVICES STANDARDS
SERVICE PROGRAM NO. 7: IN-HOME SUPPORTIVE SERVICES

TABLE OF CONTENTS

CHAPTER 30-700 SERVICE PROGRAM NO. 7: IN-HOME SUPPORTIVE SERVICES

MANUAL LETTER NO. SS-06-03 CALIFORNIA-DSS-MANUAL-SS Effective 10/12/06

EXERCISE: EMILY

Strategizing for the interview

IHSS
IN-HOME SUPPORTIVE SERVICES
TRAINING ACADEMY

Congratulations!

You have completed Day 1 Comprehensive Assessment

CDSS
CALIFORNIA
DEPARTMENT OF
SOCIAL SERVICES

SAN DIEGO STATE
UNIVERSITY

IHSS
TRAINING ACADEMY
AT SAN DIEGO STATE UNIVERSITY

Comprehensive Assessment

DAY 2

AGENDA

- IHSS and Minors
  - Minor Eligibility
  - Age Appropriate Guidelines
- Working with Consumers with Mental Illness

IHSS and Minors

AUTISM SPEAKS™

It's time to listen.

IHSS

ELIGIBILITY FOR MINORS

- Meets Medi-Cal eligibility
- Meets place of residency requirements
  - “Own home”
  - CA residence
- Blind or Disabled
- Health Care Certification (SOC 873)
- Functionally Impaired
- Four Programs: IHSS –R, PCSP, IPO, CFCO
- Household composition/availability of parents
  - Who can get paid to provide IHSS

HOUSEHOLD COMPOSITION AND AVAILABILITY OF PARENTS

- Liv
- Liv
- On
- Pa
- Pa

View Household Member: [redacted]

Companion Case Details

Companion Case Number:		**Protective Supervision Status:**	No

Household Member Details

Relationship:	Parent	**Date of Birth:**	4/7/1975
Last Name:	[redacted]	**First Name:**	[redacted]
Spouse / Parent:	Parent - provides all services	**Protective Supervision Proration:**	No

LIVING WITH OTHER THAN PARENT

- Is it a licensed facility?
- Is the minor receiving the nonmedical out-of-home rate SSI/SSP?
  - If “Yes” to either, the minor is ineligible for IHSS
  - If “No” to both, the minor may be eligible

IHSS

NON-PARENT PROVIDER

IHSS may be purchased from a provider other than the parent(s) when no parent is able and available to provide the services for any of the following reasons:

- .441 when the parent(s) is unavailable because of employment or education or training for vocational purposes.
- .442 if the parent(s) is physically or mentally unable to perform the needed services.
- .443 when the parent is unavailable because of on-going medical, dental or other health-related treatment.

NON-PARENT PROVIDER

.444 When the parent(s) must be unavailable to perform shopping and errands essential to the family, search for employment, or for essential purposes related to the care of the recipient's minor siblings, IHSS may be purchased from a provider other than the parent(s) for up to eight hours per week to perform IHSS tasks necessary during the unavailability of the parent(s).

These are not additional hours but hours gleaned from the assessed hours.

PARENT PROVIDER

IHSS may be purchased from a parent under the follow conditions:

.451 The parent has left full-time employment or is prevented from obtaining full-time employment because no other suitable provider is available and the inability of the parent to perform supportive services may result in inappropriate placement or inadequate care.

> (a) For the purposes of this section, full-time employment means working an average of 40 or more hours per week regardless of worksite location. A parent providing IHSS-funded care to his/her own child is not full-time employment.

FOR THE PURPOSE OF MPP §30-763.452

Suitable Provider

.452 For the purposes of Section 30-763.451, a suitable provider is any person who is willing, able, and available to provide the needed IHSS. A suitable provider who is a person having a duty pursuant to the Family Code need only be able and available to provide the needed IHSS; the person is only considered to be unavailable if that unavailability occurs during a time the recipient must receive a specific service, for the following reasons: employment, enrollment in an educational or vocational training program, or employment searches.

IHSS SERVICES AND THE PARENT PROVIDER

.456 The IHSS provided shall be limited to:

(a) Related services, as specified in Section 30-757.13.

(b) Personal care services, as specified in Section 30- 757.14.

(c) Accompaniment when needed during necessary travel to health-related appointments or to alternative resource sites, as specified in Section 30 757.15.

(d) Protective supervision, as specified in Section 30-757.17, limited to protective supervision needed because of the functional limitations of the recipient. This service shall not include routine child care or supervision.

(e) Paramedical services, as specified in Section 30-757.19.

LIVING WITH PARENT(S)

A parent provider who meets the requirements in Section 30-763.455 shall be paid for performing authorized service regardless of the presence of the other parent in the home, including non-work hours, weekends, and holidays.

THE INSTITUTIONALLY DEEMED EXCEPTION

- Aid Code
  - 6V (Institutional Deeming without SOC) or
  - 6W (Institutional Deeming with SOC)
- Parent(s) income is not considered when determining Medi-Cal eligibility
- Non-parent provider may be paid to provide services even when the parent is in the home (PCSP)
- If parent wants to be paid IHSS provider then all other rules apply

Assessing Minors: Age Appropriate Guidelines

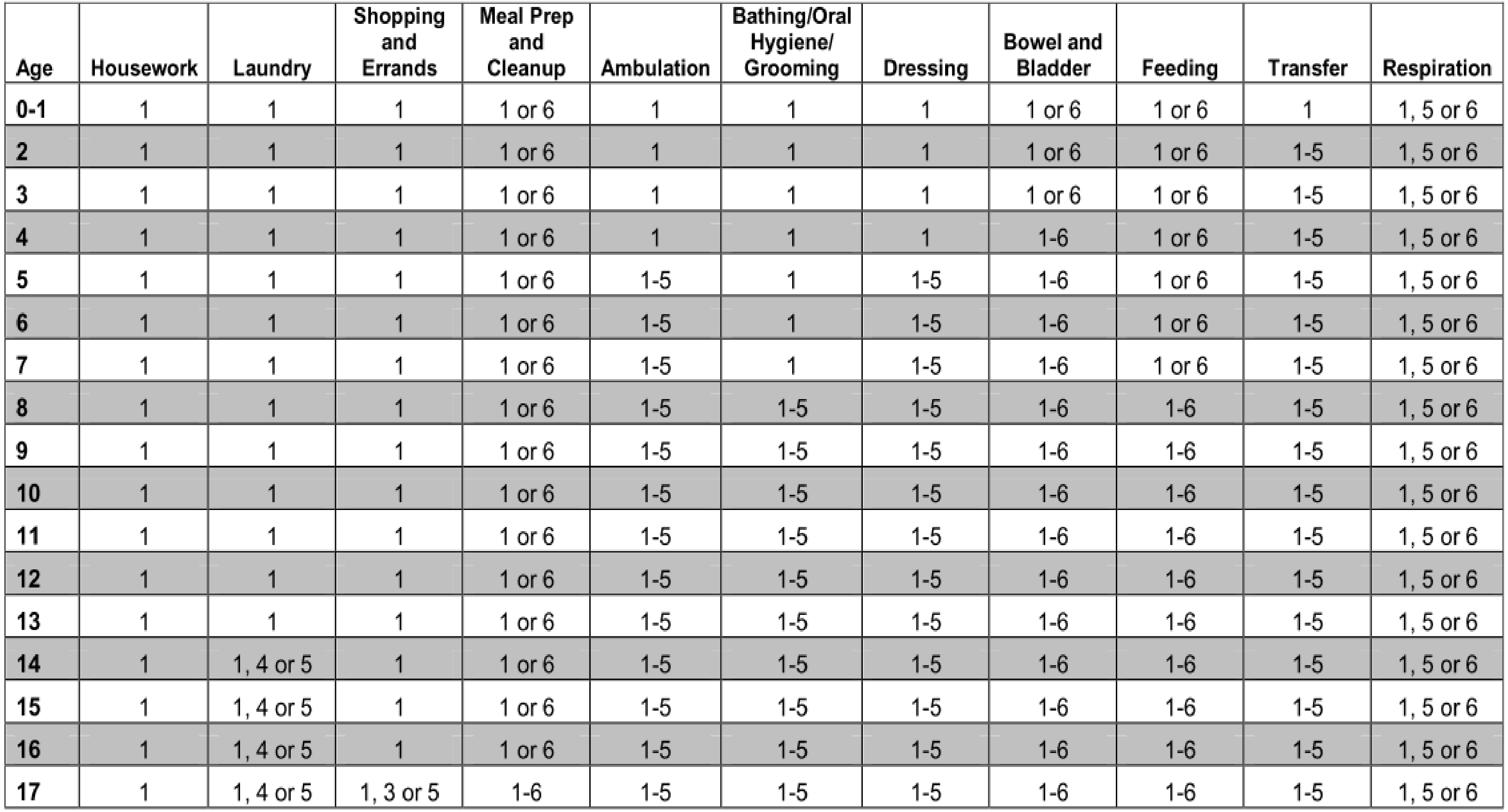
WHY WE NEED GUIDELINES FOR ASSESSING MINORS

- Provides a baseline for understanding the developmental stages of minors
  - Helps us to uniformly assess minors
  - Helps us delineate between normal parental roles and extraordinary needs of disabled minors

TOOLS FOR ASSESSING MINORS

Developmental Milestone Tools

AGE APPROPRIATE GUIDELINES



Age	Housework	Laundry	Shopping and Errands	Meal Prep and Cleanup	Ambulation	Bathing/Oral Hygiene/ Grooming	Dressing	Bowel and Bladder	Feeding	Transfer	Respiration
0-1	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1	1, 5 or 6
2	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1-5	1, 5 or 6
3	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1-5	1, 5 or 6
4	1	1	1	1 or 6	1	1	1	1-6	1 or 6	1-5	1, 5 or 6
5	1	1	1	1 or 6	1-5	1	1-5	1-6	1 or 6	1-5	1, 5 or 6
6	1	1	1	1 or 6	1-5	1	1-5	1-6	1 or 6	1-5	1, 5 or 6
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11	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
12	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
13	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
14	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
15	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
16	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
17	1	1, 4 or 5	1, 3 or 5	1-6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6

ASSESSING HOUSEWORK FOR MINORS

- Domestic services are **never** authorized for minors under 18 who live with their **provider** parent(s).
- Regulations do allow authorizing Domestic services for minors who **do not live with their parents**.

WAYNE

Wayne is a 5-year-old who wears braces on both legs and is able to ambulate short distances in the house without assistance unless he gets too tired, at which time he uses a wheelchair and must be pushed.

TYLER

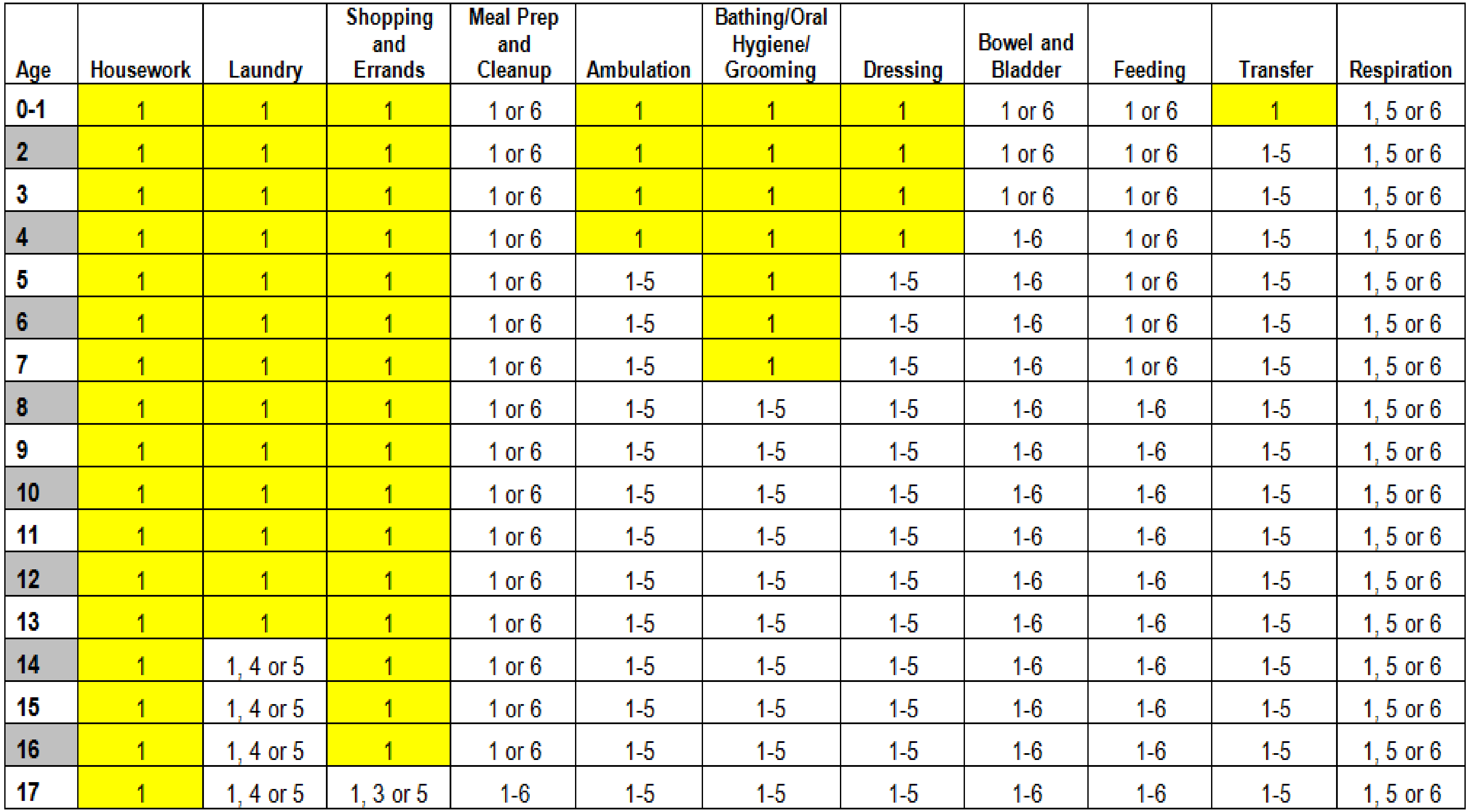
What if a minor can perform some but not all of the tasks within a service category independently?

Tyler is 14 years old and has congenital birth defects which limit his mobility. He is able to get around the house in a motorized wheelchair without assistance because of modifications that have been done to the house. He attends a regular school where he eats lunch. When he comes home from school, he fixes a sandwich or other snack and cleans up. His mother cooks breakfast and dinner for the family.

EXTRAORDINARY NEEDS

- Need that is beyond what would normally be expected for a minor of that age
- Based on the functional impairment due to the minor’s disability

HIGHLIGHTED AAG



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17	1	1, 4 or 5	1, 3 or 5	1-6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6

BEN

Ben is a 12-year-old with a diagnosis of autism spectrum disorder. He experiences behavior problems, but is able to manage most of his personal care needs independently with some direction. He is independent in bowel and bladder care. His mother does laundry for all of the family together.

HAYDEN

Hayden is a 12-year-old who has congenital birth defects. He is incontinent of bowel and bladder. Although he wears diapers, he has accidents which require frequent clothing and bed linen changes. Because of his disabilities, he is not able to do any laundry tasks. Hayden lives with his mother and 15-year-old sister. You determine that the household need for normal laundry is 1:00 hour per week. Hayden's mother states that she spends an additional 1:00 hour per week doing the extra laundry caused by Hayden's disability.

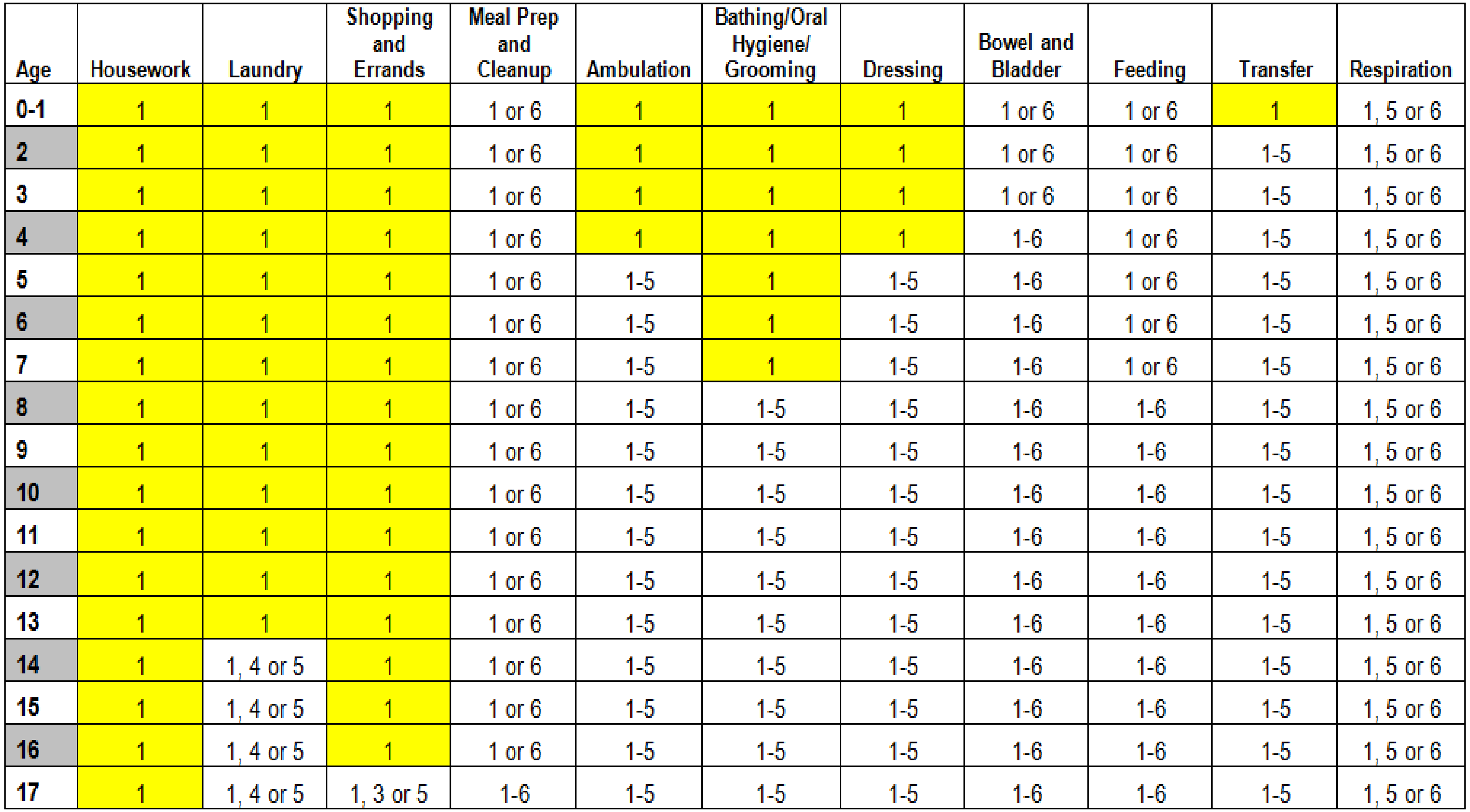
IHSS

HAYDEN'S EXTRAORDINARY NEED FOR LAUNDRY

Total Assessed Need	Adj.	Ind. Assessed Need	Alt. Resource/ Voluntary/ Refused	Net Adjusted Need	Unmet Need
2:00	1:00	1:00	0	1:00	0

ACTIVITY: EXTRAORDINARY NEED

HIGHLIGHTED AAG



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17	1	1, 4 or 5	1, 3 or 5	1-6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6

Working with the Consumer with a Mental Disorder

IMPORTANT CONCEPTS

Important Concepts

- Mental disorders can have a significant impact on functional ability.
- People with mental disorders have a range of symptoms.
- The person with a mental disorder is not in control of their symptoms.
- Functional ability can change significantly and frequently for some consumers with mental disorders.

STIGMA OF MENTAL DISORDERS

"Behaviors are controllable."

"The person can overcome the disorder if had enough will power."

"A mental disorder reflects the person's character and intelligence."

SCHIZOPHRENIA

Schizophrenia

- Affects around 1.1% of the American population.
- “Positive” and “negative” symptoms:
  - Positive symptoms: active symptoms, including delusions, hallucinations, disorganized thinking, and disorganized behavior.
  - Negative symptoms: loss in functioning, including withdrawal or lack of motivation, inability to feel pleasure, lack of verbal speech, or flat affect.

SCHIZOPHRENIA: IHSS FUNCTIONAL LIMITATIONS

- Concentration or sleep deterioration
- Delusions or hallucinations
- Total lack of motivation due to “negative” symptoms

SCHIZOPHRENIA TECHNIQUES FOR INTERACTIONS

- Use **short, simple phrases** when asking questions or giving information.
- Use a **calm and unhurried** tone of voice.
- **Never shout or try to argue** with the consumer.
- Give the consumer some **physical space**.
- **Try to avoid too much direct eye contact**.
- **If the consumer is tangential**, politely interrupt by recapping what he/she said, and then move on to your questioning.

IHSS

SCHIZOPHRENIA TECHNIQUES FOR INTERACTIONS

- **Never be judgmental or put blame** on the consumer for their condition.
- **Do not try and convince** the consumer their delusions or hallucinations are fake.
- Eliminate **unnecessary noises.**
- **End interview** if consumer is not able to cooperate.

SCHIZOPHRENIA: JERRY

"Jerry"

SCHIZOPHRENIA: STEVE

"Steve"

BIPOLAR DISORDER (MANIC-DEPRESSION)

Bipolar Disorder (Manic-Depression)

- Unusual shifts in a person’s mood, energy, and ability to function.
- Different from the normal ups and downs that everyone goes through; the symptoms of bipolar disorder are severe.
- “Higher highs and lower lows”

BIPOLAR DISORDER IHSS FUNCTIONAL LIMITATIONS

Manic episode(s)

- Severe manic episodes may not feel the need to keep themselves well groomed or their apartment clean
- Risk with physical impairments – taking risks with manic episodes
- Not taking medications
- Need for sleep or for eating regularly may become less

BIPOLAR DISORDER IHSS FUNCTIONAL LIMITATIONS

Depressive episode(s)

- Problems with toileting, dressing, grooming, preparing food, and taking medication
- Handling finances, shopping, or cleaning one’s house can be extremely daunting tasks
- Suicidal behaviors may be more for those with a bipolar disorder than for consumers with general depression.

BIPOLAR DISORDER TECHNIQUES FOR INTERACTION

Manic episode(s)

- **Don't try to calm down**
- **Avoid intense conversations** if in manic state
- **Do not debate** or argue
- Try and **gently steer the conversation** to your interview goals
- May say hurtful or mean things **- Do not become offended or act defensive**
- **Speak calmly** and at a low level

BIPOLAR: CRAIG

PERSONALITY DISORDERS

Personality Disorders

People with personality disorders have “an enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early adulthood, is stable over time, and leads to distress and impairment.”

(DSM-5: APA, 2013)

PERSONALITY DISORDERS

Cluster A

Cluster A includes personality disorders marked by **odd, eccentric behavior**, including paranoid, schizoid and schizotypal personality disorders.

Cluster B

Cluster B personality disorders are those defined by **dramatic, emotional behavior**, including antisocial, borderline, histrionic, and narcissistic personality disorders.

Cluster C

Cluster C personality disorders are characterized by **anxious, fearful behavior** and include avoidant, dependent, and obsessive-compulsive personality disorders.

PERSONALITY DISORDERS AT RISK

- Social isolation
- Suicide
- Substance abuse
- Depression, anxiety and eating disorders
- Self-destructive behavior
- Violence and homicide
- Incarceration

SUBSTANCE ABUSE AND MENTAL DISORDERS

Substance Abuse and Mental Disorders

- As much as 50% of adults with mental disorders also have substance abuse problems
- Substances used to augment medication/ treatment
- Need for referrals

SUICIDE AND MENTAL DISORDERS

Suicide and Mental Disorders

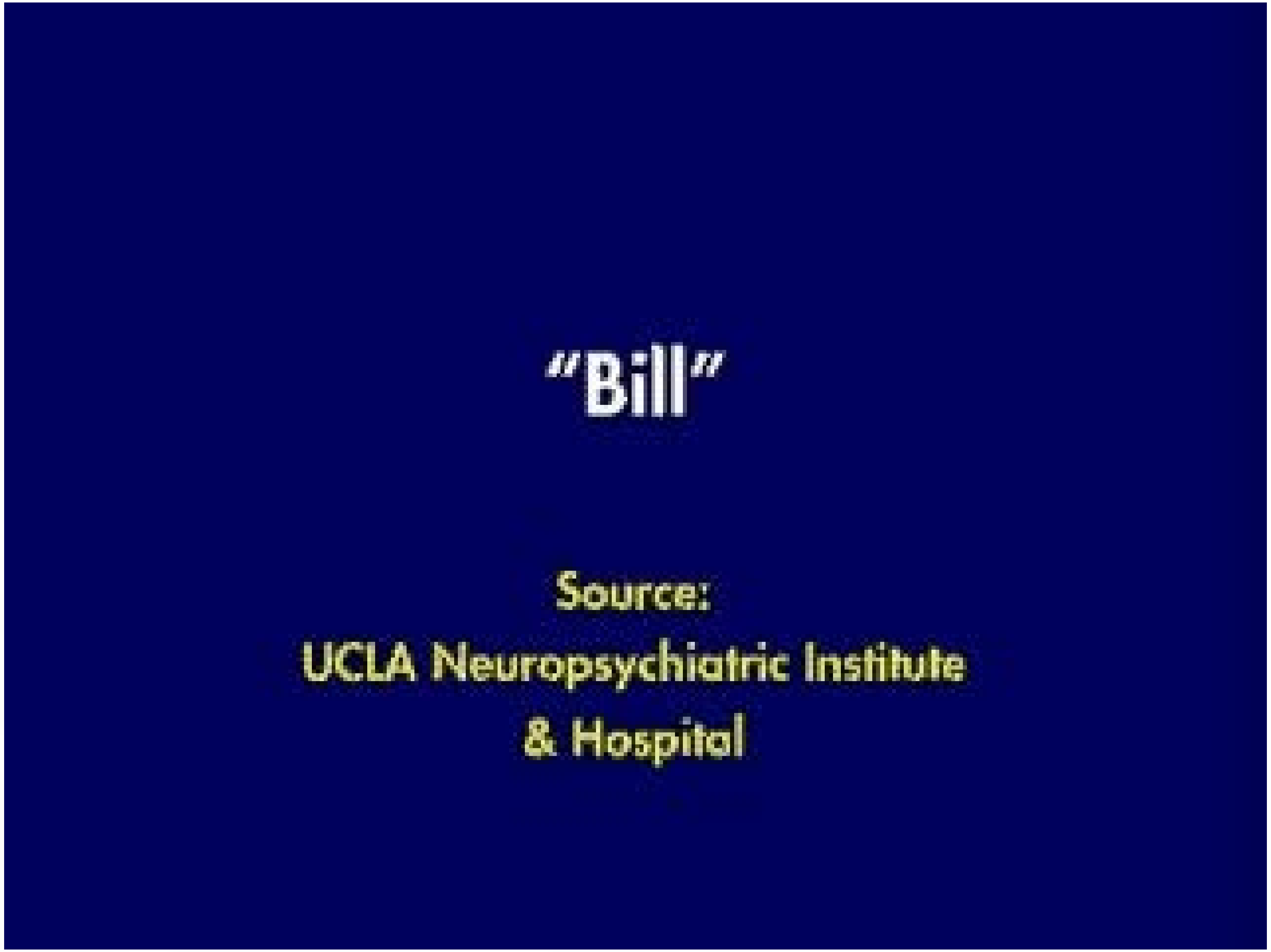
- Greater incidence of suicide in people with mental disorders
- Greatest amongst those with severe depressive disorder
- Incidence increases with substance abuse
- Risk increases in old age
- Higher among men than women

MENTAL ILLNESS – TEACH BACK ACTIVITY

Report out should include:

- How the consumer relates to the diagnosis / content
  - Characteristics
  - IHSS Functional Limitations
  - Techniques In Interacting With
- Collateral information would be helpful to your accurate assessment of this consumer’s needs.
- Needs consumers with this impairment will probably have.
- Community resource or other referrals would you make.

OBSESSIVE-COMPULSIVE DISORDER- BILL



"Bill"

Source:
UCLA Neuropsychiatric Institute
& Hospital

COMMON THEMES…

Common Themes

- Don’t buy into delusions
- Be non-confrontational
- Use clear and concise questions
- Make sure the consumer understands who you are and why you are there
- Utilize mental health professional resources
- Be cognizant of your safety

SCENARIO: GEORGE

IHSS
TRAINING ACADEMY
AT SAN DIEGO STATE UNIVERSITY

Congratulations!

You have completed
Day 2 of Comprehensive Assessment

IHSS
IN-HOME SUPPORTIVE SERVICES
TRAINING ACADEMY

Comprehensive Assessment

DAY 3

CDSS
CALIFORNIA
DEPARTMENT OF
SOCIAL SERVICES

SAN DIEGO STATE
UNIVERSITY

AGENDA

- Protective Supervision
  - Eligibility
  - Factors that Affect PS Calculations
  - Removing PS
- Protective Supervision for Minors

Protective Supervision

Eligibility

IHSS

PROTECTIVE SUPERVISION

Regulations

Protective Supervision consists of observing recipient behavior and intervening as appropriate in order to safeguard the recipient against injury, hazard, or accident.

[MPP §30-757.17]

PROTECTIVE SUPERVISION

Regulations

Protective Supervision is available for observing the behavior of non-self-directing, confused, mentally impaired, or mentally ill persons only.

[MPP §30-757.171]

Regulations

Protective Supervision may be provided through the following or combination of the following arrangements:

1. In-Home Supportive Services Program;
2. Alternative resources such as adult or child day care centers, community resource centers, senior centers, respite centers;
3. Voluntary resources.

[MPP §30-757.171(a)(1-3)]

PROTECTIVE SUPERVISION

Protective Supervision shall NOT be authorized for:

a. Friendly visiting or other social activities.
b. A medical condition where the type of supervision required is medical.
c. In anticipation of a medical emergency.
d. To prevent or control anti-social or aggressive recipient behavior.
e. To guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.

[MPP §30-757.172(a-e)]

PROTECTIVE SUPERVISION

Regulations

Social services staff shall explain the availability of Protective Supervision and discuss the need for twenty-four-hours-a-day supervision with the recipient, or recipient's parent(s), or the recipient's guardian or conservator, and the appropriateness of out-of-home care as an alternative to Protective Supervision.

[MPP §30-757.174]

PROTECTIVE SUPERVISION

Lawsuits that affect Protective Supervision:

- Marshall et al., v. Linda McMahon
    - PS not available in anticipation of medical emergency
- Calderon v. Anderson
    - Consumer must be able to put self at risk
    - PS not available in anticipation of environmental emergency
- Garrett / Lam v. Anderson
    - PS and kids

PROTECTIVE SUPERVISION

Memory

Orientation

Judgment

- Utilize Annotated Assessment Criteria for proper ranking.

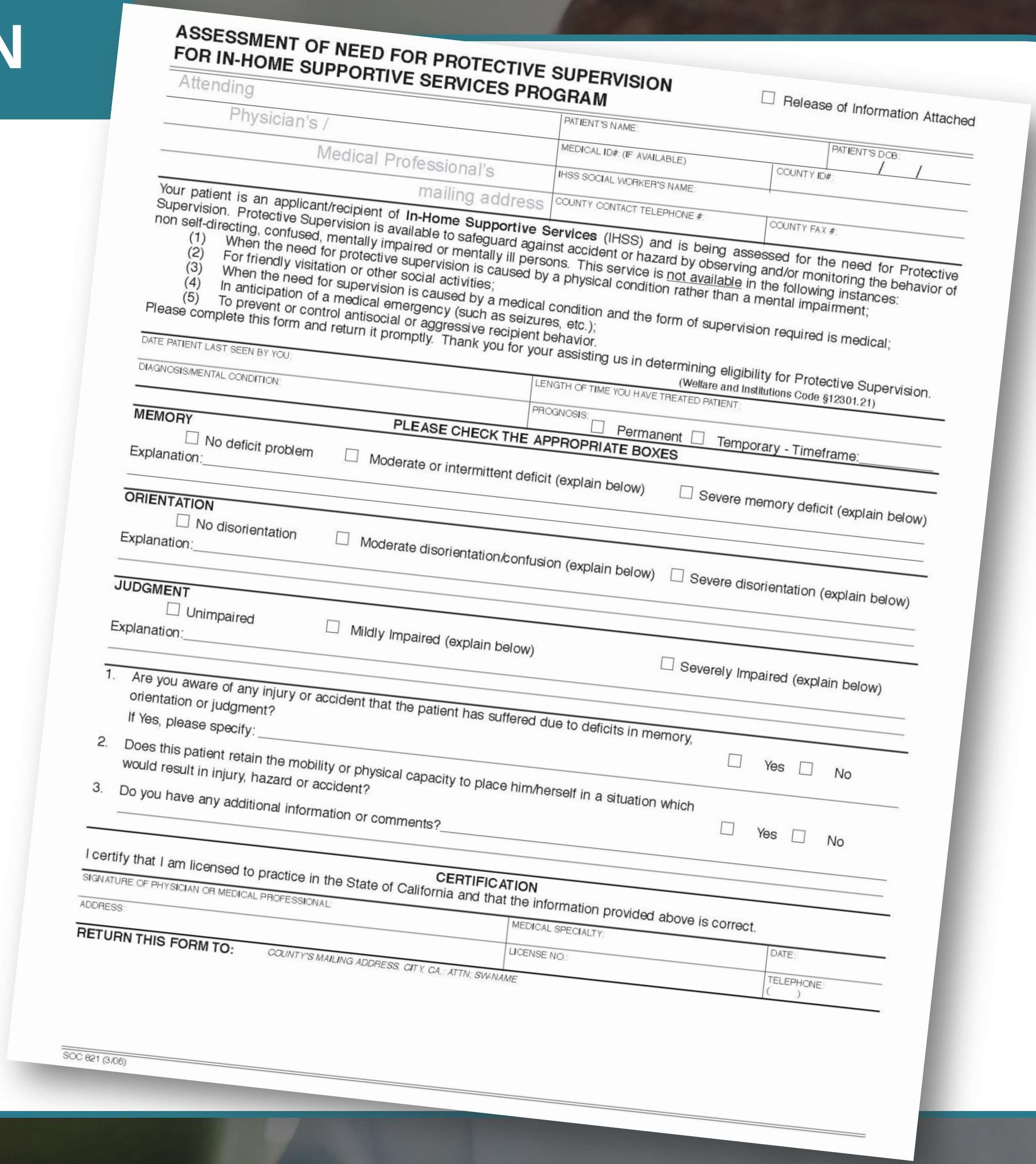
IHSS

PROTECTIVE SUPERVISION

Remember: The need for protective services is NOT diagnosis driven

PROTECTIVE SUPERVISION

Assessment of Need for Protective Supervision Form [MPP §30-757.173]



ASSESSMENT OF NEED FOR PROTECTIVE SUPERVISION FOR IN-HOME SUPPORTIVE SERVICES PROGRAM

☐ Release of Information Attached

Attending Physician's / Medical Professional's mailing address

PATIENT'S NAME:
MEDICAL ID#: (IF AVAILABLE)
PATIENT'S DOB: / /
IHSS SOCIAL WORKER'S NAME:
COUNTY ID#:
COUNTY CONTACT TELEPHONE #:
COUNTY FAX #:

Your patient is an applicant/recipient of **In-Home Supportive Services** (IHSS) and is being assessed for the need for Protective Supervision. Protective Supervision is available to safeguard against accident or hazard by observing and/or monitoring the behavior of non self-directing, confused, mentally impaired or mentally ill persons. This service is not available in the following instances:

(1) When the need for protective supervision is caused by a physical condition rather than a mental impairment;
(2) For friendly visitation or other social activities;
(3) When the need for supervision is caused by a medical condition and the form of supervision required is medical;
(4) In anticipation of a medical emergency (such as seizures, etc.);
(5) To prevent or control antisocial or aggressive recipient behavior.

Please complete this form and return it promptly. Thank you for your assisting us in determining eligibility for Protective Supervision.

(Welfare and Institutions Code §12301.21)

DATE PATIENT LAST SEEN BY YOU:
LENGTH OF TIME YOU HAVE TREATED PATIENT:
DIAGNOSIS/MENTAL CONDITION:
PROGNOSIS: ☐ Permanent ☐ Temporary - Timeframe:

PLEASE CHECK THE APPROPRIATE BOXES

MEMORY

☐ No deficit problem ☐ Moderate or intermittent deficit (explain below) ☐ Severe memory deficit (explain below)

Explanation:

ORIENTATION

☐ No disorientation ☐ Moderate disorientation/confusion (explain below) ☐ Severe disorientation (explain below)

Explanation:

JUDGMENT

☐ Unimpaired ☐ Mildly Impaired (explain below) ☐ Severely Impaired (explain below)

Explanation:

1. Are you aware of any injury or accident that the patient has suffered due to deficits in memory, orientation or judgment? ☐ Yes ☐ No
   If Yes, please specify:
2. Does this patient retain the mobility or physical capacity to place him/herself in a situation which would result in injury, hazard or accident? ☐ Yes ☐ No
3. Do you have any additional information or comments?

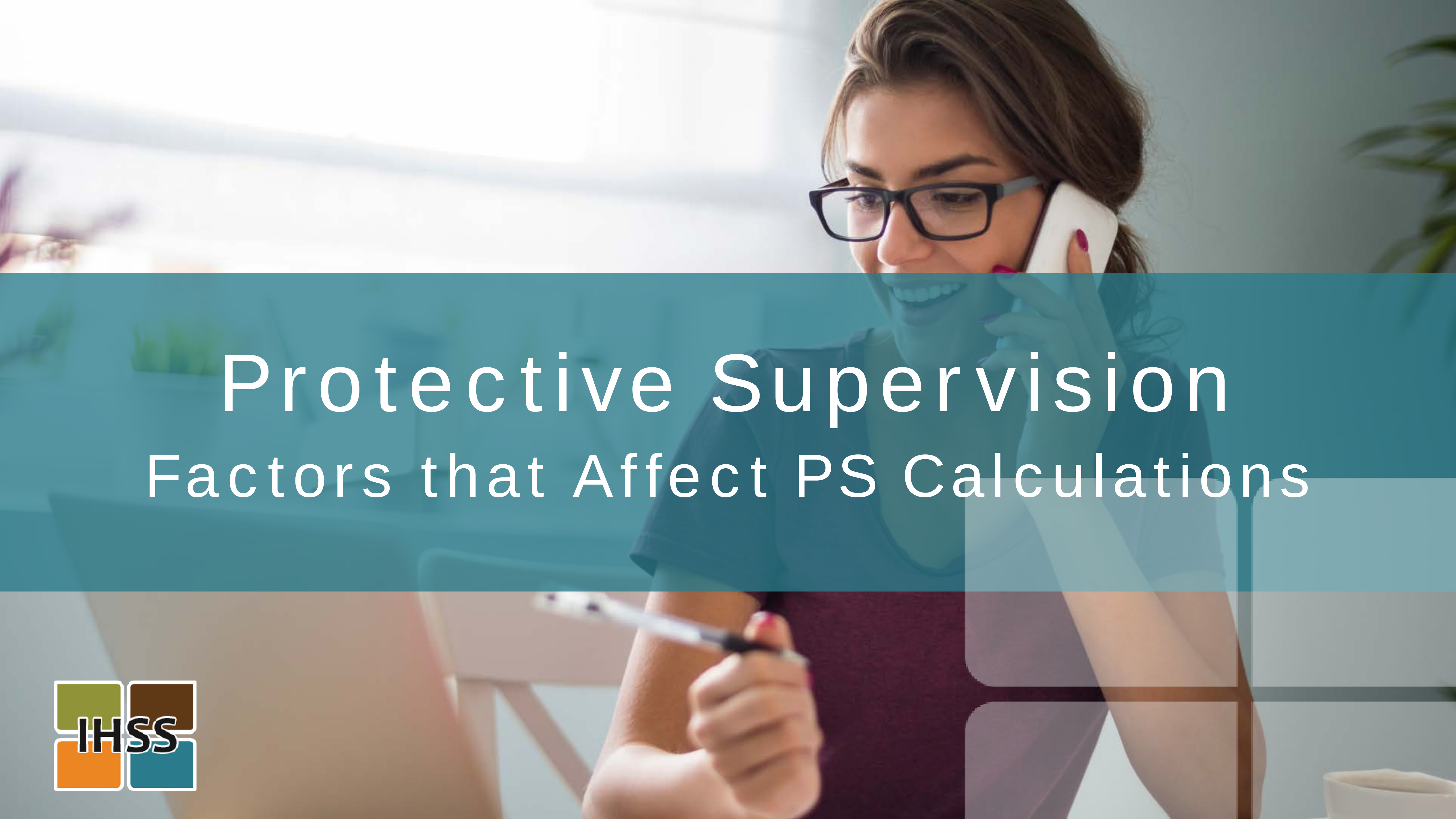
CERTIFICATION

I certify that I am licensed to practice in the State of California and that the information provided above is correct.

SIGNATURE OF PHYSICIAN OR MEDICAL PROFESSIONAL:
ADDRESS:
MEDICAL SPECIALTY:
LICENSE NO.:
DATE:
TELEPHONE: ( )

RETURN THIS FORM TO: *COUNTY'S MAILING ADDRESS, CITY, CA.: ATTN: SW-NAME*

SOC 821 (3/06)



Protective Supervision

Factors that Affect PS Calculations

IHSS

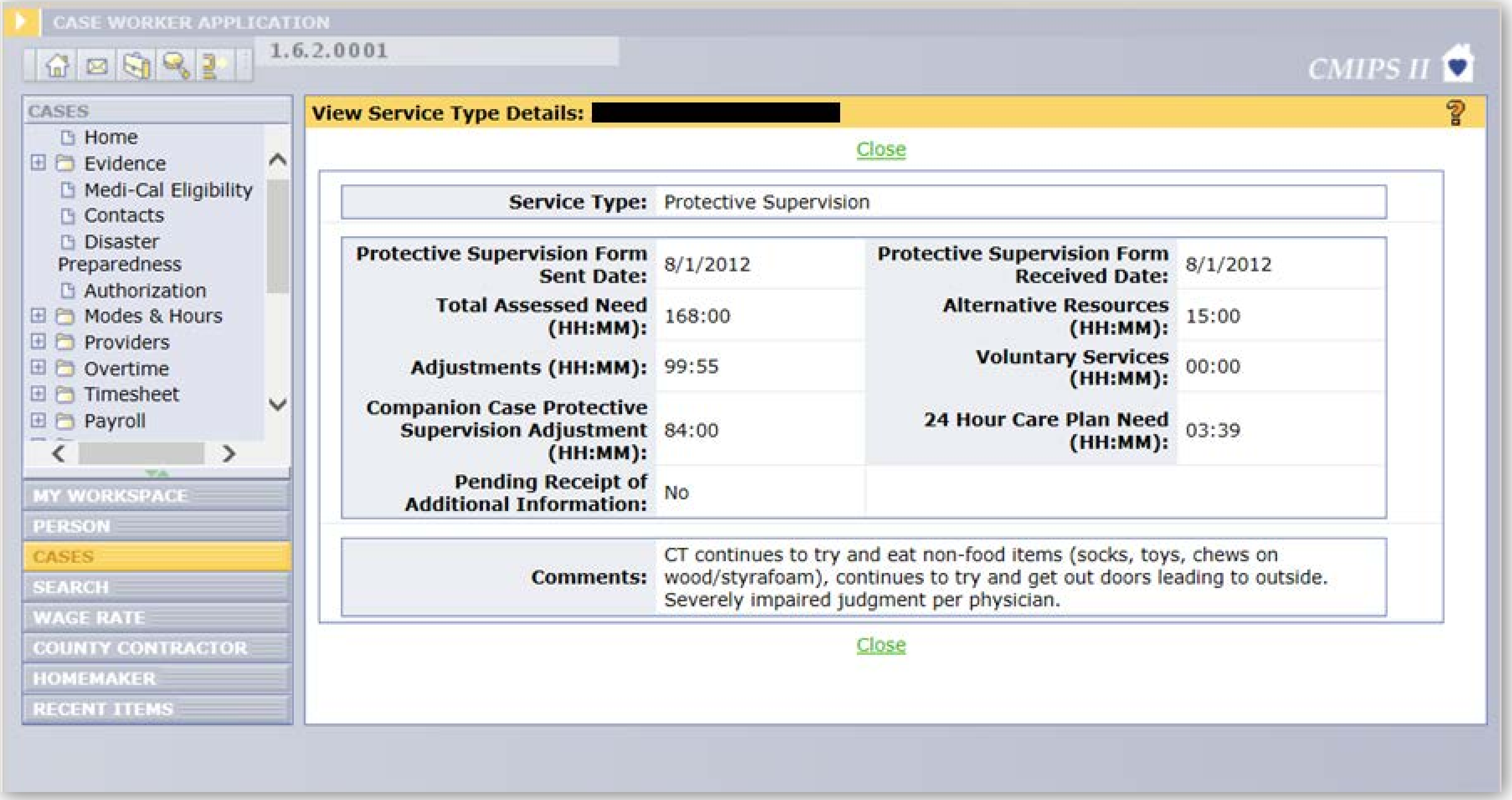
PROTECTIVE SUPERVISION

Factors that affect calculation of Protective Supervision hours

- NSI and SI
- Number of recipients in household
- Number of recipients receiving PS
- Alternative resources
    - True Alternative resources
    - Voluntary resources

PROTECTIVE SUPERVISION

Service type: Protective Supervision



View Service Type Details: [redacted]

Service Type:	Protective Supervision		
Protective Supervision Form Sent Date:	8/1/2012	**Protective Supervision Form Received Date:**	8/1/2012
Total Assessed Need (HH:MM):	168:00	**Alternative Resources (HH:MM):**	15:00
Adjustments (HH:MM):	99:55	**Voluntary Services (HH:MM):**	00:00
Companion Case Protective Supervision Adjustment (HH:MM):	84:00	**24 Hour Care Plan Need (HH:MM):**	03:39
Pending Receipt of Additional Information:	No		
Comments:	CT continues to try and eat non-food items (socks, toys, chews on wood/styrafoam), continues to try and get out doors leading to outside. Severely impaired judgment per physician.		

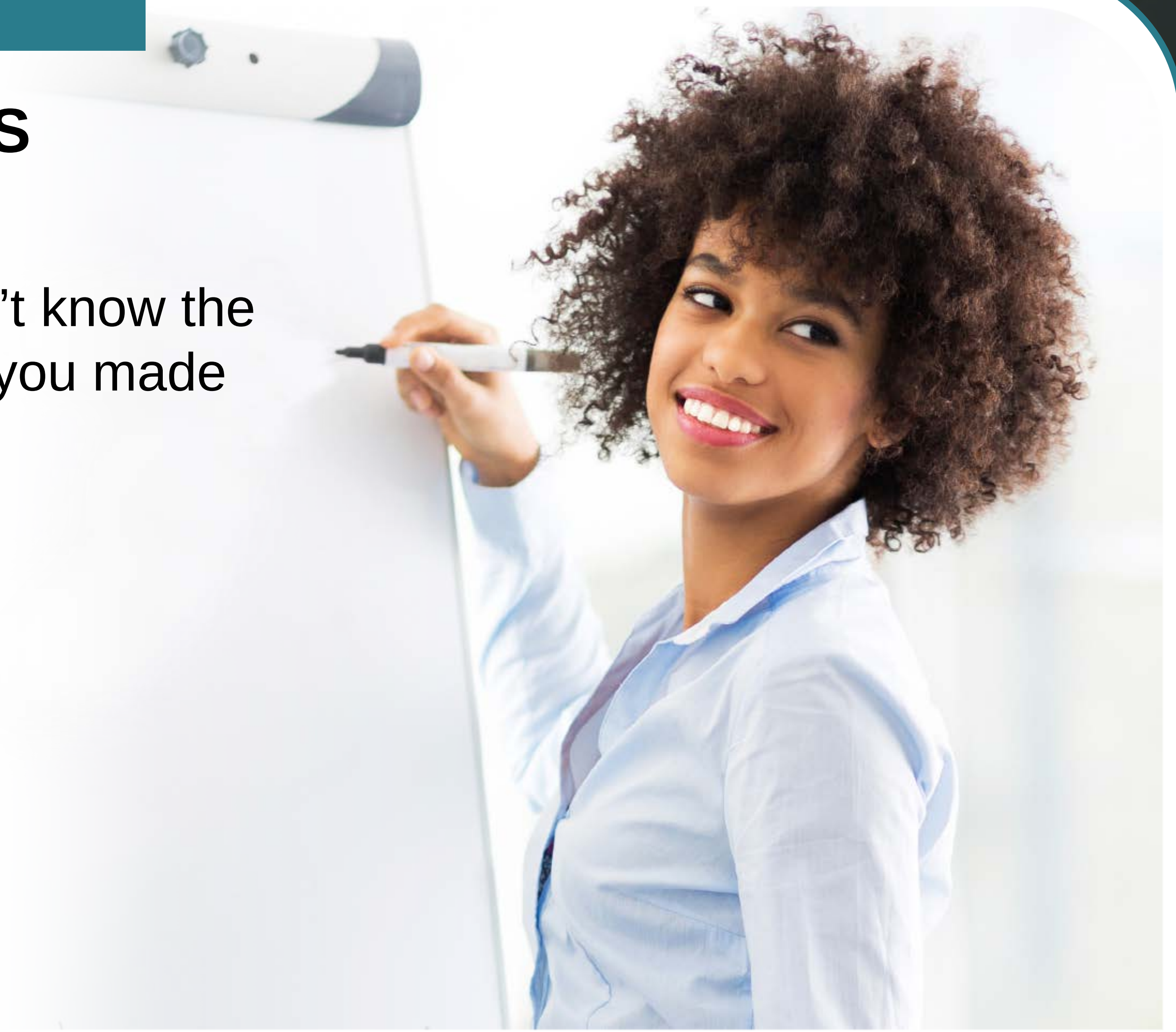
PS Adult Scenarios

IHSS

PROTECTIVE SUPERVISION

Activity: Documenting PS for Ineligible Consumers

- Would someone that doesn’t know the consumer understand why you made your decision?
- Paint the picture.
- Include specifics.



Protective Supervision

Removing Protective Services

PROTECTIVE SUPERVISION

Removing Services

- **Consider progression** of condition may lessen need.
- Authorization should change when the consumer deteriorates and is **no longer capable** of putting self at risk.
- Consider family stress and refer to **alternative resources**.
- **Document clearly** for possible consumer challenge of decision to include using regulation language.

PROTECTIVE SUPERVISION

Margaret

PROTECTIVE SUPERVISION

Other resources for people who do not qualify for Protective Supervision

- Local mental health agencies
- 5150 if suicidal
- APS
- Day programs
- County mental health

PROTECTIVE SUPERVISION

IHSS Provider Issues

Protective Supervision

For Minors

IHSS

PROTECTIVE SUPERVISION FOR MINORS

Define Protective Supervision

Protective Supervision consists of observing recipient behavior and intervening as appropriate in order to safeguard the recipient against injury, hazard, or accident.

PROTECTIVE SUPERVISION FOR MINORS

Protective Supervision shall NOT be authorized:

a. For friendly visiting or other social activities.
b. Where the type of supervision required is medical.
c. In anticipation of a medical emergency.
d. To prevent or control anti-social or aggressive recipient behavior.
e. To guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.

PROTECTIVE SUPERVISION FOR MINORS

What governs PS for minors?

- Protective Supervision rules in MPP §30-757.17
- Functional Index rules in MPP §30-756
- Assessing minor rules found in MPP §30-763.44 and .45
- Provisions of the settlement agreement reached in the Garrett v. Anderson and Lam v. Anderson court cases

PROTECTIVE SUPERVISION FOR MINORS

Assessing PS need for minors

- MPP §30-763.456(d) states that Protective Supervision does not include routing child care or supervision
- Must consider:
  - Age of the minor
  - Type of care
  - Supervision needed

PROTECTIVE SUPERVISION FOR MINORS

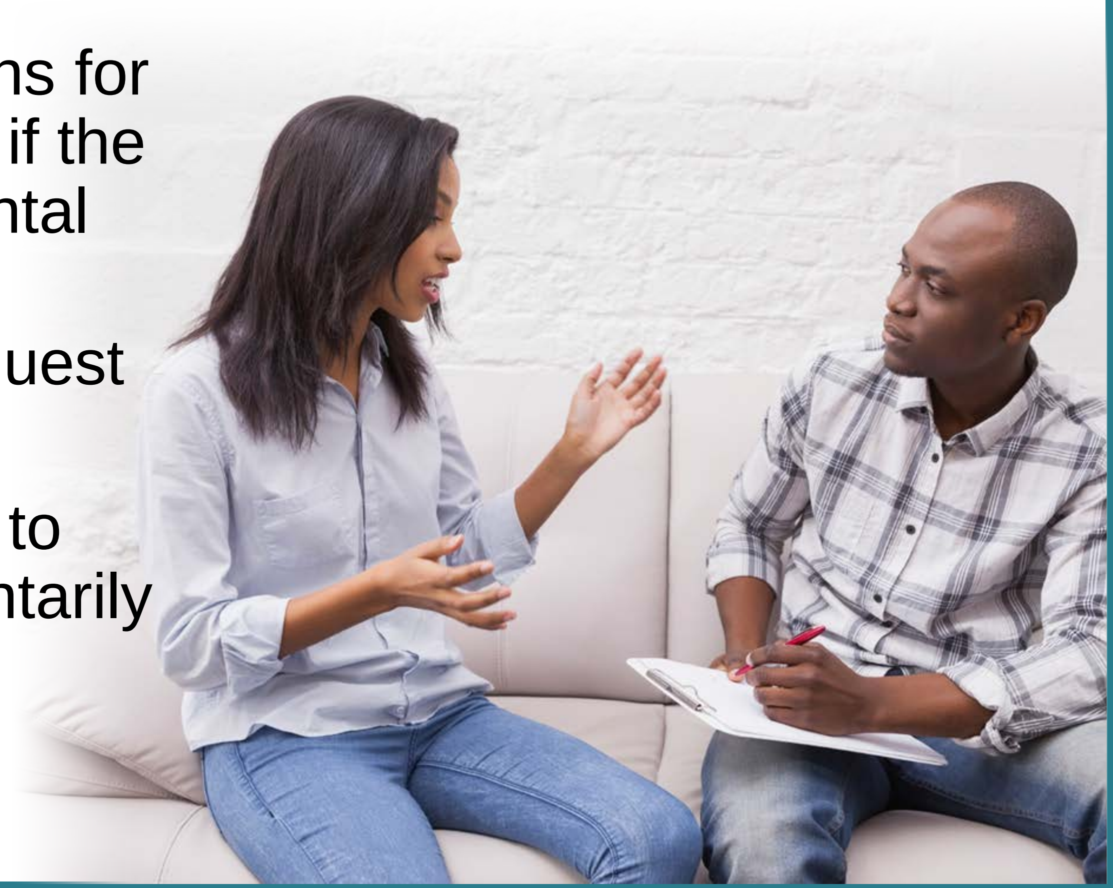
Assessment of minor’s mental functioning

- Minor’s cognitive and emotional impairment
- Functional limitations of the minor
  - Actual behavior must be considered regardless of the age of the minor
  - Must not presume that a minor of a particular age has a mental functioning score of “1” in Memory, Orientation and/or Judgement

PROTECTIVE SUPERVISION FOR MINORS

Informing the parent/guardian of the existence of Protective Supervision

- The parent/guardian:
  - Must be informed of the conditions for receiving Protective Supervision if the minor has any evidence of a mental impairment
  - Does not need to specifically request Protective Supervision
- A parent's or guardian's willingness to provide Protective Supervision voluntarily cannot be assumed



PROTECTIVE SUPERVISION FOR MINORS

Review of the minor’s mental functioning

- Obtain available information and documentation about the existence of a minor’s mental impairment
  - Determine if the minor’s SSI eligibility is based on a mental impairment
  - Determine if the minor is eligible for regional center services

PROTECTIVE SUPERVISION FOR MINORS

Review of the minor’s mental functioning

Information will also come from:

- Ability to perform self-care
- Ability to perform daily chores
- Capacity to perform functions safely
- Diagnosis

PROTECTIVE SUPERVISION FOR MINORS

Additional Information for the assessment

- Assessment of need for Protective Supervision for In-Home Supportive Services program (form SOC 821)
- PHN (if available)
- Other medical reports
- Collaboration with other social service agencies such as a regional center or CPS

PROTECTIVE SUPERVISION FOR MINORS

The existence of a mental impairment, in itself, does not qualify a minor for Protective Supervision.

PROTECTIVE SUPERVISION FOR MINORS

24 HOUR NEED

- A need exists for 24 hours a day of supervision in order for the consumer to remain at home safely.
- If the parent leaves the minor for some fixed period of time, like five minutes, the minor may still qualify for PS.

PROTECTIVE SUPERVISION FOR MINORS

Importance of documenting PS and alternative resources

- What alternative resources exist?
- Who is providing?
- What services are being provided?
- What is the frequency of services provided?

PROTECTIVE SUPERVISION FOR MINORS

THE REST OF THE STORY…

- Is there a mental illness/mental impairment?
- Is there a behavior that puts him/her at risk?
- Is the behavior non-self directed?
- Is supervision protective in nature?
- Is the supervision above and beyond what you would provide a minor of the same age without a mental impairment?
- Is there a 24 hour need?
- Are there any interventions in place?

IHSS
IN-HOME SUPPORTIVE SERVICES
TRAINING ACADEMY

Congratulations!

You have completed

IHSS Comprehensive Assessment: Day 3

CDSS
CALIFORNIA
DEPARTMENT OF
SOCIAL SERVICES

SAN DIEGO STATE UNIVERSITY

ASSISTIVE DEVICES
DURABLE MEDICAL EQUIPMENT (DME)

- Importance of DME
    - Promotes the consumer’s independence.
    - Improves quality of life and satisfaction.
    - Can greatly affect the consumer’s functional ability.

- Assess the consumer’s use of and possible need for DME.

- Must have medical prescription for payment of DME.

- Social Workers should tell consumers if they believe DME would be helpful/necessary, and encourage them to discuss with their physician and/or supplier of equipment.

- Document DME and how it affects the consumer’s independence when assigning functional scores and authorizing services.

- DME is important for improving consumer functional status, in promoting self-esteem and independence, as well as in decreasing the need for human support services.

- IHSS cannot require that the consumer obtain/utilize DME even if it would result in decreased hours.

- Equipment supplier is usually familiar with what various insurance carriers require and may be able to assist in getting necessary prescriptions, etc. For Medi-Cal recipients, the supplier must often get a pre-authorization called a Treatment Authorization Request (TAR).

DOING THE INTERVIEW: HOW TO REALLY ASK THOSE QUESTIONS

The assessment interview is a valuable tool in assessing the needs of clients. If done correctly the assessment can be an enjoyable and rewarding experience for both the client and the assessor. If done incorrectly the assessment can be biased, frustrating and a waste of everyone's valuable time. The most common mistakes made in any kind of assessment are:

- Failure to ask the questions on the tool.
- Not spending time to develop rapport with the client.
- Bias or leading the client.
- Inappropriate probing.
- Avoiding difficult situations.

Ask The Questions

If your assessment is done correctly you should be able to:

- Determine eligibility of the client.
- Better respect the rights of the client.
- Identify services that will fit the needs of the client.
- Become more familiar with future needs of the client.

For the client's sake, the assessment should be taken seriously. You may think you know how the client feels, but unless you ask the questions you are only guessing. For example: If the client has recently lost a spouse and you don't ask related questions dealing with mood and outlook because you assume you know the answers, you have lost valuable information. You do not know if the client is handling the situation within the normal range of grief, or is not facing the situation and may need help. You may just assume he/she is depressed. Depression, sadness, and grief are very different. It is far better to learn how to talk to the grieving client and how to ask questions in difficult situations than to answer for the client.

A common problem is not asking the questions when they are embarrassing to the assessor. The interviewer is often uncomfortable talking about incontinence or income or both. Generally, clients don't mind describing toileting issues if discussed matter-of-factly. If questions are handled in a respectful manner people will not mind discussing these issues. If you have developed rapport with the client early on you will not feel as embarrassed. The client will understand that what you are doing is important and you will feel confidence in the rapport established. The assessment is not to embarrass, but to provide appropriate services. Incontinence is a common problem with older people and is not embarrassing. If an individual becomes embarrassed by questions it is your responsibility to comfort that person. You may want to say, "I talk to a variety of people in many different situations and all questions are important in determining your needs. All questions may not be relevant to your or your situation but they are all an important part of the assessment."

Spend Time to Develop Rapport

The next thing to learn is developing rapport with the client. The time you spend in the beginning to develop rapport can make or break an assessment. If the client feels comfortable with you, he/she will speak more openly with you. Spending time to develop rapport can make the interview go more quickly, you will gather more valuable information, and the conversation will be more enjoyable. You develop rapport by:

- Speaking in a conversational tone.
- Spending time talking something other than the assessment (small talk).
- Not being afraid to answer questions. Approach questions as an opportunity to explain further, not as an obstacle to overcome.
- Listening to the client and making a mental note of speech patterns. This will help you pace the assessment to the characteristics of the client. It is important early on to note whether the client is talkative or quiet.
- Letting clients know you are enjoying talking with them; it will help them relax.
- Observing the client's behavior in the presence of others. If there are other family members or providers in the room, this will give you an opportunity to view how openly the client speaks in front of others.
- Spending some time talking about the assessment before you begin. Tell the client the type of questions you will be asking and why, i.e. "I will ask you some general questions about activities you may be involved in. This will help us work together to figure out your needs and how we can be helpful to you".
- Always be professional, but not being afraid to enjoy yourself. You can laugh and be relaxed while doing your job. If you are relaxed the client will know that they too can be relaxed.

The time you spend developing rapport with the client will help you better understand him/her. This knowledge of the client will help you direct conversation, know when to probe more, give you an idea of how talkative the client is and how much time the assessment will take.

Avoiding Bias

This is an area where many professionals will err. A bias is any influence that changes an answer or opinion from what it might have been without that influence. It is important to be aware of your own bias and how that would conflict with the assessment. Once you say to the client "so what you are trying to say is" you have given your opinion and biased the assessment.

It is important to be aware of interviewing errors. It is easy to relax your objective attitude and thus bias responses. To avoid influencing or biasing, follow these rules:

- DO NOT express your own opinions or how you think the client should respond (i.e. "I think everyone should have physical therapy"). Clients will change their answers to please you or change their answer to what you believe would be the correct answer. Try to reassure the client that you really do want their opinions and are interested in what they experience or feel about a certain situation. The whole purpose of an assessment is defeated when you answer for a client, lead the client or bias the client's responses.
- DO NOT suggest answers even if the client wants your help. Help the client sort out their opinions or responses; don't give them the answer. Repeat the question slowly, pause, and tell the client to "take a moment and think about it". If you take your time and do not rush the client, you will be less likely to suggest an answer. The client will appreciate your kindness and patience.
- DO NOT use leading probes. Any probe which suggests an answer is a leading probe and can bias the interview. Do not make the assumption that you know what the client is talking about; let

the client explain. Don’t lead the client to an answer or response you think seems right or fits their situation.

- DO NOT rush the client. Some people need time to sort out their responses. If the client is not answering, do not take this as if they are objecting to the assessment, but allow them a moment to think through their answers. If you jump too soon, you will try to answer for them. You may think the client does not understand or does not like the question when he/she is just trying to think of answers. Do not appear impatient; appear interested. You can acknowledge that ‘it is sometimes difficult to decide these answers’.

The obvious and most unfair way to bias the assessment is not to ask the questions. Give the clients the opportunity to tell you their responses, and what type of care they do or don’t want. The only way you will find this out is if you let the client tell you. The last ten people you talked to might have felt a certain way, but the next person is different. If you don’t ask the clients you will never know.

How to Probe

One of the most common mistakes in probing is to use an inappropriate probe that is a probe that either leads or would bias the interview. Correct probing is probably the most difficult part of the assessment. Inappropriate probing will occur when the interviewer is having difficulty obtaining a response from the client or when a question is asked and the client does not know how to answer it. A correct probe is a prompt which encourages further conversation without biasing the response. The probes you would use most often are:

- Probing for correctness.
- Probing for clarity.
- Probing for completeness.

<u>Probing for correctness</u> is used where you want the client to answer within a category or within set responses. The best way to probe for correctness is:

- Repeat the question. When doing this, change your tone or where you pause, and it may sound different; speak slowly; and look up at the client. Try to add small talk before you repeat the question.
- If you probe in a pleasant, conversational manner your probes will not seem repetitive or obtrusive. Keep telling the client how important it is to get their views and what they feel are their needs.

<u>Probing for clarity</u> often entails asking the client for a more specific response or an explanation to their answers. The client has answered your question, but you need to clarify what is meant by that answer. Always try to help the client when probing for clarity; let the client know what you don’t understand and what you need clarified. The most common probes for clarity are:

- “What do you mean by that?” You said that you were tired a lot; tell me what that means to you.” You want the client to open up and talk to you. Does tired mean bored or sleepy or you can’t get out of the chair to answer the telephone when it rings? If the client doesn’t explain tired to you, it is left to your interpretation of what tired means to you. It is much better to find out what it means to the client.

- "Could you explain that, tell me more about that?" If you are interested in what the client is saying and the conversation is going smoothly, asking the client to explain or tell you more will seem natural.
- "I'm not sure I understand." Simply direct the client's comments by letting him/her know what you do not understand.

When assessing a client for mental health issues, the answers do require probing. For example, you ask, "Do you see things that others don't see?" and the client answers "Yes." Before deciding to refer to a mental health specialist, a probe "Can you tell me more about what you see?" would be helpful. The client might say, "I've always been intuitive and perceptive, and people say I understand their feelings when others don't." That's very different from a hallucination.

Adapted from: *Doing the Interview: How to ask those questions and really enjoy it*. By: Colleen King, September 1990.

CLARIFYING INFORMATION

It is important to probe for details and clarify information in order to get the best outcomes from the interview. Look for:

1. **Conflicting information.**
   - **What is observed is not consistent with information given.**
     For example, consumer says she can't feed herself but she has been knitting, an activity that demonstrates manual dexterity. Perhaps the consumer's difficulty is in lack of strength. Probing questions would be needed to tease out the basis of the statement that she cannot feed herself. Also, consider good days versus bad days. You may be seeing the consumer whose condition and abilities fluctuate.

   - **What the consumer says is inconsistent.**
     For example, he says that he has no trouble bathing himself yet tells you that he is unable to walk without someone's constant assistance because he can't hold onto the handrails of a walker or a cane and he's unsteady on his feet. Perhaps the consumer who is at risk of falling is extremely modest and doesn't want anyone to see his naked body.

   - **What the consumer says and the family says are in conflict.**
     For example, the consumer says that he needs no help in dressing. The daughter with whom he lives and who is also his primary caretaker says that she dresses him every day. Probing questions are needed to determine whether the daughter is dressing her father because it's faster than to let him do it himself, or if he is unable to dress himself. Issues to be considered would include his ability to reach, balance when standing, and ability to perform tasks that require manual dexterity such as buttoning and zipping.

2. **Unrealistic expectations of the program.**
   For example, the consumer had fallen and broken her hip. When she fell, she had lain on the floor for seven hours until a neighbor heard her calling for help. The consumer just returned home from a rehab facility for therapy following hip replacement. She wants around-the-clock care so that if she falls again, she will get immediate help. Her concerns are understandable, but not within the Program scope. An alternative would be to make referrals to organizations that can provide her with a panic button so that she can summon assistance in the event of another fall.

3. **Safety issues.**
   For example, a consumer says she is independently bathing. Though she's unsteady on her feet, she says that she holds onto the towel rack to aid in stability. You look in the bathroom and confirm that what she's using to stabilize her is not a properly installed grab bar but a towel rack that is starting to come loose from the wall behind the bathtub. She needs help getting into and out of the tub and a grab bar and shower bench. If she discusses this with her physician and obtains a prescription for these items, it's possible that Medi-Cal will pay for these safety devices. Without assistance into and out of the tub, she's at risk of falling.

How to Probe for Clarifying Information:

When probing to clarify information, the goal is to check that you have heard the consumer correctly, you are clear on the details of the information, and you have a complete picture of the situation. The following are a few methods that can be used to verify information and to decrease the risk of misunderstanding what the consumer has said.

1. **Paraphrasing:** Repeat the consumer's ideas in your own words. For example, the consumer says that he doesn't go to church anymore because he can't be far from a toilet after taking his diuretic. You say, "I see, you take a diuretic in the morning and have to be close to the toilet. How long does that last?"

2. **Stating your observations:** Tell the consumer your observations about his behavior, actions, and environment to find out if they are on target. For example, if you see that he can't get out of the chair without help, say so.

3. **Demonstration:** Have the consumer to show you an activity. For example, you wonder how well the consumer transfers. You ask the consumer to show you the apartment. That gives you the opportunity to see the consumer transfer without specifically asking the consumer to demonstrate.

4. **Asking clarifying questions:** These questions are questions that get to details. For example:
    - "What do you mean by that? You said that you were tired a lot; tell me what that means to you." If the consumer doesn't explain what they mean it is open to interpretation.
    - "Could you explain that? Can you tell me more about that?"
    - "I'm not sure I understand." This simply directs the consumer's comments by letting him/her know you do not understand.

CHOOSING THE RIGHT QUESTIONS

Direct or Closed-ended Questions:

- Questions that seek a simple “yes” or “no” answer.
- Specifically ask for information. For example: “Are you coming tomorrow?” or “Do you eat three times a day?”
- These questions do not encourage or allow for an explanation of why the answer was chosen, or for an elaboration of thought or feeling about the answer.
- They can be leading. They ask a question in narrow terms so that they seem to be “hinting” at the answer.

Open-ended Questions:

- Can not be answered by yes or no.
- These questions begin with “who,” “what,” ‘where,” “when” or “how.”
- They give consumers more choice in how they answer and will encourage them to describe the issue in their own words.
- Open-ended questions seek out the consumer’s thoughts, feelings, ideas, and explanations for answers.
- They encourage elaboration and specifics about a situation. For example: “How are you able to bathe yourself?”

Indirect Questions:

- Ask questions without seeming to.
- They are not stated as a question.
- In these, the interviewer is asking a question without stating it in question format. For example: “You seem like you are in a great deal of stress today.”

OPEN-ENDED QUESTIONS FOR INTERVIEWS

Open-ended questions cannot be answered by yes or no. These questions usually begin with “who,” “what,” “why,” “where,” and “when.”

1. How have you been managing at home since I saw you last/since you got home from the hospital?
2. What do you need in the way of help right now?
3. Let’s talk about things you are able and not able to do.
4. Help me understand….
5. What do you mean by________?
6. Would you tell me more about…?
7. What else can you tell me that might help me understand?
8. Could you tell me more about what you’re thinking?
9. I’d be interested in knowing…
10. Would you explain…?
11. Is there something specific about __________that you are asking for?
12. Would you explain that to me in more detail?
13. I’m not certain I understand…Can you give me an example?
14. I’m not familiar with____________, can you help me to understand?
15. What examples can you give me?
16. You say that you’re not able to [cook/bathe/…_] . How have you been managing [your meals/bathing/…]?
17. When you say _______, what do you mean?
18. I’d like to help you get the best possible service; what more can you tell me that will help me understand your need?

Adapted from: *Understanding Generalist Practice*, Kirst-Ashman and Hull Nelson-Hall Publisher

INTERVIEW SKILLS

Establishing Rapport – Warmth, Empathy, and Genuineness:

- **Warmth** – Conveys a feeling of interest, concern, and affection to another individual. It promotes a sense of comfort and well being in the other person. Examples: "Hello. It's good to meet you." "I'm glad we have the chance to talk about this." "It's pleasant talking with you."
- **Empathy** – Being in tune with how a consumer feels, as well as conveying to that consumer that you understand how she/he feels. Does not mean you agree. Helps consumer trust that you are on his/her side and understand how he/she feels. It also is a good way to check to see if you are interpreting what you observe correctly. Mirroring non-verbal can send empathetic messages. Example of leading phrases: "My impression is that…" "It appears to me that…" "Is what you're saying that…" "You seem to be…." "I'm hearing you say that…"
- **Genuineness** – Means that you continue to be yourself, despite the fact that you are working to accomplish goals in your professional role. Being yourself and not pretending to be something you are not conveys honesty and makes consumers feel like you are someone they can trust.

General Interviewing Skills:

Before the Interview – Review the case and think about the possible things you will need to assess with this consumer. Are there any cues from the initial information that help you to come up with an approach to the interview? For example: Is the consumer a native English speaker, blind, or mentally impaired?

Pre-interview Planning – Be Prepared

- Review case file and gather cues about consumer
- Formulate questions based on cues
- Plan interview approach

Meeting the Consumer – Establish Rapport

- Introductions should be formal and cordial
- Small talk to get the conversation going
- Pay attention to verbal and non-verbal cues

Begin Assessment Interview – Explain Process

- Explain purpose of interview
- Explain your role to the consumer
- Ask the consumer for feedback – do they understand the process and purpose?

Concluding the Interview

- Clarify – Next steps
- Explain – Additional paperwork needed before authorization of services
- Discuss – Notification process of authorized hours
- Answer – Questions the consumer may have

COMPLETING THE SOC 864
IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM
INDIVIDUALIZED BACK-UP PLAN AND RISK ASSESSMENT

☐ The Individualized Back-Up Plan and Risk Assessment form (SOC 864) is required for all HSS cases. This individualized Back –UP and Risk Assessment process identifies risks and mitigates these potential issues through program services, referrals to other available programs and services, identified individuals person to the recipient, emergency contacts, and disaster preparedness and is agreed upon by the recipient and social worker completing this process.

☐ The SOC 864 is designed to facilitate a discussion between the social worker and recipient and any others whom the recipient wants involved in order to ensure the recipient is making informed decisions about risk and their options. During the discussion, individuals in the recipient's life that may be called upon when a provider has not arrived as scheduled, or another issue arises that could potentially put the recipient at risk, should be discussed and identified. These individual's contact information (telephone, pager, etc.) must be included in the Individual Back-Up Plan, along with entities (Police, Fire Department, Adult Protective Services, etc.) and their contact numbers, plus 9-1-1, that are provided to assist the recipient, if needed.

☐ When working with recipients, there are needs that the IHSS program cannot meet because the program does not provide for that service.

☐ When filling out the SOC 864 Section 2, help the recipient to look for all available resources to support them for non-emergency and emergency needs. Section 3 of the form is the General Risk Assessment, Section 4 is the Disaster Preparedness section and section 5 contains areas for recipient/authorized representative and social worker signatures. If necessary, you may need to help them identify resources that aren't obvious. Make sure you reinforce how to contact other resources that are available to them.

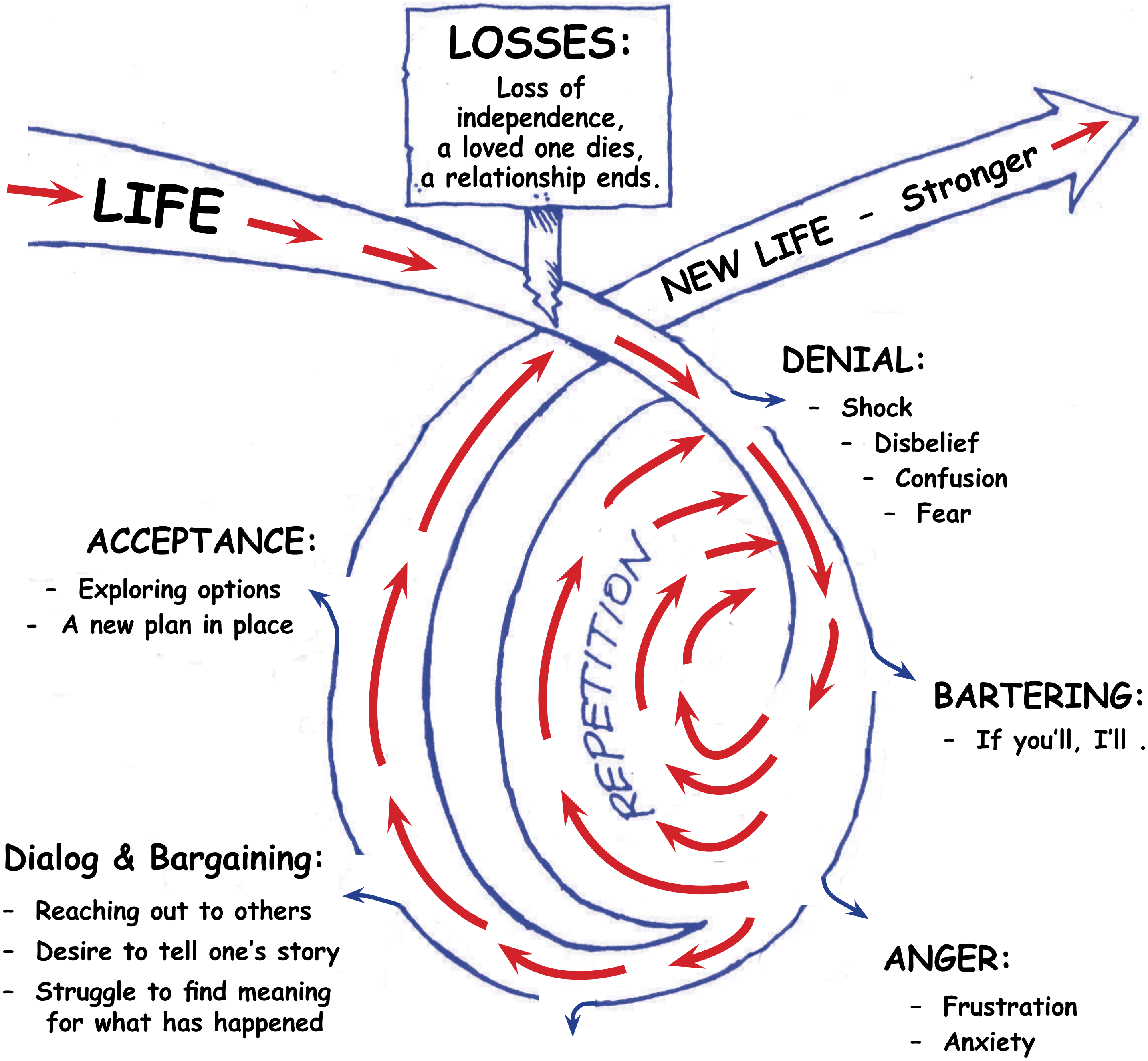
☐ When discussing risk, you should be mindful of the following:
  - What risks you are aware that exist.
  - The factors that are influencing the recipient's decisions.
  - Influences on decisions by other involved persons such as family and providers.
  - Available resources that can be considered to augment the recipient's options.

☐ Even though you may not be able to provide a solution, you can help the recipient see risk and its potential concerns, and refer them to services that may be able to help them mitigate these risks and meet their needs.

☐ The discussion that occurs should be well documented by using the SOC 864, and if necessary, documenting further information in the recipient's CMIPS file either in the narrative note or case note.

THE LOSS CYCLE

The Normal Cycle for All Losses



LOSSES:

Loss of
independence,
a loved one dies,
a relationship ends.

DENIAL:

- Shock
- Disbelief
- Confusion
- Fear

BARTERING:

- If you'll, I'll ...

ANGER:

- Frustration
- Anxiety
- Irritation
- Embarrassment
- Shame

DEPRESSION:

- Hopeless
- Helpless
- Overwhelmed
- Lack of energy

Dialog & Bargaining:

- Reaching out to others
- Desire to tell one's story
- Struggle to find meaning for what has happened

ACCEPTANCE:

- Exploring options
- A new plan in place

SOME FACTS ABOUT GRIEF

Two simple **definitions** of grief are:

1. The conflicting feelings caused by the end of or change in a familiar pattern or behavior.
2. A normal, natural, and painful emotional reaction to loss.

Causes of Grief:

- Passing of a human life.
- Death of a relationship (divorce).
- Loss of health and function and loss of independence.
- Loss of a pet.

Grieving involves intense feelings - love, sadness, fear, anger, relief, compassion, hate, or happiness, to name a few. These feelings are intense, disorganizing, and can be long-lasting. Grieving has been described as drowning in a sea of painful emotions.

Stages of Grief:

1. **Shock** – Immediately following the death of a loved one, it is difficult to accept the loss. A feeling of unreality; a feeling of being out-of-touch.
2. Emotional Release – Awareness of enormity of loss is realized accompanied by intense pangs of grief. In this stage a grieving, an individual sleeps poorly and weeps uncontrollably.
3. **Panic** – Feelings of mental instability, wandering around aimlessly, forgetting things, physical symptoms.
4. **Guilt** – Feelings of guilt about failures in relationship, inability to change situation or to save deceased.
5. **Hostility / Anger** – Feelings of anger over the situation, cause of death, and sometimes even at the deceased.
6. **Inability to Get Back to Normal** – Difficulty in regaining normality of daily living. Difficulty in concentrating on the day-to-day activities. The grieving person's entire being, emotional, physical, and spiritual, is focused on the loss that just occurred.
7. **Acceptance of Loss** – Life balance slowly returns. There are no set timeframes for healing. Each individual is different.
8. **Hope** – The pains of grief are still present but the grieving person is able to find hope for the future. The individual is able to move forward in life with good feelings knowing they will always remember and have memories of the loved one.

Note: Consumers may pass through each stage more than once and may be in more than one stage at a time. There is no particular order in which they may work through these stages. Even if they appear to have reached the end, another loss may trigger them to go back in to another stage.

Helping Consumers through the Grief Process:

- Encourage consumer to take his/her time going through the grief process. Offer support and encourage consumer and family not to try to rush the process.
- Explain to the consumer that because this is a time of instability and high emotions, it is not a good time to make major life decisions.
- Encourage use of support groups for drug and alcohol if consumer / family have history of dependency.
- Help consumer to understand that they will have good days and bad days.
- Encourage the consumer to seek out people who can listen to stories and remember the loved ones.
- Reinforce that grief is a very personal and individual process – no one experiences it the same way.

FACT SHEET: GRIEF AND LOSS

Introduction

Grief is a natural process, an intense fundamental emotion, a universal experience which makes us human. It is a process that entails extremely hard work over a period of many painful months or years. People grieve because they are deprived of a loved one; the sense of loss is profound. The loss of a spouse, child or parent affects our very identities – the way we define ourselves as a husband, wife, parent or offspring. Moreover, grief can arise from the survivor's sudden change in circumstances after a death and the fear of not knowing what lies ahead.

The death of someone close can be a life-changing experience. If you are the primary caregiver of someone you love, this experience can affect every aspect of your life for some time. It is natural to grieve the death of a loved one before, during and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about.

Anticipatory Grief

If someone has had a prolonged illness or serious memory impairment, family members may begin grieving the loss of the person's "former self" long before the time of death. This is sometimes referred to as "anticipatory grief." Anticipating the loss, knowing what is coming, can be just as painful as losing a life. Family members may experience guilt or shame for "wishing it were over" or seeing their loved one as already "gone" intellectually. It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues and seek out the support of spiritual advisors, family and friends. And, depending on the impaired person's intellectual capacity, this can be a time to identify your loved one's wishes for burial and funeral arrangements.

Sudden Loss

A death that happens suddenly, unexpectedly, is an immeasurable tragedy. This type of loss often generates shock and confusion for loved ones left behind. Incidents such as a fatal accident, heart attack, or suicide can leave family members perplexed and searching for answers. In these cases, family members may be left with unresolved issues, such as feelings of guilt that can haunt and overwhelm a grieving person. These feelings may seem to take over your life at first. But over time it is possible to get past these thoughts and forgive yourself and your loved one. Give yourself plenty of time; it's virtually impossible to make yourself "move on" before you're ready.

People experiencing the sudden loss of a loved one have a particular need for support to get through the initial devastating shock, pain and anger. Family members, close friends, and clergy can be vital lifelines for the griever.

How Long Does Grieving Last?

Grief impacts each individual differently. Recent research has shown that intense grieving lasts from three months to a year and many people continue experiencing profound grief for two years or more. Others' response to this extended grieving process may sometimes cause people to feel there is something wrong with them or they are behaving abnormally.

This is not the case. The grieving process depends on the individual's belief system, religion, life experiences, and the type of loss suffered. Prolonged bereavement is not unusual. Many people find solace in seeking out other grievers or trusted friends. However, if feelings of being overwhelmed continue over time, professional support should be sought.

Symptoms of Grief

Grief can provoke both physical and emotional symptoms, as well as spiritual insights and turmoil.

Physical symptoms include low energy or exhaustion, headaches or upset stomach. Some people will sleep excessively, others may find they are pushing themselves to extremes at work. These activity changes may make an individual more prone to illness. It is important to take care of yourself during this period of bereavement by maintaining a proper diet, exercise and rest. Taking care of your body can help heal the rest of you, even if you do not feel inclined to do so.

Emotional symptoms include memory gaps, distraction or preoccupation, irritability, depression, euphoria, wailing rages and passive resignation. Some people identify strongly with the person who died and his/her feelings. If you have experienced a loss and are hurting it is reasonable that your responses may seem "unreasonable." Nonetheless, it is important not to judge yourself too harshly as you experience conflicting and overwhelming emotions.
Like grief itself, people's coping strategies vary. Some people cope best through quiet reflection, others seek exercise or other distractions. Some have a tendency to engage in reckless or self-destructive activities (e.g., excessive drinking). It is vital to obtain support in order to regain some sense of control and to work through your feelings. A trained counselor, support group, or trusted friend can help you sort through feelings such as anxiety, loss, anger, guilt, and sadness. If depression or anxiety persist, a doctor or psychiatrist may prescribe antidepressant drugs to help alleviate feelings of hopelessness.

Spirituality: You may feel closer to God and more open to religious experiences than ever before. Conversely, many people express anger or outrage at God. You may feel cut off from God or from your own soul altogether – a temporary paralysis of the spirit. If you are a person of faith, you may question your faith in God, in yourself, in others or in life. A member of the clergy or spiritual advisor can help you examine the feelings you are experiencing. Learning to deal with grief is learning to live again.

Stages of Grief

Often portrayed as a grief "wheel," these stages do not necessarily follow a set order. Some stages may be revisited many times as an individual goes through a grieving period.

- Shock.
- Emotional release.
- Depression, loneliness and a sense of isolation.
- Physical symptoms of distress.
- Feelings of panic.
- A sense of guilt.
- Anger or rage.
- Inability to return to usual activities.
- The gradual regaining of hope.
- Acceptance as we adjust our lives to reality.

Most people who have lost someone close go through all or some of these stages, although not necessarily in this specific order. This kind of healthy grieving can help a person move through a significant loss with minimal harm to self, either physical or mental.

Ethical Issues

Often family members and caregivers are faced with the decision to allow someone to die naturally or to prolong their death and maintain life through artificial means. Physician training, hospital and nursing home policies often dictate the use of "heroic means" to sustain life. "Reviving" a very ill person after a stroke or using a respirator for someone deemed medically "brain dead" are standard procedures used in many hospitals.

If at all possible, it is important to learn and document a person's wishes about using artificial life support before any crisis arises. A living will or durable power of attorney for health care (DPAHC) expresses a person's wishes when he or she can no longer speak for him/herself. These documents can help instruct hospitals or nursing homes on an appropriate course of action to be taken at a critical moment. By law, all hospitals must now inform patients about their right to fill out these documents.

When a person is confused, or otherwise unable to express preferences, family members are often put in the position of becoming surrogate decision makers. Such decisions present a thorny array of medical, legal, and moral questions. Decisions to provide or withhold life support are based on personal values, beliefs, and consideration for what the person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt or blame which may surface.

Tips for Helping the Bereaved

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own. This can have the effect of dismissing the grieving person's pain.
- Allow the grieving person to use expressions of anger or bitterness, including such expressions against God. This may be normal behavior in an attempt to find meaning in what has happened.
- Realize that no one can replace or undo the loss. To heal, the individual must endure the grief process. Allow him/her to feel the pain.
- Be patient, kind and understanding without being patronizing. Don't claim to "know" what the other person is feeling.
- Don't force the individual to share feelings if he/she doesn't want to.
- Physical and emotional touch can bring great comfort to the bereaved. Don't hesitate to share a hug or handclasp when appropriate.
- Be there later, when friends and family have all gone back to their routines.
- Remember holidays, birthdays, and anniversaries which have important meaning for the bereaved. Offer support during this time. Don't be afraid of reminding the person of the loss; he/she is already thinking about it.

Practical Assistance for the Bereaved

Things a person can do without asking:

- Send a card or flowers.
- Bring food.
- Water or mow their lawn.
- Donate blood.
- Contribute to a cause which is meaningful to your friend or family member.

Things a person can do to help but should ask first:

- Offer to stay in the home to take phone calls, receive food and guests.
- Offer child care on a specific date.
- Offer to care for pets.
- Offer transportation.

Credits

Ballard, E. L., *Managing Grief and Bereavement: A Guide For Families and Professionals Caring for Memory Impaired Adults and Other Chronically Ill Persons*, Duke Family Support Program, Durham, NC.

Bozarth-Campbell, A., 1982, *Life Is Goodbye, Life Is Hello*,CompCare Publications, Minneapolis, MN.
Harris Lord, J., 1990, *Beyond Sympathy*, Pathfinder Publishing, Ventura, CA.

Sankar, Andrea, 1991, *Dying at Home: A Family Guide for Caregiving*, Johns Hopkins University Press, Baltimore, MD.

Westberg, Granger E., 1976, *Good Grief*, Philadelphia: Fortress Press.

Recommended Readings

Caring For a Dying Relative: A Guide for Families, D. Doyle, 1994, 2001 Evans Road, Cary, NC 27513, Oxford University Press. (919) 677-0977.

On Death and Dying, Elisabeth Kubler-Ross, 1969, The Macmillan Co., New York, NY. Available at bookstores or P.O. Box 1387, Bryan, TX 77806. (800) 364-2665.

Don't Take My Grief Away, Doug Manning, 1979, P.O. Box 42467 N.W. Expressway, Suite 100, Oklahoma City, OK 73116, In-Sight Books. (800) 658-9262.

Dying at Home: A Guide for Caregiving, Andrea Sankar, 1991, The Johns Hopkins University Press, 701 W. 40th St., Baltimore, MD 21211-2190.
<<span class="bodycopy" />*How Can I Help?/What Will Help Me?,* James E. Miller, 1994, Willowgreen Publishing, 509 W. Washington Blvd., P.O. Box 25180, Fort Wayne, IN. (219) 424-7916.

Managing Grief and Bereavement: A Guide for Families and Professionals Caring for Memory Impaired Adults and Other Chronically Ill Persons (booklet), 1993, Duke Family Support Program, Duke University Medical Center, Durham, NC 27710. (919) 660-7510.

Resources

Family Caregiver Alliance
785 Market Street, Suite 750
San Francisco, CA 94103
(415) 434-3388
(800) 445-8106
Web Site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.
Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.
For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

Center for Loss and Life Transition
3735 Broken Bow Road
Fort Collins, CO 80526
(970) 226-6050

Foundation for Hospice and Home Care
513 C Street, NE
Stanton Park
Washington, DC 20002-5809
(202) 547-6586

National Hospice Organization
1901 N. Moore St., Suite 901
Arlington, VA 22209
(800) 658-8898

National Research and Information Center
(Death, Grief and Funerals)
2250 East Devon Ave., Suite 250
Des Plaines, IL 60018
(800) 662-7666

Reviewed by Patrick Arbore, Ed.D., Center for Elderly Suicide Prevention & Grief Related Services, and Andrew Scharlach, Ph.D., Professor, School of Social Welfare, University of California, Berkeley. Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health. Printed December 1996. © All rights reserved.

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OTHER ASSESSMENT CUES

Non-verbal assessment cues:

- **Your body speaks your mind**
    - Between 60-80% of our message is communicated through our body language. Only 7-10% is attributable to the actual words of a conversation.
    - Whenever there is a conflict between verbal and non-verbal, we almost always believe the non-verbal messages without necessarily knowing why.

- **Eye contact**
    - It is important to look a consumer directly in the eye. Hold your head straight and face the consumer. This establishes rapport and conveys that you are listening to the consumer. This is not staring, but being attentive. However, be conscious of cultural differences and respect them.

- **Facial Expressions**
    - These are the strongest non-verbal cues in face-to-face communication. Be aware of your own non-verbal – what are your habits that could be interpreted incorrectly?
    - Make certain that your facial expressions are congruent with your other non-verbal behavior. (Crossing arms, hands on hips, other…not portraying your interest) What do you see in the other person's face? If unclear, ask for interpretation.

- **Body Positioning**
    - Good posture and open arms (not crossed) are positive body language.
    - When interviewing consumers, look for cues in their body positioning and be aware of your own. Sitting in an attentive manner communicates you are interested.

Environmental Cues:

- Discrepancies between the environment and what the consumer reports as service needs.
- Importance of observations (i.e., house condition, cleanliness of consumer, tour house, etc.).

Sensory Cues:

- Data obtained by smelling.
- Tactile information – sticky floors, surfaces.

COMMUNICATING IN EMOTIONALLY CHARGED SITUATIONS

Tips for difficult conversations:

1. Listen for full understanding of the person’s perspective. Allow the opportunity to gain a clear picture of what he/she is trying to say.

2. Put the person at ease using non-verbal cues that show interest and concern.

3. Take the time you need to really understand the situation. In the long run, spending a few more minutes now will save time in avoiding conflict in the future.

4. Respond to concerns the person may have in an affirming manner. Restate his/her concerns in a way that shows you have heard the issues at hand.

5. Focus on the overall goal of the situation. Avoid personalization of the issues. Keep the conversation professional.

6. Understand what you do today will have an effect on tomorrow. The more effective you are in dealing with the issue at hand, the less the issue will grow and consume your energies.

Tips for handling hostility:

1. Don’t get angry or defensive. Recognize your own reactions. Remember that this is a professional, not personal, issue.

2. Don’t patronize or lecture. Saying things such as, “Why don’t you just calm down!” will only escalate the problem.

3. Allow the person to voice his/her concerns. Respond with acceptance and understanding. Be empathetic. Try to understand the situation from the person’s perspective.

4. Be positive – don’t attack him/her. Show respect for his/her discomfort.

5. Greet anger with calmness – set the mood for calm discussion and resolution.

6. Understand the facts regarding the situation that is upsetting the person. If you don’t have the facts, state what you will need to find out and when you will get back to him/her.

7. Focus on present and future. Emphasize what can be done positively in the future, not what has happened in the past.

8. Ask questions – “How can I help?” Often the person knows what he/she wants from you. If you understand those wants you will be able to discuss future possibilities with that in mind.

9. Summarize for clarification and understanding.

10. Be honest about your next steps. If you can’t fix the problem outright, don’t make promises that you cannot keep. If there are consequences to the behavior, let the person know.

Things to consider when dealing with someone who is hostile:

1. Try to evaluate as honestly as you can by reasoning with yourself whether his/her anger is justified.

2. Put hostile people in perspective. You are probably nothing but an afterthought to this person, so don’t take the antics personally. This person is not concerned about you because he/she is too busy worrying about his/her own self.

3. Take your pick – positive or negative. It will be difficult to concentrate on constructive, creative alternatives or solutions if you cling to negative feelings. Vent your emotions to a fellow worker or your supervisor and cool off. Think about the result you really want, the consequences or outcome that will benefit the individual the most.

4. Don’t expect hostile people to change. They will not, and in a way that is good because their behavior becomes predictable. They may not change but by choosing a better approach you can change the outcome.

5. Learn to respond as well as listen. Ask questions instead of making accusations. If you let others save face, you give them room to change their minds.

6. Request feedback. Use open-ended questions to let emotional people vent their feelings before you try to reason with them and explore options.

7. Be straightforward and unemotional. The more you remain calm and matter-of-fact, the sooner you gain another’s confidence. People want to feel you are leveling with them and that they can trust you.

8. Be gracious. Someone else’s rudeness does not give us the right to be rude. Treat the other with the kindness you would like to be shown and allow him/her to feel important.

DISABILITY ETIQUETTE:

ENGAGING PEOPLE WITH DISABILITIES

Don't let fear and uncertainty keep you from getting to know people with disabilities. Fear of the unknown and lack of knowledge about interacting can lead to uneasiness when meeting a person who has a disability.

Remember: a person with a disability is a person with feelings. Treat him or her as you would want to be treated, and then let common sense and friendship break down any barriers you may encounter.

TENNESSEE
DISABILITY
COALITION

INSIDE:

- Meeting a person with a disability
- Engaging a person who uses a wheelchair
- Meeting someone with a cognitive impairment
- And more …

Meeting a person with a disability

1. **A handshake is NOT a standard greeting for everyone.** When in doubt, ASK the person whether he or she would like to shake hands with you. A smile along with a spoken greeting is always appropriate.
2. **Speak directly to the person with a disability,** not just to persons who may be accompanying him or her.
3. **Don't mention the person's disability,** unless he or she talks about it or it is relevant to the conversation.
4. **Treat adults as adults.** Don't patronize or talk down to people with disabilities. Likewise, don't lavish praise on a person with a disability for having the "courage" to overcome a disability.
5. **Be patient and give your undivided attention,** especially with someone who speaks slowly or with great effort.
6. **Never pretend to understand what a person is saying.** Ask the person to repeat or rephrase.
7. **It is okay to use common expressions** like "see you soon" or "I'd better be running along."
8. **Relax. We all make mistakes.** Offer an apology if you forget some courtesy. Keep a sense of humor and a willingness to communicate.

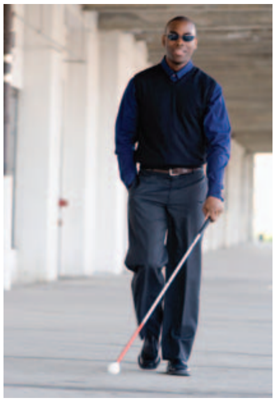
Interacting with a wheelchair user

1. **Personal space –** Do not push, lean on, or hold onto a person's wheelchair unless the person asks you to. The wheelchair is part of his or her personal space.
2. **Eye-to-Eye –** Try to put yourself at eye level when talking with someone in a wheelchair. Sit or kneel in front of the person.
3. **Clear a path –** Rearrange furniture or objects to accommodate a wheelchair before the person arrives.
4. **Know the geography –** If asked, know where someone can find accessible restrooms, telephones, and water fountains in the building.
5. **Directions –** When giving directions to a person in a wheelchair, consider distance, weather conditions, and physical obstacles (curbs, stairs, steep hills, etc.).

Meeting someone with a cognitive impairment that affects learning, intelligence, or brain function

1. **Keep your communication simple.** Use short sentences and rephrase comments or questions for better clarity.
2. **Stay on point** by focusing on one topic at a time.
3. **Allow the person time** to respond, ask questions and clarify your comments.
4. **Focus on the person** as he or she responds to you and pay attention to body language.
5. **Repetition.** If appropriate, repeat back any messages to confirm mutual understanding.

Engaging someone who is blind or has a disability that affects vision



1. **Greetings –** When meeting the person, identify yourself and introduce others who may be present.
2. **Departing –** Don't leave the person without excusing yourself first.
3. **Guiding –** When asked to guide someone, never push or pull the person. Offer your arm and allow him or her to reach for you, then walk slightly ahead. Point out doors, stairs, and curbs as you approach them.
4. **The landscape –** As you guide a person into a room, describe the layout, the location of furniture, and note who else is nearby.
5. **Details matter –** Be specific when describing the location of objects. (Example: "There is a chair three feet from you at eleven o'clock.")
6. **Guide dogs –** Don't pet or distract a guide dog. The dog is responsible for its owner's safety and is always working. It is not a pet.

Meeting a person with a disability that affects speech

1. **Pay attention, be patient, and wait** for the person to complete a word or thought. Do not finish it for the person.
2. **Ask the person to repeat what is said** if you do not understand. Tell the person what you heard and see if it is close to what he or she is saying.
3. **Be prepared for persons who use assistive technology** to enhance or augment speech. Don't be afraid to communicate with someone who uses an alphabet board or a computer to communicate.

Communicating with someone who is deaf or uses an assisted hearing device

1. **Let the person take the lead** in establishing the communication mode, such as lip-reading, sign language, or writing notes.
2. **Talk directly to the person** even when a sign language interpreter is present.
3. **If the person lip-reads,** face him or her directly, speak clearly and with a moderate pace.
4. **With some people** it may help to simplify your sentences and use more facial expressions and body language.

Service animals

1. **It takes all kinds** – Service animals come in all shapes and sizes. In addition to the traditional guide dog, a variety of dogs and other service animals may detect seizures before they occur, enhance therapies for children with autism, provide a calming presence for adults, or assist with a wide range of daily living activities.
2. **Engaging animal** – A service animal is a physical extension of a person with a disability and is there to work. It may be tempting to pet or call for a service animal's attention. However, for the safety and well-being of the team ask permission from the service animal's owner first.
3. **Questions** – The law varies widely so if you have a specific question, please contact the Tennessee Disability Coalition.

Using appropriate language

Life for most people with mental or physical disabilities has vastly improved over the past forty years. However, some things have been slow to change; namely, attitudes and perceptions about people with disabilities. The use of outdated language and words to describe people with disabilities contributes to perpetuating old stereotypes.

If public opinion about people with disabilities is to evolve, then awareness and usage of more appropriate language needs to become part of everyday discourse.

1. **Disability relevance –** Do not refer to a person's disability unless it is relevant to a situation or discussion.
2. **Disability vs. handicap –** The use of the word "handicap" is considered offensive, and the preferred term is "disability." Generally, it is only acceptable to use "handicap" when referring to accommodations such as handicap parking, although accessible parking is preferred today.
3. **People first language –** Say "person with a disability" rather than a "disabled person." This emphasizes that individuals with disabilities are people first and thus should not be defined by their disability.
4. **Referencing groups –** Avoid referring to a group of individuals as the disabled, quadriplegics, or the retarded. Instead, use references such as "persons with a disability," "persons with quadriplegia," and "persons with an intellectual disability." An exception involves people who are deaf and prefer the phrase "The Deaf."
5. **Negative and sensational descriptions –** Do not say "suffers from," "a victim of," "afflicted with," or "crippled." Never say "invalid." These portrayals elicit unwanted sympathy, or worse, pity toward individuals with disabilities.
6. **Gratuitous, but well-meaning praise –** Don't portray people with disabilities as overly courageous, brave, special, or superhuman because they have "overcome" a disability. Doing so implies that it is unusual for people with disabilities to have talents, skills, and the ability to contribute in society.
7. **Wheelchairs and adaptive technology –** Never say "wheelchair-bound" or "confined to a wheelchair." People use mobility or adaptive equipment as tools of greater independence.
8. **Presume competence –** Never assume that a person who looks or speaks differently has a cognitive disability.

TALKING ABOUT DISABILITY

The preferred "people first language" recognizes that someone is a person first, and that the disability is a part of, but not the whole person. However, some people with disabilities reject use of people first language. These guidelines have developed independently within distinct disability communities, and they may sometimes appear contradictory. For example, some persons with reduced vision find the term "visually-impaired" acceptable, but some persons with reduced hearing find the term "hearing-impaired" offensive and prefer "hard of hearing."

WORDS & PHRASES TO AVOID	PREFERRED ALTERNATIVES
a disabled person	person with a disability
the handicapped or the crippled	person with a disability
normal, healthy or able-bodied person/people	people without disabilities typical person
wheelchair-bound or confined to a wheelchair	a wheelchair user uses a wheelchair
birth defect or affliction	congenital disability or birth anomaly
a victim of cerebral palsy (or other condition)	has cerebral palsy has (insert condition)
suffers from polio, afflicted with polio or post-polios	has had polio, experienced polio has a disability due to polio
mentally retarded, a retard slow or special	person with an intellectual or developmental disability
the Down's person or Mongoloid	person with Down Syndrome
the epileptic or epileptics fits or epileptic fits	person with epilepsy person with a seizure disorder seizure or epileptic episode
the mentally ill crazy, psycho, nuts, mental case	people who have mental illness person with a mental or emotional disorder
the blind or blind as a bat	people who are blind or visually impaired
hearing-impaired deaf-mute, deaf and dumb	person who is hard of hearing the Deaf, a person who is deaf

COMMON COURTESIES FOR ENGAGING PEOPLE WITH DISABILITIES

1. **Personal Questions –** Avoid asking personal questions about someone's disability. If you must ask, be sensitive and show respect. Do not probe if the person declines to discuss it.
2. **Patience –** It may take extra time for a person with a disability to do or say something.
3. **Offering Assistance –** Be polite and friendly when offering assistance and wait until your offer is accepted. Listen or ask for specific instructions.
4. **Meetings & Events –** Create an environment that is welcoming to everyone. Anticipate specific accommodations that a person with a disability or group might need and contact them for information on how to best meet their needs.

ABOUT THE TENNESSEE DISABILITY COALITION

The Coalition is an alliance of organizations and individuals who have joined to promote the full and equal participation of men, women and children with disabilities in all aspects of life. We work together to advocate for public policy that ensures self-determination, independence, empowerment, and inclusion for people with disabilities in areas such as accessibility, education, health care, housing, and voting rights.

Organizational Membership – If your organization would like to join the Coalition, then please give us a call at the phone number below or contact our Executive Director at coalition@tndisability.org

Individual Membership – If you would like to join the Coalition as a member of our Disability Action Network, please give us a call at the phone number below or contact a member of our Public Policy Team at news@tndisability.org.

Disability
Action
Network

TENNESSEE DISABILITY COALITION
955 Woodland Street • Nashville, TN 37206
Phone: 615.383.9442 • Fax: 615.383.1176 • On the web: www.tndisability.org

WORKING WITH VISUALLY IMPAIRED CONSUMERS IN IHSS

Aid codes for blind aid are “20”, “26”, “28”, etc.

- Best corrected vision for statutory blindness 20/200 or visual field <15º

Most common causes of blindness:

- Lack of oxygen and other delivery impairments at birth
- Macular degeneration (degenerative blemishes on the retina), which results in “tunnel vision”
- Glaucoma (increased pressure and hardening of the eyeball)
- Diabetes (diabetic retinopathy)
- Cataract (lens becomes opaque) – now often corrected or improved by surgery
- Retinal detachment (retina is light-sensitive cells at back of eyeball. If they detach from the optic nerve, visual image cannot reach the brain)
- Diseases of the cornea

Things to Know:

- Most persons who are blind have some sight rather than no sight at all.
- Many people who are blind are mobile and independent. Some people who are blind view blindness not as a disability as much as an inconvenience.
- While many people who are blind can read Braille, the majority of persons who are blind do not.
- A person may have a visual disability that is not obvious. Be prepared to offer assistance, for example, in reading when asked.

Things to Do:

- Introduce yourself. Identify who you are and what your job or role is. Be sure to introduce any others who are with you.
- If you have met before, remind consumer of the context, as they won't have the visual cues to jog their memory.
- Be descriptive when giving directions. Saying "over there" has little meaning to someone who cannot see you point.
- Always ask someone if assistance is needed and how you can assist.
- Lead someone who is blind only after he/she has accepted your offer to do so. Allow them to hold your arm, rather than you holding them. It is important to let people with vision impairments control their movements.
- Many techniques are used as tools for independence, but individuals with disabilities use only things that work for them.
- If the person has a guide dog, walk on the side opposite the dog. As you are walking, describe the setting, noting any obstacles, such as stairs (“up” or “down”) or a big crack in the sidewalk.
- If you are going to give a warning regarding a hazard, be specific. Shouting, “Look out!” does not tell the person if he should stop, run, duck or jump.
- Remember to describe sights or objects from their perspective, not yours. Tell them when you have brought new items into their environment, describing what they are and, most importantly, where you have put them.

- Offer to read written information.
- If you need to leave a person who is blind, inform him/her first.

Things to Avoid:

- Do not move items (furniture, personal items) after their position has been learned by the person. This can be frustrating and, in some cases, dangerous for the person with a disability.
- Do not use references that are visually oriented like "over there near the green plant."
- Don't touch the person's cane or guide dog. The dog is working and needs to concentrate. The cane is part of the individual's personal space. If the person puts the cane down, don't move it. Let him know if it's in the way.

Things to Consider:

- People who are blind have more often been told what to do rather than asked what they would prefer doing. This attitude is not acceptable towards any person.

People with Low Vision

Things to Know:

- Persons with low vision may not be wearing dark glasses or using a cane and therefore are not easily identifiable.
- A person with low vision may need written material in large print.
- It is easiest for most people with low vision to read bold white letters on a black background.

Things to Do:

- Ask the person what size and type font they prefer to read.
- Remember that you can use a copy machine to enlarge print.
- Good lighting is very important.
- Have a simple (drug store brand) magnifying glass available.
- Use a thick point black marker when writing down information. Check with the person to determine what size to write letters/numbers so he/she can see it.
- Keep walkways clear of obstructions.

Things to Avoid:

- Avoid using all uppercase letters because it is more difficult for people with low vision to distinguish the end of a sentence.
- Do not move items (furniture, personal items) after their position have been learned by the person. This can be frustrating and, in some cases, dangerous for the person with a disability.

Assessment of home care needs of the blind and vision-impaired:

- **Legal blindness covers a wide range of vision. Don't make assumptions about consumer capabilities.**
    - Ask the consumer how much vision he/she has.
    - As in any IHSS interview, carefully observe the consumer to determine their abilities. Do not assume complete blindness or helplessness.
    - Allow the consumer to describe his/her vision and how it impacts function.
    - Examples might be to hand them a pen, if they do not reach for it then tell them you are handing them a pen and that you will need them to sign their name.
    - Always look directly at the consumer as you or they are speaking and note if they respond to your movements, smiles etc.

- **Ask the consumer about adaptations to the home and adaptive training they may have received. (Example: stove knobs marked in braille)**
    - What kind?
    - How much mobility training?
    - Have they developed their own systems or do they use tools which allow them to complete some tasks?
    - Those with intensive schooling are often Braille capable and very adept to getting around.
    - Those who are blind from birth may have mental health issues overlay basic blindness or experience isolation due to never having sight.
    - Those with late or adult onset tend to have a slower diminution of sight, allowing time to adapt.
    - Those new to the loss may have some depression and may not yet availed themselves of training nor be aware of what is available to them.

- **Community resources:**
    - Department of Vocational Rehabilitations
    - OCB
    - Living Skills Centers
    - Guide dogs
    - Special mobility training
    - Non-profit organizations serving the blind
    - Special services from utilities
    - Large print books

- **Explore other health problems and their impact on functioning.**

- **IHSS Tasks – Some things to consider:**
    - Domestic: Examine floors and counter surfaces for sign of vermin too small for consumer to see, crumbs, grease, or mold. Check refrigerators for spoiled food.
    - Meals & Cleanup: Same as above. Explore for vermin. The consumer currently may be cooking out of necessity. Make sure that this can be done safely.
    - Laundry: Observe spots and stains on clothing and linens. Consumers often have trouble with use of bleach, pre-spotting, coordination of colors, storing clothing in matching sets to facilitate dressing.

  - Dressing: How is clothing stored? Are clothes stored in matching styles, colors? Consumers may feel seams to determine right-side-out and labels to tell back from front. These are some of the skills taught in the training programs.
  - Feeding: Consumers rely on things being in place. Ask what system they are currently using for meals.
  - Bathing and Grooming: Most men use an electric razor. Observe hairstyles as a factor in grooming time. Provider may need to do set-ups.
  - Accompaniment to MD Visits: Can be approved only for consumers who need physical assistance. Many impaired persons are adept at using public transportation.
  - Paramedical: Can be involved with administration of insulin injections/ testing.
  - Setting up medi-sets can be helpful. For low vision consumers, have they asked their pharmacy to provide large print prescriptions?

- **Determine if adaptive items are used by the consumer to facilitate independence for any of the above tasks. If not and consumer is interested, refer to a low vision living skills center.**

Other Resources

- The Pub 13 Rights and Responsibilities Pamphlet is available in large print, Braille, and in audio versions. www.cdss.ca.gov/civilrights/PG594.htm
- CDSS website: Handbook and services for the visually impaired. http://www.cdss.ca.gov/cdssweb/PG1941.htm

COMMUNICATING WITH DEAF AND HARD OF HEARING CONSUMERS

Good communication is the first step to a positive working relationship with a consumer. The following tips will improve your communication by allowing a consumer to effectively use visual cues and what hearing he/she does have to receive as much information as possible. All of these tips are easy to follow but may require a conscious effort at first.

- **Choose a quiet environment.** Avoid communicating where there is a lot of noise or visual activity. If there is a TV or radio in the room, ask the consumer if you can turn it off or mute it for the conversation.

- **Avoid standing in front of a light source when speaking.** Bright light behind you (from a window or desk lamp) will make it harder to see your face. Make sure the light is shining on your face, not from behind you.

- **In groups, make sure only one person at a time is talking.** Whoever speaks should be sure to have the attention of the person with hearing loss. Remember that a hard of hearing person might not be able to understand casual conversation taking place in the room.

- **Make sure you have the consumer's attention before speaking.** Waving a hand or a light touch on the shoulder or arm are acceptable ways to get attention. You can ask your consumer how he/she prefers to be alerted.

- **Look directly at the consumer and maintain eye contact.** Avoid filling out forms or reading while talking.

- **Allow the consumer to see your mouth when you are speaking.** Beware of covering your mouth with a hand or having a long mustache or beard.

- **Avoid eating or chewing gum when you are speaking.** This can interfere with lip reading.

- **Ask the consumer what will make communication easier.** This may be accomplished by writing a note to ask him/her if there are changes you can make in your communication style or if a communication aid would be helpful.

- **When writing back and forth, keep your word choices simple and sentences short.** When communicating by writing notes, keep in mind that some individuals may lack good English reading and writing skills. If the person understands you well and uses more complex sentences and vocabulary, you may do the same. Take your cue from the consumer.

- **State the topic of discussion as you begin.** When you change the topic, make sure the consumer is aware of the new topic.

- **Speak clearly and at a normal pace.** If you tend to speak quickly, slow down. Use a normal speaking voice and pace at first. If the consumer has difficulty understanding, slow your speech more, break the sentences into smaller portions, and check for understanding again.

- **Repeat the statement, then re-phrase if the consumer is unable to hear the words spoken.** This might include using shorter, simpler sentences if necessary.

- **Avoid shouting.** A loud voice may increase distortion or give the impression you are angry, without improving comprehension. If a person is deaf, your voice will not be heard clearly no matter how loud it is.

- **Use gestures, facial expression and body language to assist with communication.**

- **Be patient and take time to communicate.** Saying phrases like "never mind" or "it's not important" can cause a person with hearing loss to feel they are not important. Remember that hearing loss does not mean a loss of intelligence.

- **Be aware of fatigue.** People who are hard of hearing must work harder to communicate and this can be extremely tiring.

- **When using an interpreter, speak directly to the consumer.** When the interpreter voices what a deaf person signs, look at the deaf person, not the interpreter.

- **For a late deafened person, a computer and word processor can be a useful communication tool**. Enlarge the font so it is easy to read. Let the consumer speak, and if they do not understand your speech, type and allow the consumer to read the computer screen.

- **Do not be afraid to make mistakes.** Most deaf or hard of hearing people are very comfortable communicating with hearing people. Most will appreciate any attempt to communicate, even if the process seems difficult to you.

COMMUNICATING WITH CONSUMERS WITH SPEECH IMPEDIMENTS

Speech is an important part of our daily lives and interactions. When a consumer has trouble speaking clearly, it presents barriers to effective communication. It might feel uncomfortable for you to communicate with a consumer who is hard to understand. There are simple actions you can take to help a consumer with a speech impediment feel comfortable and communicate most effectively.

- **Remember, it may be only the speech that's impaired**
  - Many people have trouble speaking without any other disabilities or difficulties. Do not assume that you must speak slowly or use simple language around someone with a speech impediment. The consumer might hear and understand you but have trouble speaking or responding. Speak clearly and distinctly but naturally, and be aware that the consumer might feel like you are “talking down” to him/her if you speak too slowly. It might be useful to use ‘yes or no’ questions depending on the severity of the speech impediment.

- **Do not be afraid to ask the consumer to repeat him/herself**
  - People who stutter or struggle with words or do not speak clearly usually know that they can be difficult to understand. Everyone wants to be heard and understood, so if you did not catch what a consumer with a speech impediment said, let him or her know so they can make their point. You can also repeat back to the consumer what you have understood to make sure it is correct.

- **Be careful about other corrections**
  - It may be tempting to tell your consumer to “slow down” or “take a deep breath” but these suggestions may not help the situation and might actually make communication more difficult. Corrections of this kind might make the consumer nervous which could cause the speech impediment to worsen. In addition, finishing your consumer’s sentences can be frustrating and cause the consumer to feel rushed.

- **Use other clues**
  - Speech is not the only form of communication. Watch the consumer’s face, reaction, and body language (including facial or hand responses), as these may help you in understanding. Be an active listener: look for hints from eye gaze and gestures and then take a guess (e.g. "Are you talking about the TV news? Yes? Tell me more. I didn't see it.").

- **Be patient**
  - Be willing to work at communicating. In some cases, this may mean learning basic sign language or being aware of special communication devices for consumers who are nonverbal. If appropriate, become familiar with devices, systems, and programs that have been developed to assist. Do not be afraid to ask the consumer if there are ways to improve communication with him/her or ask the consumer’s family or friends any tips they have learned.

HANDLING INTERVIEW CHALLENGES

Most of the time the interview will go smoothly, but there are times when issues will arise that will make acquiring good information more difficult. Here are some hints to help make each situation more successful.

1. **The angry consumer** – It is best to try to handle the anger at the beginning of the interview. This shows the consumer you care and aren't there just to accomplish your agenda. It never helps to ignore the anger, as it will be a constant barrier to getting useful information.
   - Acknowledge the anger. Gently confront the consumer by saying something like, "You seem very upset and I am not sure why. Can we talk about what is upsetting you before we start?"
   - To get an angry person to open up, explain (or re-explain) your purpose and that you need them to help you so you can best understand their needs and how the program can help them.

2. **The consumer who is very sad / grieving** – If the consumer is overcome by sadness and starts to cry.
   - Don't ignore or pretend the consumer is not upset or crying. In some cases, it may not be obvious about the reasons for the sadness/grief, which may not become apparent until you ask a specific question that triggers the grief/sadness. Be direct but polite and sensitive. Let them talk briefly about the reason for the sadness/grief. You may say something like: "I'm sure that is very difficult for you," or "I'm sorry."
   - Try to be reassuring and let them know it is safe to express their feelings. A comment like: "It is OK to cry, we all cry," or, "I understand," can be effective.
   - Validate the situation by saying something like: "I have had other consumers who have the same reaction. It is hard." Or: "These are difficult issues you're dealing with, it is very normal."
   - If the consumer is too distraught about a recent death or other stressful event to focus on the issues you need to discuss for your assessment, it might be most appropriate to offer to reschedule the interview.

3. **The consumer who rambles without focus** – These consumers often want to tell long stories and often have a difficult time getting to 'the point.'
   - Remind the consumer of the goal of the interview. "That is very interesting Mrs. Jones, I really need to find out the details of how you get along each day so that I can help you get the services that you need. Can you tell me specifically how you prepare your meals?"
   - Rephrase the question in a more close-ended question, "I understand there have been many issues with your personal care. Do you need help with bathing?" If so, you can then probe for specifics.

4. **The consumer who answers with only a word or two** – This can be very difficult because without information it is hard to get an accurate picture of the consumer's need.
   - Use open-ended questions to try to get the consumer to give you more information.

- Ask the consumer to paint you a picture of their day: “Tell me what your day normally looks like.” It is difficult to answer a question like this with one or two words and may get them to open up, or will allow you opportunities to probe for further information.

5. **The consumer who is embarrassed** – Some of the questions asked during the interview may be embarrassing to consumers. Especially those related to bowel and bladder care and menstruation.
    - Reassure the consumer and acknowledge these may be embarrassing questions but that you need the information so they can get the assistance they need. “I know this may be embarrassing for you, but I need to find out exactly what your needs are. Now you had said you have problems getting around. I’m wondering if that makes if difficult for you to get to the bathroom in time and causes you to have accidents.”

6. **Communication blocks** –
    - Hearing difficulties.
        - Ask the consumer if they have a hearing aide. If they do, check to see if it is in and if it is on. If the consumer cups his/her hand over the ear, the hearing aid will whistle if it is turned on.
        - Talk slowly without jargon.
        - If the person doesn’t seem to understand, paraphrase yourself.
        - Ask if one ear is better than another and position yourself on that side.
        - You may need to follow-up with a family member to get clarification of information.

    - Language barriers.
        - If the consumer understands and speaks some English, make sure you go slowly, give them plenty of time to think of their answers, and do not compound your questions.
        - Follow State regulations (MPP 21-115) and county procedures to arrange for an interpreter if the consumer does not speak English and you do not speak his/her language.

PROGRAMS/SERVICES THAT INTERACT WITH IHSS

The following programs provide services that are identical or similar to those provided by IHSS. They are all publicly funded with a combination of federal, state and/or county funding. Help provided by other agencies, churches, family or friends are Alternative Resources to IHSS to the extent that they meet the needs of a consumer that IHSS would otherwise provide. However, if other agencies, churches, family or friends provide assistance to a consumer that IHSS would not provide (such as paying bills or taking the consumer to a movie), there is no impact to IHSS.

Program/Service	Sponsor/Funder	IHSS Treatment	Authority for Exemption
Adult Day Health Care (ADHC) / Community Based Adult Services (CBAS)	California Department of Aging (CDA) and local site	Services they provide are Alternative Resources to IHSS.	N/A
AIDS Waiver	California Department of Health Care Services (DHCS)	IHSS authorization not impacted by these services.	ACL
Alzheimer's Day Care Resource Centers (ADCRC)	CDA and local site	Services they provide are Alternative Resources to IHSS.	N/A
Early Periodic Screening, Diagnosis and Treatment (EPSDT)	DHCS	If the IHSS is provided by the EPSDT provider, EPSDT services are considered an Alternative Resource to IHSS.	ACL 02-43
Home Health Agency care	Medi-Cal and/or Medicare	Services they provide are Alternative Resources to IHSS.	N/A
In-Home Operations (IHO) Waiver	DHCS	IHSS authorization not impacted by these services; IHO augments them.	ACL
Local Case Management Programs	Local (not available in all counties)	N/A –provides case management services.	N/A

Program/Service	Sponsor/Funder	IHSS Treatment	Authority for Exemption
Institutional Deeming Waiver	Department of Developmental Services (DDS) and local Regional Centers	IHSS eligibility available to anyone certified under this waiver, regardless of income and resources. IHSS authorization not impacted by these services.	MPP 30-780.2 and MPP 30-785(b)(2)(B); DHS regulation section 51350(b) and ACL 98-53
Meals on Wheels	CDA, California Area Agencies on Aging (AAA) and local organization.	Services they provide are Alternative Resources to IHSS meal preparation and, to some extent, shopping.	N/A
Multipurpose Senior Services Program (MSSP)	CDA and local site	IHSS authorization not impacted by these services.	ACL
Regional Center Services	DDS and local Regional Centers	IHSS services provided within consumer's home are not impacted by these services. IHSS Services provided at other locations (such as school, day programs) should be considered Alternative Resources.	ACL 98-53

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY

CALIFORNIA DEPARTMENT OF SOCIAL SERVICES

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM
HEALTH CARE CERTIFICATION FORM

A. APPLICANT/RECIPIENT INFORMATION (To be completed by the county)

Applicant/Recipient Name:	Date of Birth:
Address:	
County of Residence:	IHSS Case #:
IHSS Worker Name:	
IHSS Worker Phone #:	IHSS Worker Fax #:

B. AUTHORIZATION TO RELEASE HEALTH CARE INFORMATION (To be completed by the applicant/recipient)

I, ______________________________________, authorize the release of health care information
(PRINT NAME)
related to my physical and/or mental condition to the In-Home Supportive Services program as it pertains to my need for domestic/related and personal care services.

Signature: ____ Date: ____/_____/_____
(APPLICANT/RECIPIENT OR LEGAL GUARDIAN/CONSERVATOR)

Witness (if the individual signs with an "X"): _________________________________ Date: _____/_____/_____

TO: LICENSED HEALTH CARE PROFESSIONAL* –

The above-named individual has applied for or is currently receiving services from the In-Home Supportive Services (IHSS) program. <u>State law requires that in order for IHSS services to be authorized or continued a licensed health care professional must provide a health care certification declaring the individual above is unable to perform some activity of daily living independently and without IHSS the individual would be at risk of placement in out-of-home care. This health care certification form must be completed and returned to the IHSS worker listed above</u>. The IHSS worker will use the information provided to evaluate the individual's present condition and his/her need for out-of-home care if IHSS services were not provided. The IHSS worker has the responsibility for authorizing services and service hours. The information provided in this form will be considered as one factor of the need for services, and all relevant documentation will be considered in making the IHSS determination.

IHSS is a program intended to enable aged, blind, and disabled individuals who are most at risk of being placed in out-of-home care to remain safely in their own home by providing domestic/related and personal care services. IHSS services include: housekeeping, meal preparation, meal clean-up, routine laundry, shopping for food or other necessities, assistance with respiration, bowel and bladder care, feeding, bed baths, dressing, menstrual care, assistance with ambulation, transfers, bathing and grooming, rubbing skin and repositioning, care/assistance with prosthesis, accompaniment to medical appointments/alternative resources, yard hazard abatement, heavy cleaning, protective supervision (observing the behavior of a non-self-directing, confused, mentally impaired or mentally ill individual and intervening as appropriate to safeguard recipient against injury, hazard or accident), and paramedical services (activities requiring a judgment based on training given by a licensed health care professional, such as administering medication, puncturing the skin, etc., which an individual would normally perform for him/herself if he/she did not have functional limitations, and which, due to his/her physical or mental condition, are necessary to maintain his/her health). The IHSS program provides hands-on and/or verbal assistance (reminding or prompting) for the services listed above.

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*Licensed Health Care Professional means an individual licensed in California by the appropriate California regulatory agency, acting within the scope of his or her license or certificate as defined in the Business and Professions Code. These include, but are not limited to: physicians, physician assistants, regional center clinicians or clinician supervisors, occupational therapists, physical therapists, psychiatrists, psychologists, optometrists, ophthalmologists and public health nurses.

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM HEALTH CARE CERTIFICATION FORM

Applicant/Recipient Name:	IHSS Case #:

C. HEALTH CARE INFORMATION (To be completed by a Licensed Health Care Professional Only)

NOTE: ITEMS #1 & 2 (AND 3 & 4, IF APPLICABLE) <u>MUST</u> BE COMPLETED AS A CONDITION OF IHSS ELIGIBILITY.

1.	**Is this individual <u>unable</u> to independently perform one or more activities of daily living (e.g., eating, bathing, dressing, using the toilet, walking, etc.) or instrumental activities of daily living (e.g., housekeeping, preparing meals, shopping for food, etc.)?**	■ **YES** ■ **NO**
2.	**In your opinion, is one or more IHSS service recommended in order to prevent the need for out-of-home care (See description of IHSS services on Page 1)?**	■ **YES** ■ **NO**

If you answered "NO" to either Question #1 OR #2, skip Questions #3 and #4 below, and complete the rest of the form including the certification in PART D at the bottom of the form.

If you answered "YES" to both Question #1 AND #2, respond to Questions #3 and #4 below, and complete the certification in PART D at the bottom of the form.

3. Provide a description of any physical and/or mental condition or functional limitation that has resulted in or contributed to this individual's need for assistance from the IHSS program:

4.	**Is the individual's condition(s) or functional limitation(s) expected to last at least 12 consecutive months?**	■ **YES** ■ **NO**

Please complete Items # 5 - 8, to the extent you are able, to further assist the IHSS worker in determining this individual's eligibility.

5. Describe the nature of the services you provide to this individual (e.g., medical treatment, nursing care, discharge planning, etc.):

6. How long have you provided service(s) to this individual?

7. Describe the frequency of contact with this individual (e.g., monthly, yearly, etc.):

8. Indicate the date you last provided services to this individual: ____ / ____ / ____

NOTE: THE IHSS WORKER MAY CONTACT YOU FOR ADDITIONAL INFORMATION OR TO CLARIFY THE RESPONSES YOU PROVIDED ABOVE.

D. LICENSED HEALTH CARE PROFESSIONAL CERTIFICATION

By signing this form, I certify that I am licensed in the State of California and/or certified as a Medi-Cal provider, and all information provided above is correct.

Name:	Title:
Address:	
Phone #:	Fax #:
Signature:	Date:
Professional License Number:	Licensing Authority:

PLEASE RETURN THIS FORM TO THE IHSS WORKER LISTED ON PAGE 1.

CDSS
WILL LIGHTBOURNE
DIRECTOR

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES
744 P Street • Sacramento, CA 95814 • *www.cdss.ca.gov*

EDMUND G. BROWN JR.
GOVERNOR

July 27, 2011

REASON FOR THIS TRANSMITTAL

[x] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

ALL-COUNTY LETTER NO.: 11-55

TO: ALL COUNTY WELFARE DIRECTORS
IHSS PROGRAM MANAGERS

SUBJECT: **IN-HOME SUPPORTIVE SERVICES (IHSS) MEDICAL CERTIFICATION FORM SOC 873**

The purpose of this All-County Letter is to instruct counties on the implementation of Senate Bill (SB) 72 as it relates to obtaining certification from a licensed health care professional for all In-Home Supportive Services (IHSS) applicants and recipients.

BACKGROUND

SB 72 added Section 12309.1 to the Welfare and Institutions Code (WIC) that requires the development of a medical certification form. The completed medical certification form must be received prior to the authorization of IHSS services for new applicants and to allow the continuation of IHSS services for recipients. In order for IHSS to be authorized or continued, WIC section 12309.1 requires the medical certification form include a declaration from a licensed health care professional that the applicant/recipient is unable to independently perform some activity of daily living and that without the assistance of IHSS services, the applicant/recipient would be at risk of placement in out-of-home care. The form must also include a description of any condition or functional limitation that has resulted in, or contributed to, the applicant/recipient’s need for assistance. The California Department of Social Services (CDSS), in consultation with the Department of Health Care Services and stakeholders, developed the In-Home Supportive Services Program Medical Certification Form (SOC 873) to meet the requirements of WIC section 12309.1.

COUNTY RESPONSIBILITIES

For IHSS applicants, beginning August 1, 2011, counties must inform each applicant or their authorized representative of the new certification requirements using SOC 874 the “IHSS Program Notice to Applicant of Medical Certification Requirement" (attached).

Applicants have 45 calendar days from the date the county requests the SOC 873, to provide the county with a completed and signed SOC 873 or alternative documentation in lieu of the SOC 873. Before IHSS services can be authorized counties must ensure that both questions 5 and 6 on the SOC 873 are answered "yes." If both questions 5 and 6 are answered "yes", the county may continue to assess the applicant's need for IHSS and determine eligibility. Once the applicant is determined eligible for services, eligibility may go back to the effective date of the application. If either question 5 or 6 is answered "no", then the application must be denied based on no need for services using Notice of Action (NOA) code 443. If the SOC 873 or alternative documentation is not provided within the 45 calendar day timeframe the application for IHSS services must be denied using NOA message 507.

For IHSS recipients beginning August 1, 2011, counties must inform each recipient or their authorized representative of the new certification requirements using SOC 875 the "IHSS Program Notice to Recipient of Medical Certification Requirement" (attached) at or before the first in-home reassessment). Recipients will have 45 calendar days from the date of the in-home reassessment to provide the completed and signed SOC 873 or alternative documentation to the county. In order to complete the reassessment and reauthorize hours, counties must ensure that both questions 5 and 6 on the SOC 873 are answered "yes." If both questions 5 and 6 are answered "yes" the county may complete the reassessment following normal procedures. If either question 5 or 6 is answered "no" IHSS services must be terminated based on no need for services using NOA code 443. If the SOC 873 or alternative documentation is not provided within the 45 calendar day timeframe, and good cause does not exist, services must be terminated using NOA message 507.

After the initial SOC 873 or alternative documentation is received and the county finds the applicant/recipient eligible for IHSS services, a new SOC 873 is not required at subsequent reassessments. Counties may request a new SOC 873 or their own county medical certification form at their discretion but a new SOC 873 is not required for continued eligibility.

The SOC 873 must be signed by a licensed health care professional. In accordance with WIC section 12309.1(a), "Licensed health care professional" means an individual licensed in California by the appropriate regulatory agency, acting within the scope of his or her license or certificate as defined in the Business and Professions Code. A licensed health care professional includes, but is not limited to, a physician, physician's assistant, regional center clinician or clinician supervisor, occupational therapist, physical therapist, psychiatrist, psychologist, optometrist, ophthalmologist or public health nurse.

Counties must give the applicant/recipient the option to take the SOC 873 to their licensed health care professional to be completed and returned to the county. However, if the applicant requests assistance in obtaining the SOC 873 from the licensed health professional, the county must assist; this includes sending the SOC 873 directly to the applicant/recipient's licensed heath care professional. In either case, the applicant/recipient is ultimately responsible for ensuring the completed SOC 873 is returned to the county within the appropriate timeframes. An applicant/recipient, legal guardian, conservator, or a person with power of attorney for medical purposes (who is recognized by the licensed health care professional) may sign "Part B" of the SOC 873. Counties may contact the licensed health care professional for clarification or additional information if the SOC 873 is not completed properly. Questions 5, 6, and 7 (when questions 5 and 6 are answered "yes") on the SOC 873 are pivotal for determining eligibility and are required to be answered to meet the requirements in WIC section 12309.1.

Counties are expected to use the SOC 873 or alternative documentation submitted by the applicant/recipient as a factor in assessing the need for IHSS, but it shall not be the sole determining factor, unless questions 5 or 6 are answered "no". The SOC 873 or alternative documentation is used to help the social worker evaluate the applicant/recipient's present condition and the need for out-of-home care if IHSS services are not provided. The social worker must consider all relevant documentation in making the IHSS determination.

ALTERNATIVE DOCUMENTATION

In lieu of obtaining the SOC 873, applicants/recipients may provide alternative documentation to the county. Acceptable alternative documentation must be dated no earlier than 60 calendar days prior to submission and include all the following elements:

- A statement or description indicating the applicant/recipient is unable to independently perform one or more activities of daily living,
- A description of the applicant/recipient's condition or functional limitation that has contributed to the need for assistance, and
- A signature from a licensed health care professional.

Alternative documentation may include, but is not limited to, hospital or nursing facility discharge plans, minimum data set forms, and individual program plans, all of which must meet the criteria shown above. County designed medical certification forms are not acceptable alternative documentation. Counties must accept alternative documentation that they determine meet all the conditions listed above.

GOOD CAUSE

The timeframe for recipients to obtain the SOC 873 or alternative documentation may be extended for good cause. Good cause extensions, however, cannot be granted for applicants. Good cause means a substantial and compelling reason beyond the recipient's control, and in order to be granted, the recipient must show good faith efforts in trying to obtain the SOC 873 or alternative documentation. Counties have the discretion to determine on a case-by-case basis when good cause exists. Recipients must notify the county of the need for a good cause extension no later than 35 calendar days from the in-home assessment. After the 35th day, a good cause extension can no longer be granted. Examples of good cause may include, but are not limited to; serious illness or hospitalization of the recipient or the county confirms with the licensed health care professional that additional time is needed to complete the SOC 873.

Timeframe extensions granted for good cause should not be extended for more than 45 calendar days beyond the mandated 45-day timeframe for a maximum total of 90 days.

CMIPS AND CMIPS NOTICE OF ACTION (NOA) MESSAGES

To meet the mandated requirements SB 72, Legacy Case Management, Information, and Payrolling System (CMIPS) will be modified to include two new fields on the RELA screen to allow entry and tracking of the required data. A Medical Certification Date (MC DATE) field and associated Medical Certification Reason Code (MC CODE) field will be used to track the date the medical certification was requested and received and what type of documentation was received. Counties will be required to enter in the date when they request and subsequently receive the documentation and use the appropriate type code. The reason codes for the MC CODE field include:

- M – Medical Certification Received
- A – Alternative Documentation Received
- E – Exception
- P – Pending (to be used when waiting for documentation to be received)

For new applicants, counties will not be able to authorize services on the case unless a date is entered in the MC DATE field and the MC CODE field has an "M", "A" or "E" indicated. When entering the case into CMIPS counties should enter the date they requested the medical certification and enter a "P". If the county has already received the medical certification they should enter the receipt date in the MC DATE field and appropriate reason code in the MC CODE field.

For existing recipients, the MC DATE and MC CODE field must contain a valid value (M, A, E or P) for the system to allow the user to move forward to RELC and authorize the new hours after a reassessment. When entering the reassessment into CMIPS counties must enter the face-to-face date in the MC DATE field and enter a "P" in the MC CODE field if they have not received the medical certification documentation. Once the county receives the medical certification they should update the MC DATE field and MC CODE fields with the receipt date and appropriate reason code. Counties should continue to utilize the Face to Face Date field on RELB when entering authorization information for both initial assessments and reassessments.

Counties should be aware that certain actions are either required or not allowed once the new medical certification fields are used. The following effects should be noted:

- The system will not allow a user to delete a "P" from the MC CODE field. The field will only accept one of the other valid types of "M", "A" or "E".
- A soft edit has been added to the RELA screen that will be triggered if the MC DATE and/or MC TYPE field are blank. The user will be able to override this edit.
- A hard edit has been added to the RELB field that is triggered when a change has been made to the FACE-TO-FACE DATE field and the MC DATE and/or MC TYPE fields are blank. A user cannot override this edit and must return to the RELA screen and fill in the MC DATE and MC CODE fields with the appropriate values.

To assist counties with the tracking of cases that are delinquent in submitting their medical certification, a new file will be added to the existing county download which includes a list of recipients who are in danger of losing their services due to non-compliance with the medical certification requirement. This file will provide the necessary data and allow counties the flexibility to incorporate it into their existing business processes. In order for this report to be useful to the counties, it is imperative that counties utilize the MC DATE and MC CODE fields to identify which cases are "pending" medical certification so they may be identified on the monthly file.

CDSS has developed NOA messages for use on the NA 690 when an applicant/recipient fails to provide the SOC 873. As with any denial or termination, timely and adequate notice rules apply. The following NOA message 507 should be used in conjunction with the NA 690 to inform an applicant/recipient that his/her services have been denied or terminated for failure to provide the SOC 873:

CMIPS NOA Message 507

You did not provide the county with a medical certification as required to authorize services. (WIC 12309.1).

CMIPS II NOA Messages

The following messages are designed to be used (upon implementation of CMIPS II) on the corresponding IHSS Notice of Action Denial (NA 1252) or Termination (NA 1255).

Applicant Denial Message (MXX-XX):

The county has denied your application for In-Home Supportive Services (IHSS). Here is why:

When you applied for IHSS, the county informed you that you had to provide a medical certification from a licensed health care professional to the county stating that you cannot do some activities of daily living on your own and without help to do these activities you would be at risk of placement in out-of-home care.

The county asked you to provide a medical certification by ________(Date)________.

You did not provide the county with a medical certification as required by state law. Therefore, you cannot be found eligible for IHSS.

You can reapply for IHSS if you provide the county with a medical certification.

(Please note that the appropriate regulation section (WIC 12309.1) will be inserted into the rules area at the bottom of the NOA.).

Recipient Termination Message (MXX-XX):

As of _____DATE)_____, the In-Home Supportive Services (IHSS) you have been getting will stop. Here is why:

At your reassessment on ____(DATE)___, the county informed you that you had to provide a medical certification from a licensed health care professional stating that you cannot do some activities of daily living on your own and without help to do these activities you would be at risk of placement in out-of-home care.

The county asked you to provide a medical certification by __(DATE)___.

You did not provide the county with a medical certification as required by state law to continue to receive IHSS services.

If you provide the county with a medical certification, the county will assess your need and/or eligibility for IHSS. (Please note that the appropriate regulation section (WIC 12309.1) will be inserted into the rules area at the bottom of the NOA).

TRANSLATIONS

CDSS is in the process of translating the SOC 873, SOC 874 and SOC 875. Language Translation Services (LTS) will make available camera ready copies of Spanish, Armenian and Chinese translated forms and letters as soon as they have been completed. You may access these forms and letters at:

http://www.cdss.ca.gov/cdssweb/PG183.htm

Your county forms coordinator should distribute translated forms to each program and location. Each county shall provide bilingual/interpretive services and written translations to non-English or limited English proficient populations as required by the Dymally Alatorre Bilingual Services Act (Government Code section 7290 et seq.) and by state regulation (MPP Division 21, Civil Rights Nondiscrimination, section 115).

For questions, please contact Victoria Rodriguez, Analyst, Adult Programs Branch, Operations and Technical Assistance Unit, at (916) 653-3850, or by e-mail at: Victoria.Rodriguez@dss.ca.gov.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

Attachments

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY

CALIFORNIA DEPARTMENT OF SOCIAL SERVICES

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM MEDICAL CERTIFICATION FORM

A. APPLICANT/RECIPIENT INFORMATION (To be completed by the county)

Applicant/Recipient Name:

Date of Birth:

Address:

County of Residence:

IHSS Case #:

IHSS Worker Name:

IHSS Worker Phone #:

IHSS Worker Fax #:

B. AUTHORIZATION TO RELEASE MEDICAL INFORMATION (To be completed by the applicant/recipient)

I, ______________________________________, authorize the release of medical information
(PRINT NAME)
related to my physical and/or mental condition to the In-Home Supportive Services program as it pertains to my need for domestic/related and personal care services.

Signature: ____ Date: ____/_____/_____
(APPLICANT/RECIPIENT OR LEGAL GUARDIAN/CONSERVATOR)

Witness (if the individual signs with an "X"): ________________________________ Date: _____/_____/_____

TO: LICENSED HEALTH CARE PROFESSIONAL –

The above-named individual has applied for or is currently receiving services from the In-Home Supportive Services (IHSS) program. State law requires that in order for IHSS services to be authorized or continued a licensed health care professional must provide a medical certification declaring the individual above is unable to perform some activity of daily living independently and without IHSS the individual would be at risk of placement in out-of-home care. This medical certification form must be completed and returned to the IHSS worker listed above. The IHSS worker will use the information provided to evaluate the individual's present condition and his/her need for out-of-home care if IHSS services were not provided. The IHSS worker has the responsibility for authorizing services and service hours. The information provided in this form will be considered as one factor of the need for services, and all relevant documentation will be considered in making the IHSS determination.

IHSS is a program intended to enable aged, blind, and disabled individuals who are most at risk of being placed in out-of-home care to remain safely in their own home by providing domestic/related and personal care services. IHSS services include: housekeeping, meal preparation, meal clean-up, routine laundry, shopping for food or other necessities, assistance with respiration, bowel and bladder care, feeding, bed baths, dressing, menstrual care, assistance with ambulation, transfers, bathing and grooming, rubbing skin and repositioning, care/assistance with prosthesis, accompaniment to medical appointments/alternative resources, yard hazard abatement, heavy cleaning, protective supervision (observing the behavior of a non-self-directing, confused, mentally impaired or mentally ill individual and intervening as appropriate to safeguard recipient against injury, hazard or accident), and paramedical services (activities requiring a judgment based on training given by a licensed health care professional, such as administering medication, puncturing the skin, etc., which an individual would normally perform for him/herself if he/she did not have functional limitations, and which, due to his/her physical or mental condition, are necessary to maintain his/her health). The IHSS program provides hands-on and/or verbal assistance (reminding or prompting) for the services listed above.

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM MEDICAL CERTIFICATION FORM

Applicant/Recipient Name:

IHSS Case #:

****ONLY A LICENSED HEALTH CARE PROFESSIONAL SHOULD COMPLETE THE REMAINDER OF THIS FORM.****

C. MEDICAL INFORMATION (To be completed by a Licensed Health Care Professional)

1. Describe the nature of the services you provide to this individual (e.g., medical treatment, nursing care, discharge planning, etc.):

2. How long have you provided service(s) to this individual?

3. Describe the frequency of contact with this individual (e.g., monthly, yearly, etc.):

4. Indicate the date you last provided services to this individual: ____ / ____ / ____

5. Is this individual <u>unable</u> to independently perform one or more activities of daily living (e.g., eating, bathing, dressing, using the toilet, walking, etc.), or instrumental activities of daily living (e.g., housekeeping, preparing meals, shopping for food, etc.)? ■ **YES** ■ **NO**

6. In your opinion, is one or more IHSS service recommended in order to prevent the need for out-of-home care (See description of IHSS services on Page 1)? ■ **YES** ■ **NO**

If you answered "NO" to either Question #5 OR #6, skip Questions #7 and #8 below, and complete the certification in PART D at the bottom of the form.

If you answered "YES" to both Question #5 AND #6, respond to Questions #7 and #8 below, and complete the certification in PART D at the bottom of the form.

7. Provide a description of any physical and/or mental condition or functional limitation that has resulted in or contributed to this individual's need for assistance from the IHSS program:

8. Is the condition(s) or functional limitation(s) expected to last more than 12 consecutive months? ■ **YES** ■ **NO**

NOTE: THE SOCIAL WORKER MAY CONTACT YOU FOR ADDITIONAL INFORMATION OR TO CLARIFY THE RESPONSES YOU PROVIDED ABOVE.

D. LICENSED HEALTH CARE PROFESSIONAL CERTIFICATION

By signing this form, I certify that I am licensed in the State of California and all information provided above is correct.

Name:

Title:

Address:

Phone #:

Fax #:

Signature:

Date:

Professional License Number:

Licensing Authority:

PLEASE RETURN THIS FORM TO THE SOCIAL WORKER LISTED ON PAGE 1.

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM
NOTICE TO APPLICANT OF MEDICAL CERTIFICATION REQUIREMENT

There has been a change in state law* that requires each person applying for IHSS to provide a medical certification from a licensed health care professional (LHCP) before they can get IHSS.

The certification must be completed by a LHCP, such as a physician (doctor), physician assistant, regional center clinician or clinical supervisor, occupational therapist, physical therapist, psychiatrist, psychologist, optometrist, ophthalmologist, public health nurse, etc.

The certification must state that you are not able to do some activities of daily living (ADLs) on your own and that without help to do these activities you would be at risk of placement in out-of-home care.

Basic ADLs are: eating, bathing, dressing, using the toilet, walking, and getting out of bed or a chair. Other ADLs are: housekeeping, preparing meals, shopping for food or other necessities, taking medication, etc.

Attached is a blank copy of the Medical Certification Form (SOC 873) that you can give to your LHCP to complete. If you want, the county can send it to the LHCP for you but you will have to give the county the LHCP's name and address.

Whether you give the Medical Certification Form to the LHCP yourself or the county sends it for you, you are responsible for making sure it is completed and returned to the county within **45 days** from the date the county worker requested it.

The county may accept an alternate document in place of the Medical Certification Form as long as it meets all of the following requirements:

1. Indicates that you are not able to do one or more ADLs on your own,
2. Describes the medical or other condition that makes you unable to do ADLs on your own and causes you to need IHSS, and
3. Has been signed by a LHCP.

If you do not provide the Medical Certification Form or alternate document to the county within 45 days, your application for IHSS will be denied. As with any county action taken on your case, you may request a state hearing if you do not agree with the county's decision.

If you have questions about the medical certification requirement, ask the social worker who has been assigned to your case.

Due By: ____/____/____

*Welfare and Institutions Code section 12309.1

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM NOTICE TO RECIPIENT OF MEDICAL CERTIFICATION REQUIREMENT

COUNTY OF: ______________________

Notice Date: ______________________
IHSS Office Address: ______________________
____
IHSS Office Telephone Number: ______________________
Social Worker Name: ______________________
Due By: ______________________

(ADDRESSEE)

To: In-Home Supportive Services (IHSS) Recipient

There has been a change in state law* that requires each person getting IHSS to provide a medical certification from a licensed health care professional (LHCP) to continue to get IHSS.

The certification must be completed by a LHCP, such as a physician (doctor), physician assistant, regional center clinician or clinical supervisor, occupational therapist, physical therapist, psychiatrist, psychologist, optometrist, ophthalmologist, public health nurse, etc.

The certification must state that you are not able to do some activities of daily living (ADLs) on your own and that without help to do these activities you would be at risk of placement in out-of-home care.

Basic ADLs are: eating, bathing, dressing, using the toilet, walking, and getting out of bed or a chair. Other ADLs are: housekeeping, preparing meals, shopping for food or other necessities, taking medication, etc.

Attached is a blank copy of the Medical Certification Form (SOC 873) that you can give to your LHCP to complete. If you want, the county can send it to the LHCP for you but you will have to give the county the LHCP's name and address.

Whether you give the Medical Certification Form to the LHCP yourself or the county sends it for you, you are responsible for making sure it is completed and returned to the county within 45 days following your reassessment. If the county does not receive the Medical Certification Form by the 35th day, a notice will be sent informing you that your IHSS will stop, unless you had previously contacted the county and were given more time to submit the form.

The county may accept an alternate document in place of the Medical Certification Form as long as it meets all of the following requirements:

1. Indicates that you are not able to do one or more ADLs on your own,
2. Describes the medical or other condition that makes you unable to do ADLs on your own and causes you to need IHSS, and
3. Has been signed by a LHCP.

If the county does not receive the completed Medical Certification Form or alternate document within 45 days following your reassessment, your IHSS may stop. As with any county action taken on your case, you may request a state hearing if you do not agree with the county's decision.

If you are not able to get the medical certification from your LHCP within 45 days, call your social worker at the number listed above, as soon as possible.

*Welfare and Institutions Code section 12309.1

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES
744 P Street • Sacramento, CA 95814 • www.cdss.ca.gov

CDSS
WILL LIGHTBOURNE
DIRECTOR

EDMUND G. BROWN JR.
GOVERNOR

November 10, 2011

ALL-COUNTY LETTER (ACL) NO.: 11-76

TO: ALL COUNTY WELARE DIRECTORS
IHSS PROGRAM MANAGERS

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[X] Federal Law or Regulation Change
[ ] Court Order
[X] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

SUBJECT: **IN-HOME SUPPORTIVE SERVICES (IHSS) HEALTH CARE CERTIFICATION FORM SOC 873 EXCEPTIONS**

REFERENCE: All-County Letter (ACL) No. 11-55 DATED JULY 27, 2011

This All-County Letter (ACL) instructs counties on the implementation of Assembly Bill (AB) 106 (Chapter 32, Statutes of 2011) as it relates to the exceptions to the rule requiring a certification be obtained from a licensed health care professional prior to the authorization for In-Home Supportive Services (IHSS) applicants.

BACKGROUND

Senate Bill (SB) 72 (Chapter 8, Statutes of 2011) added section 12309.1 to the Welfare and Institutions Code (WIC) that requires the development of a certification form. The California Department of Social Services (CDSS), in consultation with the California Department of Health Care Services and stakeholders, developed the In-Home Supportive Services Program Health Care Certification Form (SOC 873). The completed SOC 873 must be received prior to the authorization of IHSS services for new applicants and to allow the continuation of IHSS services for current recipients. SB 72 allowed for two exceptions to this rule as it relates to applicants, one of which was amended by AB 106.

WIC 12309.1(a)(2) states “the certification shall be received prior to service authorization, and services shall not be authorized in the absence of the certification.” However, there are two exceptions that permit the authorization of services prior to the receipt of the SOC 873 or alternative documentation. Those exceptions are:

1) IHSS services may be authorized when services have been requested on behalf of an individual being discharged from a hospital or a nursing home and those services are needed to enable the individual to return safely to their own home or into the community.
2) Services may be authorized temporarily pending receipt of the certification when the county determines that there is a risk of out-of-home placement.

These authorization exceptions are temporary in nature and ultimately the SOC 873 or alternative documentation must be obtained within 45 calendar days from the date the certification is requested by the county.

GRANTING EXCEPTIONS FOR APPLICANTS

When an individual applies for IHSS services prior to being released from a hospital or a nursing home and the county determines IHSS services are needed for that individual to return home safely, IHSS can be granted temporarily prior to receipt of the SOC 873 or alternative documentation. In addition, when the county determines there is an imminent risk of out-of-home placement without immediate service authorization, IHSS services can be temporarily authorized pending receipt of the SOC 873. For example, an Adult Protective Services worker advises the county that an IHSS applicant is at imminent risk of out-of-home placement without IHSS services in place. If the county determines that waiting up to 45 calendar days for the SOC 873 to be returned would place an IHSS applicant at risk of out-of-home placement, services can be granted temporarily pending receipt of the SOC 873 or alternative documentation.

When granting one of the above exceptions, the county must request the SOC 873 as soon as administratively possible but no later than the date of the in-home assessment. If the SOC 873 or alternative documentation is not provided within 45 days from the date it was requested (or within 90 days if a good cause extension has been granted -- see below), the case must be terminated prospectively with a timely 10-day notice using Notice of Action (NOA) code 507. If the completed SOC 873 is received by the county within the 45-day timeframe and indicates no need for services, the county must terminate the case prospectively with a timely 10-day notice using NOA code 443. Applicants granted an exception will be considered temporarily eligible pending receipt of the SOC 873. If the SOC 873 or alternative documentation is received after the 45th day, counties can follow their standard operational procedures to determine whether to rescind the termination or require a new application.

For applicants who have been granted an exception, the 45-day time limit can be extended an additional 45 calendar days for good cause: for a total of 90 calendar days. Good cause means a substantial and compelling reason beyond the exempted applicant's control. In order to be eligible for a good cause extension, the exempted applicant must show good faith efforts in trying to obtain the SOC 873 or alternative documentation. Counties have the discretion to determine on a case-by-case basis when good cause exists. Exempted applicants must notify the county of the need for a good cause extension no later than 45 calendar days from the date the county requested the SOC 873. (Recipients must also notify the county of the need for a good cause extension no later than 45 calendar days from the date of the in-home assessment.) After the 45th day, a good cause extension can no longer be granted.

CMIPS INSTRUCTIONS FOR EXCEPTIONS

When entering an exception case into CMIPS, counties must enter an "E" in the Medical Certfication (MC) Code field and enter the date the SOC 873 was requested from the applicant in the MC Date field. Once the MC Code and MC Date are entered, counties can continue to authorize the case as usual.

NOTICES

When an exception to the health care certification requirements has been granted, counties shall notify the applicant that his/her application for IHSS has been temporarily approved and of the requirement to submit a completed SOC 873 within 45 calendar days of the date the certification is requested. If hours are being authorized prior to an in-home assessment, because the applicant is being discharged from a medical facility, counties must send the "In-Home Supportive Services Program Notice of Provisional Approval Health Care Certification Exception Granted" (SOC 876) in lieu of a regular NOA (NA 690). The SOC 876 (attached) lists the provisional hours assessed for each of the service categories and does not provide appeal rights because the authorized hours shown will be based on a preliminary assessment rather than the required in-home assessment. The SOC 876 must be completed manually by the counties. Following the in-home assessment, counties must notify the applicant of the assessed hours by sending the NA 690, which provides appeal rights. Counties are reminded that if the applicant's discharge planner needs a copy of the SOC 876, the county may provide this to the discharge planner with the applicant's written consent.

If hours are being authorized after an in-home assessment has been completed, but before the SOC 873 has been received, an NA 690 should be sent using the following NOA message number 508:

> "Your application has been temporarily approved pending receipt of your health care certification form. Your eligibility will be discontinued if the form is not received within 45 days of the date it was requested or if the form indicates you have no need for In-Home Supportive Services. (WIC 12309.1)"

FORMS/CAMERA-READY COPIES AND TRANSLATIONS

For a camera-ready copy of English and Spanish forms, contact the Forms Management Unit at: fmudss@dss.ca.gov. If your office has internet access, you may obtain these forms from the California Department of Social Services (CDSS) web page at: www.dss.cahwnet.gov/cdssweb/FormsandPu_271.htm.

Please note CDSS is in the process of translating the SOC 876 into the threshold languages: Spanish, Armenian and Chinese. Copies of the translated forms and publications in all other required languages can be obtained at: www.dss.cahwnet.gov/cdssweb/FormsandPu_274.htm.

For questions on translated materials, please contact Language Services at
(916) 651-8876.

Your County Forms Coordinator will distribute translated forms to each program and location. Each county must provide bilingual/interpretive services and written translations to non-English or limited-English proficient populations, as required by the Dymally-Alatorre Bilingual Services Act (Government Code section 7290 et seq.) and/or by state regulation (MPP Division 21, Civil Rights Nondiscrimination, section 115).

Questions about accessing the forms may be directed to the Forms Management Unit at fmudss@dss.ca.gov; questions about translations may be directed to the Language Services Unit at LTS@dss.ca.gov.

For questions, please contact Marshall Browne, Manager, Policy & Litigation Branch, Operations and Technical Assistance Unit, at (916) 651-5248, or by e-mail at: Marshall.Browne@dss.ca.gov.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

Attachment

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM NOTICE OF PROVISIONAL APPROVAL HEALTH CARE CERTIFICATION EXCEPTION GRANTED

TO:

County of: ______________________

Notice Date: ______________________
Case Number: ______________________
IHSS Office Address: ______________________

IHSS Office Telephone Number: ______________________

The county has provisionally approved your application for In-Home Supportive Services (IHSS). Here's what that means:

State law requires that before you can get IHSS, you have to provide the county with a health care certification completed and signed by a licensed health care professional, and you have to have an assessment of your needs completed in your own home.

The county has granted an exception so that you can get IHSS on a temporary basis **before** you meet these requirements, but you still have to provide the county with the health care certification (if you have not already provided it). You will temporarily get the services/hours shown below once you return to your own home. These services/hours are based on a preliminary assessment of your needs done while you were in a medical facility.

When you provide the county with the health care certification, the county will determine your eligibility to continue getting IHSS. If you are determined eligible, the county will do an in-home assessment to complete the determination of your services/hours.

The county asked you to provide the health care certification by ________________.
DATE

If you do not provide the county with a health care certification by this date, the IHSS you have been getting on a temporary basis will stop. If you cannot provide the certification by this date, contact your social worker before the due date to explain why and ask if the county can grant you more time.

If you have questions about the information in this notice, call your social worker.

SERVICES	AUTHORIZED # OF HOURS
DOMESTIC SERVICES (per month)	
RELATED SERVICES (PER WEEK)	
- Prepare meals	
- Meal clean-up	
- Routine laundry	
- Shopping for food	
- Other shopping/errands	
NON-MEDICAL PERSONAL SERVICES (PER WEEK)	
- Respiration assistance	
- Bowel and/or bladder care	
- Feeding	
- Routine bed baths	
- Dressing	
- Menstrual care	
- Assistance with walking (including getting in/out of vehicles)	
- Transferring: moving in/out of bed, on/off seats, etc.	
- Bathing, oral hygiene, grooming	
- Rubbing skin, repositioning	
- Assistance with prosthesis, help setting up medication	
ACCOMPANIMENT (PER WEEK)	
- To/from medical appointments	
- To/from alternative resources	
PROTECTIVE SUPERVISION (PER WEEK)	
TEACHING/DEMONSTRATION SERVICES (PER WEEK)	
PARAMEDICAL SERVICES (PER WEEK)	
HOURS OF SERVICE AUTHORIZED FOR ONE MONTH ONLY	
- Heavy cleaning	
- Yard hazard abatement	
Total weekly hours of service authorized	
Multiply by 4.33 (average # of weeks per month) to convert to monthly hours	
Add monthly authorized domestic services hours (from above)	
TOTAL HOURS OF SERVICE AUTHORIZED PER MONTH	

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES
744 P Street • Sacramento, CA 95814 • *www.cdss.ca.gov*

CDSS
WILL LIGHTBOURNE
DIRECTOR

EDMUND G. BROWN JR.
GOVERNOR

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS

December 6, 2011

ALL-COUNTY INFORMATION NOTICE NO. I-74-11

TO: ALL COUNTY WELFARE DIRECTORS
ALL COUNTY IN-HOME SUPPORTIVE SERVICES PROGRAM MANAGERS

SUBJECT: REVISED IN-HOME SUPPORTIVE SERVICES PROGRAM HEALTH CARE CERTIFICATION FORM AND RELATED NOTICES; CLARIFICATION ON INTER-COUNTY TRANSFERS IN RELATION TO HEALTH CARE CERTIFICATION REQUIREMENTS

REFERENCE: ALL-COUNTY LETTER NO. 11-55, DATED JULY 27, 2011
ALL-COUNTY LETTER NO. 11-76, DATED NOVEMBER 10, 2011

This All- County Information Notice (ACIN) transmits the revised In-Home Supportive Services (IHSS) Program Health Care Certification Form (SOC 873), Notice to Applicant of Health Care Certification Requirement (SOC 874), and Notice to Recipient of Health Care Certification Requirement (SOC 875). It also provides a clarification on policy regarding inter-county transfers of IHSS cases in relation to the health care certification requirements.

Effective immediately, counties shall begin using the revised SOC 873, SOC 874 and SOC 875. Below is a summary of the most significant revisions to the form and the notices and an explanation of the reasons for them.

REVISIONS TO THE SOC 873

- Throughout the form (e.g., the title, etc.), all references to the term “medical certification” have been changed to “health care certification.”

  This change was made because the term “health care” better conforms with the language used in Welfare and Institutions Code (WIC) Section 12309.1, as well as the intent of the statute. “Health care” is also a broader term and more consistent with the IHSS program being based on a social service model rather than a medical model.

- At the bottom of Page 1, an endnote providing the statutory definition of Licensed Health Care Professional (WIC 12309.1(a)(1)), as well as the examples specified in statute, has been added:

  > *Licensed Health Care Professional means an individual licensed in California by the appropriate California regulatory agency, acting within the scope of his or her license or certificate as defined in the Business and Professions Code. These include, but are not limited to: physicians, physician assistants, regional center clinicians or clinician supervisors, occupational therapists, physical therapists, psychiatrists, psychologists, optometrists, ophthalmologists and public health nurses.*

  The endnote was added to ensure that LHCPs understand the definition as it applies to the certification requirements and can determine whether they are authorized to complete the certification when asked by an applicant or recipient.

  Several counties that border other states have inquired whether they may accept an SOC 873 (or alternative documentation) completed by an LHCP who is licensed in the bordering state. The counties have indicated that refusing to accept documentation from an out-of-state LHCP presents a significant obstacle for recipients who either reside in areas where the nearest LHCP is located in the bordering state, or who are receiving treatment from an LHCP affiliated with the military services (e.g., the Veterans Health Administration). In response to these inquiries, the California Department of Social Services (CDSS) is granting counties the flexibility to make exceptions on a case-by-case basis and accept an SOC 873 (or alternative documentation) completed by a LHCP who has been licensed in another state <u>but who is an approved Medi-Cal provider</u>, if the applicant/recipient has been receiving treatment from the out-of-state LHCP.

  Counties have requested additional clarification on the specific types of LHCPs, in addition to the examples listed in WIC Section 12309.1, from whom they may accept a completed SOC 873 or alternative documentation. For the purposes of completing the health care certification, a LHCP is a licensed individual whose primary responsibilities are to diagnose and/or provide treatment and care for physical or mental diseases or conditions which cause or contribute to an individual’s functional limitation. Based on this definition, counties may accept an SOC 873 or alternative documentation completed by a Marriage and Family Therapist (MFT) or a Licensed Clinical Social Worker (LCSW). However, they may not accept forms completed by a pharmacist or an x-ray technician, as these individuals' primary responsibilities are not diagnosis and/or provision of treatment/care.

- The items in Section C have been reordered and renumbered. The items that, on the prior version of the form, were the last four items in the section (Items # 5 – 8) are now listed first (Items # 1 – 4).

- At the beginning of Section C, the following note has been added: *NOTE: ITEMS # 1 & 2 (AND 3 & 4, IF APPLICABLE) MUST BE COMPLETED AS A CONDITION OF IHSS ELIGIBILITY.* Also, before Item #5, the following note has been added*: Please complete Items # 5 – 8, to the extent you are able, to further assist the IHSS worker in determining this individual's eligibility.*

  Both the reordering/renumbering and the addition of these notes were done to emphasize the relative importance of the information that the LHCP provides in Items # 1 through 4 in assisting the IHSS worker to determine an individual's eligibility for IHSS compared with the information he/she provides in Items # 5 through 8.

  Please note that the reordering and renumbering of items in this section alters the instructions provided in ACL No. 11-55 for determining whether an individual is eligible for IHSS based on the SOC 873 requirements. In that ACL, Items # 5 and 6 were identified as being of primary importance in making the eligibility determination. Due to the reordering/renumbering of this section, Items # 1 and 2 are now the most critical indicators. Therefore, all references to Items # 5 through 8 in ACL No. 11-55 will now refer, correspondingly, to Items # 1 through 4.

  If the LHCP has answered "Yes" to Items #1 and 2 on the SOC 873, but he/she has failed to complete Items #3 and 4, the county may, at its discretion, contact the LHCP to obtain the information about the individual's physical and/or mental condition or functional limitation that has resulted in or contributed to his/her need for IHSS, or it may send the SOC 873 back to the LHCP to be completed. If the county opts to contact the LHCP, it should notate the outcome of the contact on the SOC 873, initial any such notation and document the case file accordingly. If the county cannot obtain the necessary information in the course of the contact, or if Items #1 or 2 are unanswered, the county must send the SOC 873 back to the LHCP to be completed. The time allowed for the LHCP to complete and/or clarify his/her original responses shall not be counted against the 45-day time limit. Counties should follow their standard operational procedures in deciding how much time to allow for return of the clarifying SOC 873.

REVISIONS TO THE SOC 874

- Throughout the notice (e.g., the title, etc.), all references to the term “medical certification” have been changed to “health care certification” in order to conform with the language used in the statute.

- Information about alternative documentation requirements has been updated to reflect that, in order to be valid, the document must be signed by a LHCP *within the last 60 days*.

- Language has been added near the bottom of the notice explaining that, under certain limited circumstances, an exception may be granted which would allow an individual to temporarily receive services prior to providing the completed SOC 873 or alternative documentation to the county. The individual is still required to provide one of the documents in order to continue receiving services.

REVISIONS TO THE SOC 875

- Throughout the notice (e.g., the title, etc.), all references to the term “medical certification” have been changed to “health care certification” in order to conform with the language used in the statute.

- The following language has been deleted from the notice: “If the county does not receive the SOC 873 by the 35th day, a notice will be sent informing you that your IHSS will stop, unless you had previously contacted the county and were given more time to submit the form.”

  This language was deleted to reflect a change in policy regarding the time frame for mailing Notices of Action (NOAs) to recipients who fail to provide the SOC 873 (or alternative documentation) within 45 days, and for which good cause does not exist. CDSS is modifying this policy to address county concerns regarding workload and operational challenges of having to send the NOA 10 days in advance of the 45th day to ensure that services do not continue beyond the 45 days. Effective immediately, unless there is good cause, counties shall send the termination NOA on the 45th day following the in-home assessment, and shall follow normal procedures for timely notice.

- Information about alternative documentation requirements has been updated to reflect that, in order to be valid, the document must be signed by a LHCP *within the last 60 days*.

- Language has been added to indicate that if a recipient is not able to obtain a completed SOC 873 or alternative documentation from his/her LHCP within 45 days, the individual should contact the county prior to the due date to explain the reason for his/her inability to meet the due date and inquire whether an extension can be granted.

  This language has been added to clarify that, as stated in ACL 11-76, dated November 10, 2011, recipients may request a good cause extension up to the 45th calendar day from the date of the in-home assessment.

Stakeholders requested the inclusion of language on the SOC 873, SOC 874, and SOC 875 relating to WIC section 14131.07, which pertains to limits on the number of provider visits a Medi-Cal recipient is allowed each year, and whether a visit to a provider for the purpose of completing the SOC 873 should be counted against the limit. However, because the California Department of Health Care Services is the state agency responsible for disseminating information about this statutory provision, until further notice, this information cannot be included on any of CDSS' forms or notices.

AVAILABILITY OF THE REVISED SOC 873, SOC 874 AND SOC 875

The form and notices referenced in this ACIN are designated as "Required – No Substitutes Permitted." Camera-ready copies of the English versions of them are now available on the California Department of Social Services (CDSS) Forms/Brochures web page at:

http://www.dss.cahwnet.gov/cdssweb/PG183.htm.

The SOC 873, SOC 874 and SOC 875 are being translated into the current threshold languages (Spanish, Armenian, and Chinese) and, upon completion, camera-ready copies of the translations will be posted on the CDSS Translated Forms and Publications web page at:

http://www.dss.cahwnet.gov/cdssweb/FormsandPu_274.htm.

Please note that the entire SOC 873 is being translated into the threshold languages so that individuals with limited English proficiency are informed of the specific information being requested from the LHCP. The county should provide the translated version to the recipient/applicant; however, the English version should be provided to the LHCP, either by the county or by the individual.

Your County Forms Coordinator will distribute translated forms to each program and location. Each county must provide bilingual/interpretive services and written translations to non-English or limited-English proficient populations, as required by the Dymally-Alatorre Bilingual Services Act (Government Code section 7290 et seq.) and/or by state regulation (MPP Division 21, Civil Rights Nondiscrimination, section 115). Questions about accessing the forms may be directed to the Forms Management Unit at fmudss@dss.ca.gov; questions about translations may be directed to the Language Services Unit at LTS@dss.ca.gov.

CLARIFICATION REGARDING INTER-COUNTY TRANSFERS (ICTs)

Counties have requested clarification regarding ICTs in relation to the health care certification requirements. When a county receives an ICT, if the SOC 873 or alternative documentation has already been provided by the recipient in the sending county, there is no need for the receiving county to obtain a new one. However, if the SOC 873 or alternative documentation has not already been provided by the recipient in the sending county, the receiving county shall request one at or before the face-to-face assessment with the recipient, which the receiving county is required to complete during the transfer period, pursuant to MPP 30-759.94. The SOC 873 (or alternative documentation) shall be due 45 days following the face-to-face assessment. However, since an ICT case is entered as a new application in the receiving county, a systems limitation prevents services from being authorized when the ‘P’ code is entered in the MC field in CMIPS. In ICT cases where the receiving county has completed the in-home assessment but is awaiting the SOC 873, the county should temporarily enter ‘E’ in the MC field to prevent unnecessary interruption of services while the SOC 873 is pending.

Should you have questions regarding the Health Care Certification requirements, please contact the Adult Programs Policy and Operations Bureau at (916) 651-5350.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

Attachments

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY
CALIFORNIA DEPARTMENT OF SOCIAL SERVICES

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM
HEALTH CARE CERTIFICATION FORM

A. APPLICANT/RECIPIENT INFORMATION (To be completed by the county)

Applicant/Recipient Name:	Date of Birth:
Address:	
County of Residence:	IHSS Case #:
IHSS Worker Name:	
IHSS Worker Phone #:	IHSS Worker Fax #:

B. AUTHORIZATION TO RELEASE HEALTH CARE INFORMATION (To be completed by the applicant/recipient)

I, ______________________________________, authorize the release of health care information
(PRINT NAME)
related to my physical and/or mental condition to the In-Home Supportive Services program as it pertains to my need for domestic/related and personal care services.

Signature: ____ Date: ____/_____/_____
(APPLICANT/RECIPIENT OR LEGAL GUARDIAN/CONSERVATOR)

Witness (if the individual signs with an "X"): __________________________________ Date: _____/_____/_____

TO: LICENSED HEALTH CARE PROFESSIONAL* –

The above-named individual has applied for or is currently receiving services from the In-Home Supportive Services (IHSS) program. State law requires that in order for IHSS services to be authorized or continued a licensed health care professional must provide a health care certification declaring the individual above is unable to perform some activity of daily living independently and without IHSS the individual would be at risk of placement in out-of-home care. This health care certification form must be completed and returned to the IHSS worker listed above. The IHSS worker will use the information provided to evaluate the individual's present condition and his/her need for out-of-home care if IHSS services were not provided. The IHSS worker has the responsibility for authorizing services and service hours. The information provided in this form will be considered as one factor of the need for services, and all relevant documentation will be considered in making the IHSS determination.

IHSS is a program intended to enable aged, blind, and disabled individuals who are most at risk of being placed in out-of-home care to remain safely in their own home by providing domestic/related and personal care services. IHSS services include: housekeeping, meal preparation, meal clean-up, routine laundry, shopping for food or other necessities, assistance with respiration, bowel and bladder care, feeding, bed baths, dressing, menstrual care, assistance with ambulation, transfers, bathing and grooming, rubbing skin and repositioning, care/assistance with prosthesis, accompaniment to medical appointments/alternative resources, yard hazard abatement, heavy cleaning, protective supervision (observing the behavior of a non-self-directing, confused, mentally impaired or mentally ill individual and intervening as appropriate to safeguard recipient against injury, hazard or accident), and paramedical services (activities requiring a judgment based on training given by a licensed health care professional, such as administering medication, puncturing the skin, etc., which an individual would normally perform for him/herself if he/she did not have functional limitations, and which, due to his/her physical or mental condition, are necessary to maintain his/her health). The IHSS program provides hands-on and/or verbal assistance (reminding or prompting) for the services listed above.

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*Licensed Health Care Professional means an individual licensed in California by the appropriate California regulatory agency, acting within the scope of his or her license or certificate as defined in the Business and Professions Code. These include, but are not limited to: physicians, physician assistants, regional center clinicians or clinician supervisors, occupational therapists, physical therapists, psychiatrists, psychologists, optometrists, ophthalmologists and public health nurses.

IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM HEALTH CARE CERTIFICATION FORM

Applicant/Recipient Name:	IHSS Case #:

C. HEALTH CARE INFORMATION (To be completed by a Licensed Health Care Professional Only)

NOTE: ITEMS #1 & 2 (AND 3 & 4, IF APPLICABLE) <u>MUST</u> BE COMPLETED AS A CONDITION OF IHSS ELIGIBILITY.

1.	**Is this individual <u>unable</u> to independently perform one or more activities of daily living (e.g., eating, bathing, dressing, using the toilet, walking, etc.) or instrumental activities of daily living (e.g., housekeeping, preparing meals, shopping for food, etc.)?**	■ **YES** ■ **NO**
2.	**In your opinion, is one or more IHSS service recommended in order to prevent the need for out-of-home care (See description of IHSS services on Page 1)?**	■ **YES** ■ **NO**

If you answered "NO" to either Question #1 OR #2, skip Questions #3 and #4 below, and complete the rest of the form including the certification in PART D at the bottom of the form.

If you answered "YES" to both Question #1 AND #2, respond to Questions #3 and #4 below, and complete the certification in PART D at the bottom of the form.

3. Provide a description of any physical and/or mental condition or functional limitation that has resulted in or contributed to this individual's need for assistance from the IHSS program:

4.	**Is the individual's condition(s) or functional limitation(s) expected to last at least 12 consecutive months?**	■ **YES** ■ **NO**

Please complete Items # 5 - 8, to the extent you are able, to further assist the IHSS worker in determining this individual's eligibility.

5. Describe the nature of the services you provide to this individual (e.g., medical treatment, nursing care, discharge planning, etc.):

6. How long have you provided service(s) to this individual?

7. Describe the frequency of contact with this individual (e.g., monthly, yearly, etc.):

8. Indicate the date you last provided services to this individual: ____ / ____ / ____

NOTE: THE IHSS WORKER MAY CONTACT YOU FOR ADDITIONAL INFORMATION OR TO CLARIFY THE RESPONSES YOU PROVIDED ABOVE.

D. LICENSED HEALTH CARE PROFESSIONAL CERTIFICATION

By signing this form, I certify that I am licensed in the State of California and/or certified as a Medi-Cal provider, and all information provided above is correct.

Name:	Title:
Address:	
Phone #:	Fax #:
Signature:	Date:
Professional License Number:	Licensing Authority:

PLEASE RETURN THIS FORM TO THE IHSS WORKER LISTED ON PAGE 1.

NOTICE TO APPLICANT OF HEALTH CARE CERTIFICATION REQUIREMENT

State Law (Welfare and Institutions Code section 12309.1) requires that each person applying for IHSS provide a health care certification from a licensed health care professional (LHCP) before they can get IHSS.

The certification must be completed by a LHCP, such as a physician (doctor), physician assistant, regional center clinician or clinician supervisor, occupational therapist, physical therapist, psychiatrist, psychologist, optometrist, ophthalmologist, public health nurse, etc.

The certification must state that you are not able to do some activities of daily living (ADLs) on your own and that without help to do these activities you would be at risk of placement in out-of-home care.

Basic ADLs are: eating, bathing, dressing, using the toilet, walking, and getting out of bed or a chair. Other ADLs are: housekeeping, preparing meals, shopping for food or other necessities, taking medication, etc.

Attached is a blank copy of the Health Care Certification Form (SOC 873) that you can give to your LHCP to complete. If you want, the county can send it to the LHCP for you but you will have to give the county the LHCP's name and address.

The county may accept alternative documentation in place of the SOC 873 as long as it meets all of the following requirements:

1. Indicates that you are not able to do one or more ADLs on your own,
2. Describes the medical or other condition that makes you unable to do ADLs on your own and causes you to need IHSS, <u>and</u>
3. Has been signed by a LHCP within the last 60 days.

Whether you give the SOC 873 to the LHCP yourself or the county sends it for you, you are responsible for making sure it is completed and returned to the county within **<u>45 days</u>** from the date the county worker requested it.

<u>If you do not provide the SOC 873 or alternative documentation to the county within 45 days, your application for IHSS will be denied. As with any county action taken on your case, you may request a state hearing if you do not agree with the county's decision.</u>

Under certain limited circumstances, such as when services are requested because you are being discharged from a hospital or nursing facility and you need services to return safely to your home, or the county determines that you are at risk of placement in out-of-home care, the county may grant an exception that would allow you to get IHSS on a temporary basis before the county receives the completed SOC 873 or alternative documentation. However, even if an exception is granted, you will still be required to provide one of these documents for the county within the 45-day timeframe to determine if you can continue getting IHSS.

If you have questions about the health care certification requirement, ask the social worker who has been assigned to your case.

DUE BY: ____/____/____

NOTICE TO RECIPIENT OF HEALTH CARE CERTIFICATION REQUIREMENT

(ADDRESSEE)

____

____

COUNTY OF: ____________________

Notice Date: ____________________
IHSS Office Address: ____________________
____
IHSS Office Telephone Number: ____________________
Social Worker Name: ____________________

DUE BY: ____________________

To: In-Home Supportive Services (IHSS) Recipient

There has been a change in state law (Welfare and Institutions Code section 12309.1) that requires each person getting IHSS to provide a health care certification from a licensed health care professional (LHCP) to continue to get IHSS.

The certification must be completed by a LHCP, such as a physician (doctor), physician assistant, regional center clinician or clinician supervisor, occupational therapist, physical therapist, psychiatrist, psychologist, optometrist, ophthalmologist, public health nurse, etc.

The certification must state that you are not able to do some activities of daily living (ADLs) on your own and that without help to do these activities you would be at risk of placement in out-of-home care.

Basic ADLs are: eating, bathing, dressing, using the toilet, walking, and getting out of bed or a chair. Other ADLs are: housekeeping, preparing meals, shopping for food or other necessities, taking medication, etc.

Attached is a blank copy of the Health Care Certification Form (SOC 873) that you can give to your LHCP to complete. If you want, the county can send it to the LHCP for you but you will have to give the county the LHCP's name and address.

The county may accept alternative documentation in place of the SOC 873 as long as it meets all of the following requirements:

1. Indicates that you are not able to do one or more ADLs on your own,
2. Describes the medical or other condition that makes you unable to do ADLs on your own and causes you to need IHSS, <u>and</u>
3. Has been signed by a LHCP within the last 60 days.

Whether you give the SOC 873 to the LHCP yourself or the county sends it for you, you are responsible for making sure it is completed and returned to the county within **<u>45 days</u>** following your reassessment.

<u>If the county does not receive the completed SOC 873 or alternative documentation within 45 days following your reassessment, your IHSS may stop. As with any county action taken on your case, you may request a state hearing if you do not agree with the county's decision.</u>

If you are not able to get the SOC 873 from your LHCP within 45 days, call your social worker at the number listed above **<u>before the due date</u>** to tell him/her why you are not able to meet the due date and ask if the county can grant you more time.

CDSS
WILL LIGHTBOURNE
DIRECTOR

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES
744 P Street • Sacramento, CA 95814 • *www.cdss.ca.gov*

EDMUND G. BROWN JR.
GOVERNOR

July 24, 2012

ALL-COUNTY LETTER NO.: 12-36

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[X] Clarification Requested by One or More Counties
[X] Initiated by CDSS

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: PROGRAM POLICY FOR THE CASE MANAGEMENT INFORMATION AND PAYROLLING SYSTEM II (CMIPS II)
INQUIRY, REFERRAL AND APPLICATION
PERSON NOTES/CASE NOTES/CASE (ASSESSMENT) NARRATIVE
PERSONAL CARE SERVICES PROGRAM/IHSS PLUS OPTION/IHSS RESIDUAL
SOCIAL SECURITY NUMBER REQUIREMENTS
IHSS RECIPIENT RESIDENCE
USE OF RANK 6
INTER-COUNTY TRANSFER

REFERENCE: All County Letter No. 88-118
All County Letters Nos. 06-34 and 06-34E2
All County Letter No. 09-30

This All-County Letter (ACL) explains the difference between an inquiry, a referral and an application for In-Home Supportive Services (IHSS) and provides policy direction related to Medi-Cal eligibility, pending Disability Evaluation Determinations (DEDs), loss of Medi-Cal eligibility and eligibility for IHSS Residual (IHSS-R). In addition, it will define the use for the following in CMIPS II: Use of new Person Note/Case Note/Narrative functionality; Social Security Number (SSN) requirements; Recipient Primary Residence; Rank 6 and Inter-County Transfer (ICT) process. In this letter, all references to IHSS shall be recognized to include the Personal Care Services Program (PCSP), IHSS Plus Option (IPO), and IHSS-R unless specified otherwise.

INQUIRY, REFERRAL AND APPLICATION

With the impending transition to CMIPS II, this ACL will explain the enhanced referral and application functionality that counties will be required to complete in CMIPS II as the system is implemented in each county. It will also clarify the differences betweenan inquiry, a referral and an application that exist today, as well as describe the required county actions related to these activities in both Legacy CMIPS and CMIPS II. In the case of CMIPS II activities, this letter will direct counties to the appropriate CMIPS II screens, but will not provide directions for screen entry; those step-by-step directions will be covered in CMIPS II training. When a county receives an initial contact regarding the IHSS program, the county may determine the nature of the contact based on the direction provided in this ACL.

Inquiry:

If a county receives a call from an individual making an informational inquiry regarding the IHSS program only, e.g., what kinds of services does IHSS provide, it is considered an inquiry and does not merit a referral or qualify as an application. During an inquiry, the county will generally not receive or respond to any person-specific information. The county is not required to take any further action.

Referral:

A referral is a contact about the IHSS program received by the county from a third party who does not have legal authority to make decisions on behalf of the potential applicant, e.g., a health care professional, neighbor, friend or religious affiliate, or a person who is not the authorized representative of the individual they are referring. The county must record the contact as a Referral until the county has contacted the individual or their authorized representative to determine whether the referred individual or their authorized representative is interested in applying for IHSS.

Legacy CMIPS: For the time that a county remains on Legacy CMIPS, the county is encouraged to enter the referral information in Record (R) status; however, counties using external tools to record and track referrals may continue to do so.

CMIPS II:

The county shall initiate a Person Search to determine if the individual calling or being referred to IHSS is already known to CMIPS II. An individual shall exist only once in CMIPS II.

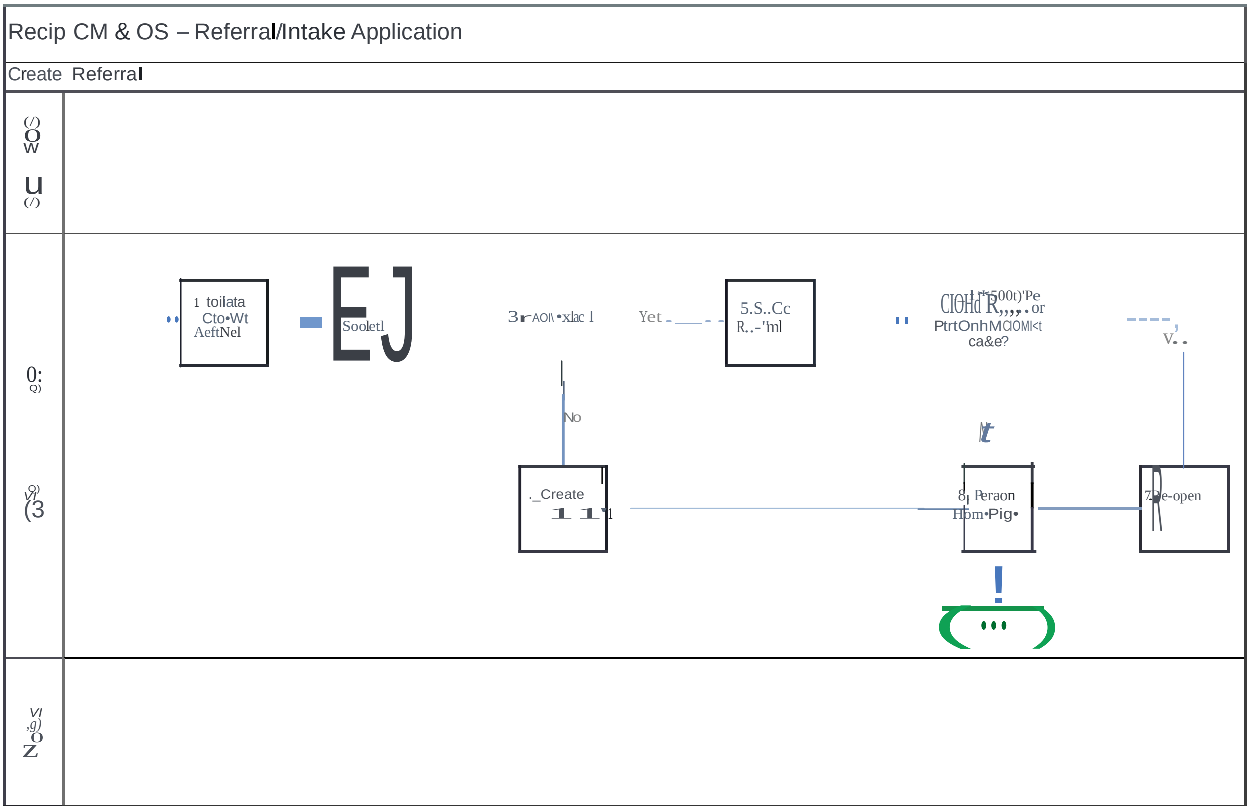
If the person calling is the individual seeking services or their authorized representative, the county shall proceed to the Create Application screen and initiate the application process. (See Create Application Flowchart below.)

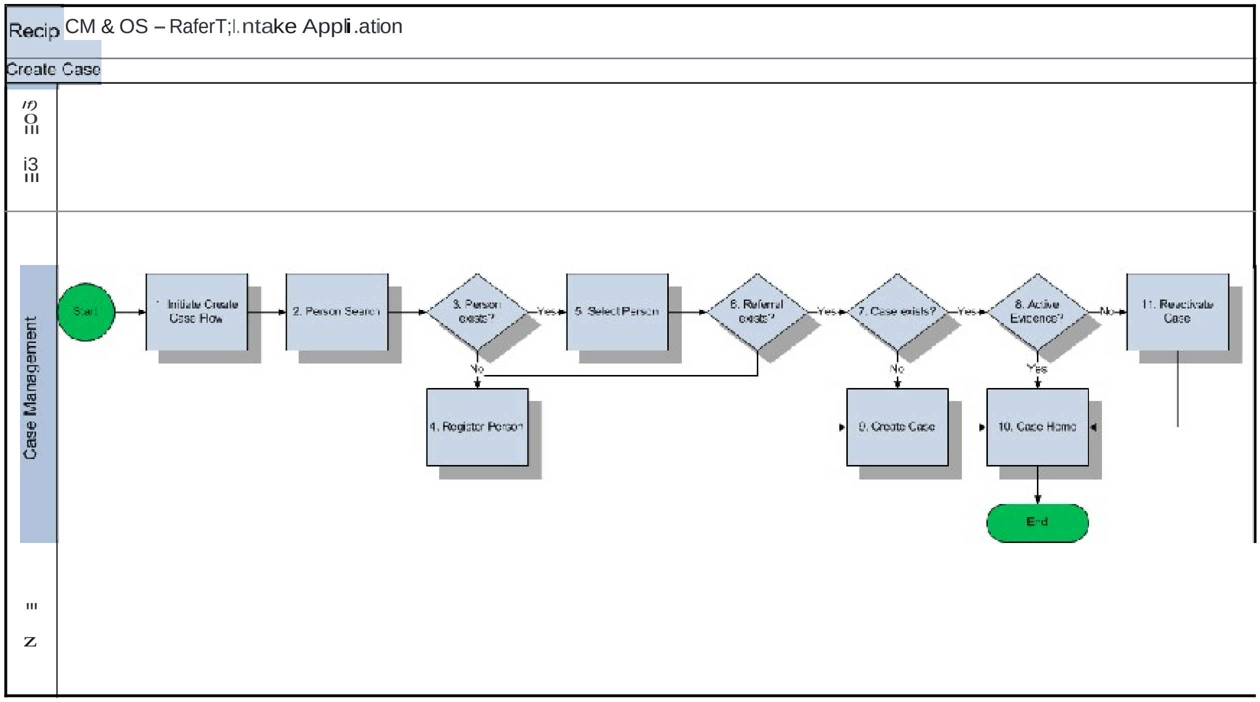
If the person calling is a third party not authorized to open an application on the referred individual's behalf, the county must initiate the Referral using the Create Referral screen. (See Create Referral Flowchart below.) The Create Referral screen allows the entry of minimal referral data regarding the individual being referred. These data include the first and last names, the referral source, and either the person's address or telephone number. When the record is saved, the Person Type is indicated as Referral.

The outcome of either the Create Referral or Create Application process in CMIPS II is the creation of a single Person Record in CMIPS II. All persons are registered and are identified with one of the following Person Type Indicators: Referral, Applicant, Recipient, or Provider. An individual may have more than one Person Type, i.e., a person can be both a Recipient and a Provider.

CMIPS II uses a new case number configuration for both Applicants/Recipients and Providers. An Applicant will be assigned a random Case Number consisting of seven (7) digits, e.g., 1234567. This number is part of the Person Record and will remain as the Case Number for an Applicant/Recipient for the life of the case record, even if the Recipient moves to another county. The county numeric identifier is no longer directly associated with the Recipient Case Number. The county that owns the Recipient case can be found on the Case Home page using the same numeric county identifiers as were used in Legacy CMIPS.

Providers will be assigned random Provider numbers consisting of nine (9) digits, e.g., 123456789. These numbers will be random and not associated in any way with the Providers SSN as they were in Legacy. Like Recipient Case Numbers, this assigned Provider identifier will be the same regardless of the number of Recipients for whom the Provider works or the number of counties in which the Provider works. This number will remain associated to the Provider for the duration of their CMIPS II record.


Recip CM & OS – Referral/Intake Application
Create Referral
Yes
No
Create
Person
Case?
7. Re-open


Recip CM & OS – Referral/Intake Application
Create Case
Case Management
Start
1. Initiate Create Case Flow
2. Person Search
3. Person exists?
Yes
No
4. Register Person
5. Select Person
6. Referral exists?
Yes
7. Case exists?
Yes
No
9. Create Case
8. Active Evidence?
No
Yes
10. Case Home
11. Reactivate Case
End

Application:

Manual of Policies and Procedures (MPP) section 30-009.221 states “Any person shall have the right to apply for services or to make application through another person on his behalf.” Once an individual or their authorized representative indicates that they wish to apply for IHSS, an application shall be taken immediately (MPP section 30-009.222). The county shall not deny or in any way dissuade the individual or their representative from making an application for IHSS based on information communicated during a phone call or face-to-face visit. The individual must be afforded due process by being allowed to make an application for IHSS if they are so inclined, and have that application assessed for eligibility based on program rules. The applicant shall receive a Notice of Action detailing the outcome of the county’s determination.

An application for IHSS may be made over the phone or in writing by submitting an Application for Social Services (SOC 295). The following data about the applicant is required to complete the Create Applicant process:

Name;
SSN or verification that the applicant has applied for an SSN;
Date of Birth;
Applicant’s preferred spoken and written languages;
Gender;
Ethnicity;
County of Residence;
Residence and mailing addresses; and
Applicant’s primary phone number.

At the time the application information is entered in either Legacy CMIPS or CMIPS II, a case number will be assigned to the applicant. Legacy counties, to the extent that current business practice allows, and all CMIPS II counties shall provide the case number to the applicant or their authorized representative before the end of the telephone call during which the application is taken, or before they leave the IHSS office so the applicant or their authorized representative will be able to refer to the case number in any communications with the county. For counties still using Legacy CMIPS where current county practice is for key data entry of the application information by a person other than the person taking the application, the county shall enter the application into CMIPS as expeditiously as possible and if the case number is requested, the county will provide it to the applicant as soon as possible.

Applications always require a signature. However, social services staff or the applicant's authorized representative can sign on the applicant's behalf to preserve the application date (MPP section 30-009.224). For those individuals who apply by phone, the SOC 295 may be signed at the IHSS face-to-face assessment.

The date the services are requested either by phone or submission of the SOC 295, whichever is earlier, shall be the applicant's "protected date of eligibility". If the applicant is not already a Medi-Cal beneficiary, the county must create the IHSS application to establish the "protected date of eligibility". While counties are still on Legacy CMIPS, non-Medi-Cal applicants should be referred to the local Medi-Cal office to apply for Medi-Cal. At the point a county goes live on CMIPS II, the system will automatically check for Medi-Cal eligibility and generate a referral if no eligibility exists. If the applicant is ultimately determined to be eligible for IHSS, the applicant may be authorized services back to the "protected date of eligibility".

LEGACY CMIPS:

> The county shall initiate a name or social security number search to determine if the individual calling or being referred to IHSS is already known to CMIPS.
>
> The county shall determine if the potential applicant is currently a Medi-Cal beneficiary. If not, the county shall take the application for IHSS and refer the applicant to the local Medi-Cal office to apply for Medi-Cal.
>
> The county shall enter into CMIPS the information necessary to establish an application and provide the assigned case number to the applicant for use in future communication with the county.

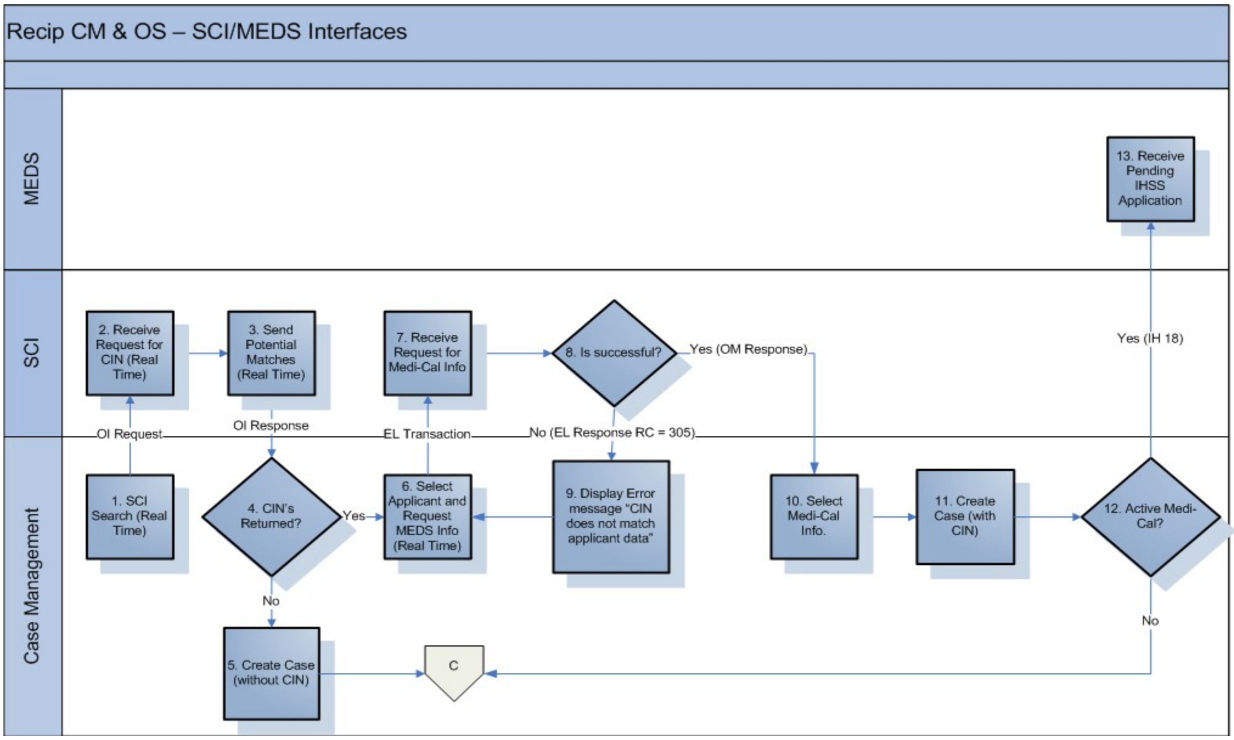
CMIPS II:

The county shall initiate a Person Search to determine if the individual calling or being referred to IHSS is already known to CMIPS II. An individual shall exist only once in CMIPS II.

From the Person Search, if the person does not exist, the user will access the Create Application screen and proceed with the application to the Create Case screen.

The county shall provide the assigned case number to the applicant for use in future communications with the county,

When an application is opened in CMIPS II, the system will check to see if the applicant has active Medi-Cal. If none exists, CMIPS II will generate a referral through an interface with the SAWS system requesting a Medi-Cal eligibility determination be completed. When the Medi-Cal eligibility determination is completed, the information will be sent back to CMIPS II through the interface. (See SCI/MEDS Flowchart below..)



PERSON NOTES/CASE NOTES/CASE (AUTHORIZATION) NARRATIVE

CMIPS II will provide counties with several areas to enter electronic notes and case narratives related to referrals, applicants, recipients and providers that were not available to counties in Legacy CMIPS. The following paragraphs will explain the use of each of these functions as they relate to IHSS case management. The technical aspects of accessing and using each of the functions will be addressed during CMIPS II Training.

CMIPS II has 2 types of notes for an individual – Person and Case. Person Notes should be used when only a referral exists for the individual. Once an application has been taken and a case created all notes regarding the individual shall be entered in Case Notes.

Person Notes and Case Notes entries are displayed in chronological order with the most recent entry displayed first. Counties are advised to instruct their staff to carefully review their entries before saving the entries in either Person Notes or Case Notes. Once an entry is saved, the system will not allow the entry to be edited and a new Person or Case Note must be initiated. CMIPS II will automatically annotate the entry with the worker's name and the current date and time.

PERSON NOTES

Person Notes are entries made in association with a Person Record. Person Notes are specific to an individual before they apply for IHSS services, meaning that Person Notes should only be entered during the "Referral" process. Once an individual moves from being a referral to an applicant or a case, all notes entries should be made in Case Notes.

Person Notes entries are also used when the entry relates specifically to a provider and should be entered on the Notes page attached to that provider's Person Record. Notes related to the provider should only be entered in Person Notes on the provider's Person Record, not in Case Notes.

Examples of Person Notes are:

Received call from daughter inquiring about possible services for mother. Daughter didn't have sufficient information to open application and wasn't sure her mother will accept services. Daughter requested IHSS application and other appropriate paperwork be mailed to her. Mailed SOC 295 and Health Cert 12/12/12.

Or

Daughter wants to be a provider for her father who is an IHSS recipient. Explained provider enrollment requirements and mailed required documents 11/12/13.

CMIPS II will automatically annotate the entry with the worker's name and the current date and time.

CASE NOTES

The Case Notes function allows users to enter information that is related to a case but not related to a specific assessment. Once the case is created, notes should be entered in Case Notes and no longer entered in Person Notes.

An example of a case note is:

Received a call from recipient's son stating recipient may be leaving to live with her daughter in Michigan and asking what steps needed to be taken to terminate her case if she decides to move. The move is still uncertain. Advised son to call when plans are firm.

CMIPS II will automatically annotate the entry with the worker's name and the current date and time.

CASE (OR ASSESSMENT) NARRATIVE

The Case (or Assessment) Narrative is used to record information relating to an initial assessment or reassessment. Each time New Evidence is added to CMIPS II a new Assessment Narrative is created. Assessment Narratives are associated with Evidence and once evidence is authorized that Assessment Narrative is no longer editable

An example of an abridged Assessment Narrative is:

Reassessment home visit to the 75-year-old female recipient: The recipient lives with her husband in a small 2-BR ground floor apartment. She suffers from severe osteoporosis, but is ambulatory. She is unable to independently perform most domestic and related activities and needs minimal assistance with bathing and dressing; however, her condition has deteriorated since my last visit and I anticipate her need for service will increase over the next year. Her husband is currently able and available, but is also having more difficulty functioning and may need assistance soon himself."

Generally, the information in the Assessment Narrative will be similar to the narratives created by social workers today. The Assessment Narrative may include observations about the recipient, the recipient's functional abilities, living arrangements, others in the household and any other information the social worker deems pertinent to the case. The Assessment Narrative is also the area in CMIPS II where information about the recipient’s diagnoses may be recorded. The Assessment Narrative is limited to 13,500 characters.

PCSP/IPO/IHSS-R

Welfare and Institutions Code (WIC) section 12300 (g) states that an individual who is eligible to receive services under PCSP or IPO shall not be eligible to receive services under IHSS-R. Therefore, all applicants for IHSS must complete a Medi-Cal eligibility determination prior to being authorized PCSP/IPO/IHSS-R. The only exception to this requirement is if an applicant is complying with all Medi-Cal requirements, but the determination of their eligibility for Medi-Cal is pending a DED, and completion of the DED will require longer than the 45-day statutory maximum for processing a Medi-Cal application. These individuals may be evaluated for potential IHSS-R presumptive eligibility in accordance with MPP section 30-759.3. If eligible, the applicant may be authorized IHSS-R services prior to Medi-Cal completing the eligibility determination. If the Medi-Cal application is denied because the applicant’s DED is turned down, IHSS-R services must be discontinued. No other applicants can be served in the IHSS-R program prior to completion of a Medi-Cal eligibility determination. An applicant who does not cooperate or fails to comply with Medi-Cal requirements during the application process is not eligible for IHSS-R.

Individuals who are eligible for Medi-Cal with full Federal Financial Participation (FFP) and who are currently linked to Medi-Cal as aged, blind or disabled; or who meet the MPP section 30-780.2 (b) criteria of a chronic, disabling condition that causes functional impairment that is expected to last at least 12 consecutive months or result in death within 12 months; and who are determined through an in-home assessment to be unable to remain safely at home without IHSS, may be authorized PCSP or IPO services. Those individuals are not required to have a DED.

IHSS applicants who are not eligible for FFP Medi-Cal or have been denied Medi-Cal eligibility for a reason other than failure to comply with Medi-Cal requirements, or failure to complete the Medi-Cal eligibility process, shall be considered for IHSS-R eligibility. These individuals shall complete a Statement of Facts for In-Home Supportive Services (SOC 310). The IHSS program staff may utilize resource and income information from the State Automated Welfare Systems (SAWS) eligibility system when determining IHSS-R financial eligibility and share of cost calculation so long as the non-FFP Medi-Cal case is active and the most current information in SAWS is used. All IHSS-R rules must be applied and any additional income and resource information required under IHSS-R rules must be collected and entered in CMIPS II. The CMIPS II system will calculate the IHSS-R financial eligibility and share of cost based on IHSS-R rules. If services are authorized, the recipient is required to pay any IHSS-R share of cost (SOC) to their provider in accordance with MPP section 30-755.233. An IHSS-R recipient who receives non-FFP full scope Medi-Cal and has a Medi-Cal SOC may submit receipts for their IHSS-R SOC payments to Medi-Cal where they will be applied toward meeting their Medi-Cal SOC obligation.

If an IHSS recipient's Medi-Cal eligibility is discontinued, CMIPS II shall generate a task to the social worker/case owner notifying them of the reason for the discontinuance. If the reason for discontinuance is failure to comply with Medi-Cal eligibility, including the annual renewal, the social worker/case owner shall terminate IHSS services. If the Medi-Cal discontinuance is due to change in circumstance the recipient should be considered for IHSS-R eligibility.

SOCIAL SECURITY NUMBER (SSN) REQUIREMENTS

Title 22 of the California Code of Regulations (CCR) section 50187 (22 CCR 50187(a) and (b)), requires that all beneficiaries of Medicaid services, which for purposes of this letter means PCSP or IPO recipients and non-FFP Full-Scope Medi-Cal (State-only Medi-Cal) beneficiaries who meet the eligibility requirements for IHSS-R, must have a valid SSN in order to receive services or show proof of an application for an SSN (form SSA 5028 Evidence of Application for SSN).

In order to be eligible for IHSS-R, applicants/recipients must meet the requirements for Supplemental Security Income (SSI) eligibility except for income. One requirement for SSI eligibility is that the applicant/recipient must have a valid SSN or must have submitted an application for an SSN before or at the same time they submit an application for SSI.

Counties must take an application from an individual requesting to apply who can provide the application criteria described above. However, in the event an applicant does not have a SSN, at the time of application the applicant must provide proof of having applied for an SSN by providing the county with a copy of an SSA 5028 form completed by the Social Security Administration (SSA). Thus, an application cannot be accepted unless it includes an SSN or proof of an application for an SSN (form SSA 5028 Evidence of Application for SSN).

SSA will issue SSN cards clearly marked "NOT VALID FOR EMPLOYMENT" to individuals who are lawfully admitted to the United States without work authorization from the Department of Homeland Security, but who have a valid non-work reason for needing an SSN, such as a federal law requiring an SSN to get a benefit or service (http://www.socialsecurity.gov/ssnumber/cards.htm). Medicaid and SSI each require an SSN for an individual to be eligible.

Qualified aliens are eligible for SSNs that include the designation "NOT VALID FOR EMPLOYMENT" based on the law requiring an SSN to receive a benefit or service. Aliens who are not in a satisfactory immigration status, and who do not have an SSN, can still receive State-Only Medi-Cal, and potentially IHSS-R, if they meet all eligibility requirements. Please see All-County Information Notice Number I-18-08 for more information on IHSS-R Eligibility for Non-Citizens.

Although DHCS has historically assigned pseudo SSNs to Medi-Cal eligible adoptees, this practice is largely out-of-date due to the current strict confidentiality laws. Neither Legacy CMIPS nor CMIPS II will accept pseudo SSNs that include an alpha character as valid entries. Adoptive parents should be directed to use the valid SSN previously assigned to their child or to apply for a new SSN for the child under his/her adopted name.

After taking the IHSS application, counties still using Legacy CMIPS should refer applicants without an SSN or an active Medi-Cal record in the Medi-Cal Eligibility Data System (MEDS) to Medi-Cal to complete a Medi-Cal eligibility determination and to the Social Security Administration (SSA) to apply for an SSN.

In CMIPS II, the county must enter the applicant's information into CMIPS II and conduct a Person Search to see if the applicant is already known to CMIPS II and perform a State Client Index (SCI) look-up to see if the applicant already has a Client Index Number (CIN) and active Medi-Cal. The CMIPS II user will be prompted to either select the correct CIN from any possible matches that are returned or send a Medi-Cal referral via interface to the local SAWS to initiate a Medi-Cal eligibility determination. If there is no CIN match, the user must select the option to send the referral to SAWS. When the Medi-Cal eligibility determination is completed, CMIPS II will receive notification through the interface of the outcome and, if approved, the aid codes assigned to the beneficiary and a notification will be sent to the case owner.

The response from MEDS will include both the MEDS Primary Aid Code and the FFP status indicator. The appropriate secondary Medi-Cal Aid Code (2L IHSS Plus Option – IPO; 2M Personal Care Services Program – PCSP; or 2N IHSS Residual Program – IHSS-R) will be determined by CMIPS II based on programmed eligibility criteria. Applicants cannot be approved for PCSP/IPO services until the individual has been granted FFP Full-Scope Medi-Cal. Counties should be aware that although the CMIPS II case record may indicate a full-scope FFP primary Medi-Cal Aid Code when compared to the list of current Medi-Cal aid codes, it does not necessarily mean the Recipient has been granted full-scope FFP Medi-Cal. For IHSS program eligibility purposes, the county should rely on the FFP status indicator and the secondary Medi-Cal Aid Code determined by CMIPS II. If CMIPS II displays a secondary aid code of 2N (IHSS-R) it means the recipient/beneficiary has been authorized full-scope, State-only (non-FFP) Medi-Cal and must be evaluated for IHSS-R eligibility using IHSS-R rules before services can be authorized.

If an applicant for IHSS submits as their own an SSN that is already associated with a Person Record in CMIPS II and which has been provided by a different individual, the county must follow the system processes that will be described in detail as part of CMIPS II user training to take the application and potentially authorize services while the issue is researched and resolved. County staff should contact their Medi-Cal program staff to determine if Medi-Cal has completed a Social Security Administration Referral Notice (MC 194) form a copy of which is attached to this letter. This form is a request to SSA to research and resolve the conflict in SSN numbers. If Medi-Cal program staff has not initiated this process, IHSS program staff should request that it be initiated. When SSA has completed its research, it will return the MC 194 with the outcome to Medi-Cal. The IHSS program should take actions consistent with the outcome SSA provides to Medi-Cal, and deny or terminate services as appropriate to the applicant/recipient determined by SSA to have provided an SSN not issued to that person.

RECIPIENTS RESIDING IN MORE THAN ONE COUNTY

An IHSS recipient may reside and receive services in more than one county. As an example, a child recipient may live a portion of the time with their mother in one county and the remainder of the time with their father in a separate county. Similarly, an elderly parent who receives IHSS may divide their time between three adult children who live in separate counties and receive services in all three counties.

In Legacy CMIPS, the recipient would likely have had a case in each county in which they received services. However, in CMIPS II, a recipient will have one Person Record and thereby one case record regardless of the number of counties in which they receive services.

If an IHSS recipient has residence in more than one county a “primary county of residence” must be designated. The primary county of residence will be the county that carries the case. In general, the primary county of residence for the IHSS case should be the same county where the recipient has active Medi-Cal. There may be exceptions to this, such as when the Medi-Cal case is carried by the county in which eligibility was initially determined regardless of the recipient's county of residence. In these types of circumstances, the recipient may choose the county they want to designate as the IHSS primary county of residence. Please note that it is perfectly acceptable for the Medi-Cal case and the IHSS case to be in different counties; it will not impact Medi-Cal eligibility or FFP for the IHSS case.

The primary county of residence is responsible for all aspects of the case including: conducting the needs assessment; authorizing services; enrolling providers; issuing timesheets; and funding the case. Other counties of residence should be viewed as "alternate service sites" similar to services received in the work place. The services received at the alternate service sites are limited to those currently authorized in the primary county of residence.

The case owner in the primary county of residence should work with the recipient to identify and designate a specific number of the authorized hours available for each alternate service site based on the time the recipient spends at that site. If the recipient chooses, the designated hours may be assigned to the provider at each alternate service site and the recipient should complete and sign an IHSS Recipient Request For Assignment Of Authorized Hours To Providers (SOC 838). The place of residence in each county must also meet the IHSS "own home" criteria. All Individual Providers for the recipient must complete the provider enrollment criteria in order to be enrolled on the case and will receive the wages of the primary county of residence and any benefits offered by that county for which they are eligible.

REINSTATEMENT OF RANK 6

In ACL 88-118 (issued September 6, 1988), the Assessment Standards specified the use of Rank 6 in the following service categories: Meal Preparation & Clean-up, Feeding and Respiration. ACL 88-118 directed counties to assess Rank 6 for these service categories when all services were exclusively paramedical. Legacy CMIPS has been programmed according to this direction since 1988. Design and development of CMIPS II has also incorporated the use of Rank 6 as described in this paragraph.

Manual of Policies and Procedures (MPP) section 30-756.41 currently states that county staff shall assess Rank 1 when all services are exclusively paramedical. It is unclear whether the MPP section has been written this way as far back as 1988, when the ACL was issued. It is uncertain if the need for Rank 6 was realized only after the regulations were promulgated and the regulations were never amended to include Rank 6, or if the MPP section was erroneously amended at some time subsequent to the 1988 ACL. Regardless, the intent of the direction in ACL 88-118 has always been clear that Rank 6 was to be used when all Meal Preparation and Clean-up, Feeding and/or Respiration services are provided under Paramedical Services.

Please note that the instructions in this ACL supersede the instructions given in ACL 88-118 and ACLs 06-34 and 06-34E2. ACL 06-34 (issued August 31, 2006) included Rank 6 in the Annotated Assessment Criteria. However, ACL Errata 06-34E2 (issued May 4, 2007) eliminated Rank 6 for Meal Preparation & Clean-up , Feeding and Respiration in the Annotated Assessment Criteria. As a result, some counties discontinued using Rank 6 to identify Paramedical needs in these service categories. The elimination of Rank 6 precluded counties from accurately reflecting recipients' needs for Paramedical Services in cases where such services were authorized in addition to human assistance.

Upon receipt of this ACL, counties shall begin using Rank 6 for the following service categories, when applicable, during initial assessments and all reassessments:

Meal Preparation & Clean-up
Feeding
Respiration
Bowel, Bladder and Menstrual Care

In ACL 09-30, Question #12 asks if there is a Rank 6 for Bowel and Bladder care. The answer stated, “No, Rank 6 is not used for Bowel and Bladder. The recipient should be ranked from one to five based on level of function, irrespective of any related Paramedical Services.”

CDSS has reconsidered its position and determined it is appropriate in certain instances for Bowel, Bladder and Menstrual Care to be provided only in the form of Paramedical Services. For instance, you have a recipient who does not need assistance toileting because he is able to get to the bathroom and urinate independently. However, he does need assistance maintaining his colostomy site (a paramedical service). He should be ranked a 6 in Bowel, Bladder and Menstrual Care because all his Bowel, Bladder and Menstrual needs are being met through a Paramedical Service. Therefore, the category of Bowel, Bladder & Menstrual Care has been added to the list of service categories where Rank 6 may be assessed if the need is met only by Paramedical Services. Please note this ACL supersedes the response provided to Question #12 in ACL 09-30.

Rank 6 will be added to the regulation sections for Meal Preparation & Clean-up, Feeding, Respiration and Bowel, Bladder & Menstrual Care in the next amendment to the MPPs. Until that time, ACL 88-118 and this ACL will serve as the authorities for including Rank 6 as part of the assessment criteria when conducting assessments and reassessments. Additionally, the Annotated Assessment Criteria will be modified to reflect these changes.

Functionality for the use of Rank 6 in Legacy CMIPS Rank 6 has not changed since the issuance of ACL 88-118. Counties should resume using Rank 6 based on the instructions in that ACL. Bowel, Bladder and Menstrual has just been added to the categories that are eligible for an assignment of Rank 6 and due to the imminent conversion to CMIPS II, Legacy CMIPS has not been modified to accept a Rank 6 for this service category.

CMIPS II expands the functionality of Rank 6 so social workers may assess and assign Rank 6, as needed, for the authorization of Paramedical Services in Meal Preparation/Clean-up, Feeding, Respiration and Bowel, Bladder and Menstrual Care.

Similar to Legacy CMIPS, CMIPS II will continue to display error messages when there are discrepancies between services authorized and its assigned functional rankings (i.e., Rank 6 has been assigned to a Service Type but there are no Paramedical Services authorized). These validation edits will appear on the screens and documents the error messages that will be displayed for each edit.

> When an attempt is made to save Create or Modify Service Type Feeding and the Functional Rank for Feeding is 6, the following error message will be displayed: Assessed Need not allowed because Functional Area Feeding is indicated as Paramedical.
>
> When an attempt is made to save a Service Type associated with Meal Prep & Clean-up and the Functional Rank for Meal Prep & Clean-up is 6, the following error message will be displayed: Assessed Need not allowed because Functional Area Meal Prep & Clean-up is indicated as Paramedical.
>
> When an attempt is made to save a Respiration Service Type and the Functional Rank for Respiration is 6, the following error message will be displayed: Assessed Need not allowed because Functional Area Respiration is indicated as Paramedical.
>
> When an attempt is made to save a Service Type associated with Bowel & Bladder Care and the Functional Rank for Bowel & Bladder Care is 6, the following error message will be displayed: Assessed Need not allowed because Functional Area Bowel & Bladder is indicated as Paramedical.

To resolve these error messages, the social worker will need to check the functional ranking for the Service Types and confirm a Rank 6 is needed and/or to reassess the functional ranking, if needed. Additionally, the social worker will need to determine why Paramedical Services have not been authorized on the Service Evidence screen if a Service Type has been assigned a Rank 6.

INTER-COUNTY TRANSFER (ICT) PROCESS IN CMIPS II

Conversion to CMIPS II will not create a need for changes to the existing regulatory requirements related to ICTs (MPP sections 30-759.9 to .972). An ICT occurs when an IHSS recipient moves from one county to another and the originating county that has been responsible for the management of the recipient case transfers management of that case to the receiving county.

When an ICT is completed in Legacy CMIPS, the recipient is terminated in the transferring county and a new case is opened and a new case number assigned in the receiving county. The process is primarily a manual exchange between the sending and receiving counties.

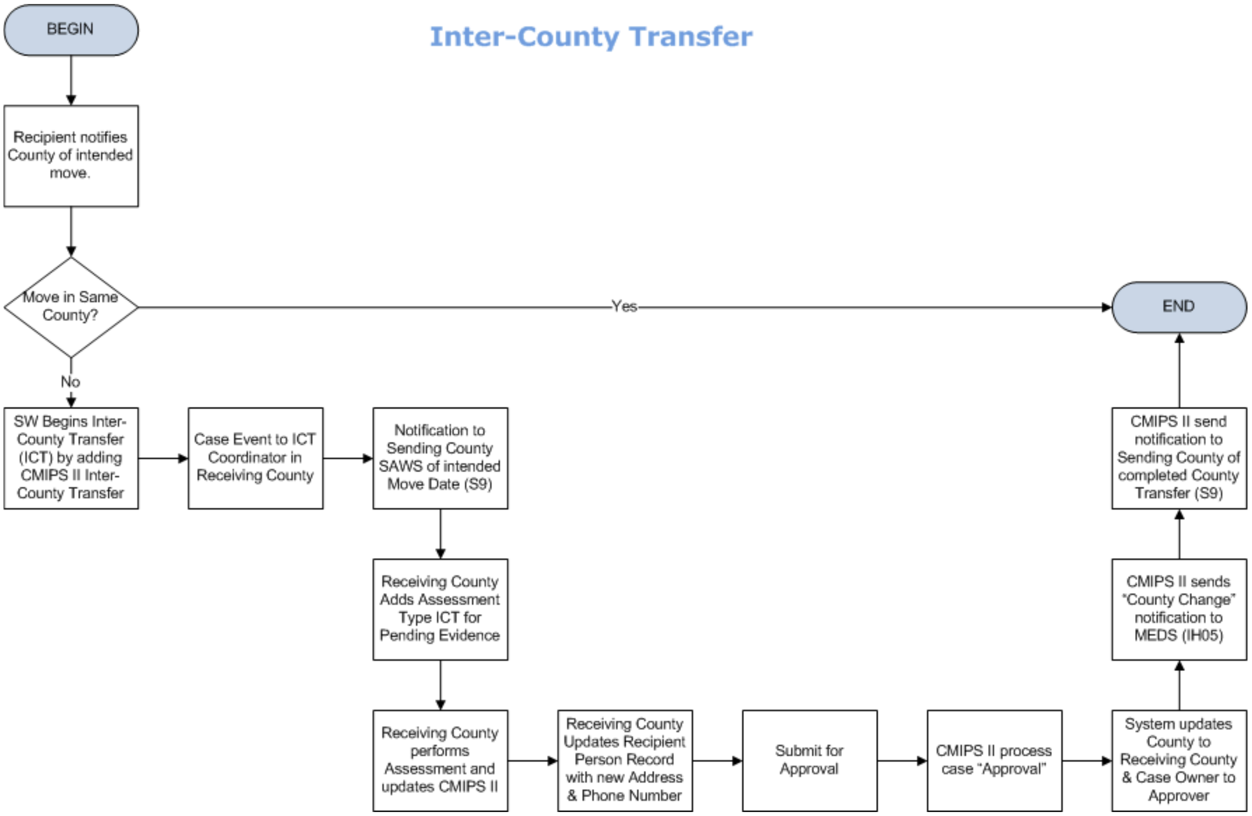
In CMIPS II, the ICT process is much more automated providing a more efficient process. For example, a recipient will have a single Person Record and case number for the life of the IHSS case that will follow the recipient during an ICT, rather than terminating the case in the sending county and creating a new case in the receiving county. In CMIPS II, when the receiving county accepts the ICT, the only change to the case number will be the numeric county indicator at the beginning of the case number. For example, in Fresno County the case number might be 10-123456; the 10 at the beginning representing the Fresno County code. After an ICT to Sacramento County, the 10 would change to 34, Sacramento County's code. The second portion of the case number, 123456, remains the same. Thus, the case number would change to 34-123456.

CMIPS II has functionality to support the ICT process including:

Generating a referral from the transferring to receiving county;
An assessment specific to ICT;
Updating county and case owner upon receiving county authorization;
Notifications to transferring county SAWS system;
Not allowing an ICT when the case has an open state hearing record in the system; and
Allowing an ICT to be canceled when necessary.

Although most ICT activities will be conducted within CMIPS II, the transferring county will still be required to fax or mail to the receiving county all completed forms/documents that are retained outside of CMIPS II, such as the Request for Order and Consent – Paramedical Services (SOC 321) form.

If the recipient moves from the receiving county to a third county during the transfer period, the original transferring county is responsible for canceling the transfer to the first receiving county and initiating the transfer to the second receiving county (MPP 30-759.922). The flow chart below documents the steps of the ICT process in CMIPS II. The CMIPS II ICT process is displayed in the flow chart below.



Inter-County Transfer (ICT) Process during CMIPS II Implementation Phase

During the period of statewide rollout of CMIPS II, ICTs may occur between two Legacy CMIPS counties, two CMIPS II counties or a Legacy CMIPS county and a CMIPS II county. The following chart provides the possible scenarios and the action to be taken in each scenario.

SCENARIO	ACTION TO BE TAKEN
Legacy CMIPS county is receiving an ICT from a Legacy CMIPS county	Follow current (pre-CMIPS II) procedure
Legacy CMIPS county is receiving an ICT from a CMIPS II county	Follow current (pre-CMIPS II) procedure
CMIPS II county is receiving an ICT from a Legacy CMIPS county	Open new application in CMIPS II
CMIPS II county is receiving an ICT from a CMIPS II county	Follow CMIPS II process to review ICT in CMIPS II and assign to worker (See flow chart above.)
CMIPS II county is sending an ICT to a Legacy CMIPS county	Terminate the case in CMIPS II and follow current (pre-CMIPS II) procedure
Legacy CMIPS county is sending ICT to a CMIPS II county	Follow current (pre-CMIPS II) procedure

Funding of the Case during Inter-County Transfer (ICT)

In accordance with existing regulations, the transferring county is responsible for the county share of the case funding until the effective date of authorization in the receiving county. MPP section 30-759.921 states, “The transferring county is responsible for authorizing and funding services until the transfer period expires, at which time the receiving county becomes responsible.” Which county maintains the Medi-Cal case is irrelevant to which county pays the county share of funding for the IHSS case. Communication between counties to ensure timely transfer of case responsibility is essential. CMIPS II produces a “Monthly Inter-County Transfer Report” to support communication between counties regarding ICT cases to help ensure ICTs are being completed timely.

If you have questions regarding this letter, contact Adult Programs at (916) 651-1069.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

c: CWDA

State of California—Health and Human Services Agency

Department of Health Care Services

SOCIAL SECURITY ADMINISTRATION REFERRAL NOTICE

Instructions:

- To CWD: Please complete Part I. Retain original for your records, copy for recipient/SSA. Client must take this form to SSA.
- To Recipients: Read the back of this form. Take the necessary documentation to the Social Security Administration Office listed below in Part I.B.
- To SSA: This form is a request for the action noted in Part I.C. Please complete Part II of this form and distribute as noted in Part I.A. If you have any questions, the eligibility worker's name and phone number are provided.

PART I: TO BE COMPLETED BY THE COUNTY WELFARE DEPARTMENT

A. Please enter the complete county welfare office name and address within the brackets provided.

SSA, after completion:

☐ Mail this form to the county welfare office.

☐ Return this form to the recipient to be returned to CWD.

B. Social Security Office Information

Name of SSA District/Regional Office

Address (number and street)

City	State	ZIP code

D. Applicant/Recipient Information

Recipient's name (last, first, middle initial)

Date of birth (month/day/year)	Sex (M or F)

County ID per MEDS

			X										

Recipient's SSN (if applicable)

Case name

E. CWO Information

Name of Eligibility Worker

Date form completed	E.W. Worker	E.W. phone number

C. The bearer of this form is an applicant for, or recipient of, Food Stamps, Cash Aid, or Medi-Cal. The following service is required:

☐ Original SSN card

☐ Duplicate SSN card SSN: ____________________

☐ Info on SSA's Numident File needs to be verified.

☐ Name ☐ DOB ☐ Sex

☐ Info on SSA's Numident File needs to be corrected.

☐ Name ☐ DOB ☐ Sex

Note: Recipient must provide verification of change.

☐ Recipient has been assigned two SSNs. Please take action to delete all but one.

☐ Two recipients appear to have been assigned the same SSN. Please verify correct number for recipient from Numident File.

F. Comments

____

PART II. TO BE COMPLETED BY THE SOCIAL SECURITY ADMINISTRATION DISTRICT/REGIONAL OFFICE

A. Date received

C. Comments

____

____

____

____

B. Result of Referral

☐ 1. Recipient has completed an SSN application (including Form SS-5 and other proof) and application is being processed.

☐ 2. Insufficient ID.

☐ 3. SSN application is not being processed. (Explain.)

____

☐ 4. Other. (Explain.)

____

D. SSA Representative—print name	Signature	Telephone number

SSA REFERRAL INFORMATION SHEET
(For Medi-Cal, Food Stamp, and CalWORKs Recipients)

YOU MUST CONTACT SOCIAL SECURITY

Public Law requires that each person who applies for or receives full-scope Medi-Cal, Food Stamps, or California Work Opportunity and Responsibility to Kids must have or apply for a social security number. For the applicant/ recipient noted on the reverse side, either (1) the Social Security Administration does not have a social security number on file, or (2) the information provided by the Social Security Administration and the information provided to the eligibility worker do not agree. To correct this situation, you must contact the Social Security Office indicated on the reverse side of this referral form. DO NOT MAIL THESE FORMS TO THEM.

NOTE: Age, citizenship or alien status, and identity must all be documented. One of the identification documents must be a birth or baptismal certificate established BEFORE age 5. If one is not obtainable, refer to Column A for acceptable substitutes. In addition, if the applicant/recipient is a U.S. citizen born outside of the U.S. or an alien, one of the items listed in Column B must be presented.

Column A

1. Evidence of Age/Citizenship
   - School records
   - Church records
   - Census records (state or federal)
   - Insurance policy
   - Marriage records
   - Draft card
   - U.S. passport
   - Other records indicating applicant's age or date and place of birth
2. Evidence of Identity
   - Driver's license
   - State identification card
   - Voter's registration
   - School records
   - Health records (doctor's, hospital's, etc.)
   - Any other document which shows applicant's signature, photograph, or description

Column B

1. If you are now a U.S. citizen born outside the U.S., take one of the following items in addition to the item(s) required in Column A:
   - U.S. citizen identity card
   - U.S. passport
   - Naturalization certificate
   - Certificate of citizenship
   - Consular report of birth
   - Form I-179 (U.S. citizen card)
   - Form I-197 (U.S. citizen resident card)
2. If you are an alien, take one of the following items in addition to the item(s) listed in Column A:
   - Form I-151 or I-551 (Alien Registration Receipt Card)
   - Form AR3a, I-94, I-95a, I-84, I-85, I-86, or SW-434
   - Letters from Immigration and Naturalization Service showing alien status

If you have a question concerning the two identification documents which you must take to the Social Security Office, please contact the Social Security Office.

SELF-REFLECTION ON CULTURAL SENSITIVITY

Review the areas below and examine how your behavior and attitude match the following criteria. Identify your strengths and weaknesses. Understanding the attributes, knowledge, and skills that are necessary for cultural sensitivity is fundamental to your role as a Social Worker in the IHSS program.

Attributes:

- ☐ Genuineness, accurate empathy, non-possessive warmth, and a capacity to respond.
- ☐ Flexibility to a range of possible solutions.
- ☐ Acceptance of ethnic differences between people.
- ☐ Comfort in working with consumers of different ethnic groups.
- ☐ Understanding of my own personal values, stereotypes, and biases about my own and other ethnicities and social classes.

Knowledge of:

- ☐ Culture (history, values, traditions, family systems, artistic expressions) of many cultural groups.
- ☐ The impact of class and race on behavior, attitudes, and values.
- ☐ Help-seeking behaviors of consumers.
- ☐ The role of language, speech patterns, and communication styles.
- ☐ The impact of social service policies on consumers.
- ☐ Resources that can be utilized and how to access them.

Skills:

- ☐ Techniques for learning about culture.
- ☐ Ability to communicate accurate information on behalf of the consumer.
- ☐ Ability to openly discuss cultural differences and respond to culturally based cues.
- ☐ Ability to assess the meaning that ethnicity has for individual consumers.
- ☐ Interviewing techniques that are culturally sensitive.
- ☐ Ability to advocate on behalf of the consumer and community.
- ☐ Ability to recognize and address racism, racial stereotypes, and myths in individuals and institutions.

How to do this:

- Skills and knowledge are gained through education, training, practice, and self-reflection and exposure to diverse cultures.
- Personal attributes can be developed through exposure to aspects of minority cultures.
- Knowledge and skills must be coupled with a willingness to let consumers determine their own future, within program parameters.

CULTURAL IMPLICATIONS FOR THE IHSS ASSESSMENT

It is important to understand cultural differences in order to have the best professional relationship with a consumer regardless of race, origin, gender, age, religion, sexual orientation, social class, economic situation, and/or disability. Most cultural beliefs are influenced by culture, age, and length of time in the U.S. Culture is one of a number of influences on behaviors in the face of illness and other life transitions, and it is important to take these factors into account when interacting with a consumer. You cannot assume that your past experiences with a person from a particular culture can be applied to everyone from that culture. It is important to seek more information by asking a consumer questions about his/her culture and how this may impact their care.

Having knowledge about a specific cultural/ethnic group does not ensure cultural awareness; however, without knowledge and understanding, cultural awareness most likely will not occur. Your own ethnicity, religion, and where you grew up can change how you perceive the world, affect the way you perceive "appropriate" behavior, and influence your interactions with the consumer.

Important Terms:

- Stereotyping – one makes an assumption about a person based on group membership without learning whether or not the individual in question fits that assumption.

Generalizing – one uses previous experiences about a cultural group to form an assumption about the group but **must gather further information** as to whether the assumption fits the individual

Common differences between cultures that may impact your work:

- **Native language:**
    - You may have a different native language than the consumer. In these circumstances, it is natural that communication may be difficult and require patience. Once you learn to listen to each other and adjust to differences in language, it will get easier.
    - If the consumer understands and speaks some English, make sure youspeak slowly, give them plenty of time to think of their answers, and do not compound your questions.
    - Follow State regulations (MPP 21-115) and county procedures to arrange for an interpreter if the consumer does not speak English and you do not speak his/her language.

- **Personal space:**
    - There are many different comfort levels. In some cultures, standing close is comfortable, while in others giving ample space is important for personal comfort.

- **Touch:**
  - Some cultures prefer not to have certain parts of the body touched, such as the head and feet. In addition, it is important to be conscientious about gender differences in comfort with touch. In some cultures, there is great sensitivity regarding opposite gender caregivers.

- **Time-orientation:**
  - Differences include being strictly oriented to clock time versus embracing personal and subjective time. The importance of being "on time" can vary.

- **Gestures:**
  - There are a number of gestures commonly used in the United States that may have a difference meaning or be offensive to those from other cultures. One example is the use of a finger or hand to indicate, "come here please." Pointing with one finger is also considered rude in some cultures.

Here are some common differences in communication between cultures that you may encounter:

- **Conversational style and pacing**
  - Silence is interpreted differently by different cultures. In some, it is a sign of respect, while in others a person will find you rude or even interpret silence as a "no" response.
  - Styles of questions and answers can be different in cultures ranging from blunt and to the point to indirect and storytelling styles.
  - In some cultures, directness, insistence, and emphasis can look like anger to others. For example, consider the difference between "Close the window!" and "Could you please close the window?"

- **Eye contact**
  - In mainstream Western culture, eye contact is interpreted as attentiveness and honesty. However, in some cultures, eye contact is thought to be disrespectful or rude and lack of eye contact does not mean a person is not paying attention.
  - Avoiding eye contact has many reasons and can be easily misinterpreted.
  - Understanding and respecting that there may be differences between you and the consumer will help in maintaining a positive relationship.

USING AN INTERPRETER

Many times, assessments are conducted by a social worker that is fluent in the consumer's language. But at times, you have to conduct an assessment or other interactions with a consumer and/or provider through an interpreter. The consumer has the right to choose who his/her interpreter is, but if the consumer needs assistance, it is important to select someone who is certified or otherwise has been arranged for by the county.

There are several techniques you may employ when using an interpreter. While behaviors may vary by cultural group, demonstrating respect is recognized and valued by all people. When using an interpreter, consider the following strategies:

- Do not use a child under the age of 18 as an interpreter except in extenuating circumstances when requested to do so by the consumer and when no other interpreter is available. For additional information, see ACL 06-20, ACL 03-56 and MPP Section 21-115.16.
- Before the interview begins, inform the interpreter that you need him/her to translate all that the consumer says and to say to the consumer all of what you say.
- Always display professionalism and let the consumer know you are interested in his/her situation by being polite and formal.
- Ask the interpreter to use the consumer's own words as much as possible.
- Ask the interpreter to refrain from inserting his/her own ideas or interpretations and from omitting information.
- When communicating with the consumer through an interpreter, look directly at the consumer when you speak, not at the interpreter.
- Address questions to the consumer, not the interpreter.
- Observe the consumer's non-verbal communication, such as facial expressions, voice intonations, and body movements.
- Avoid raising your voice in an attempt to clarify your statements.
- Do not use hand gestures to emphasize statements; they may prove to be culturally insulting or even frightening.
- Use simple, nontechnical language and avoid using acronyms.
- Do not use slang.
- Check the consumer's understanding and accuracy by asking him/her to repeat the message or instructions in his/her own words with help from the interpreter.
- Provide instruction in the proper sequence and discuss one topic at a time.
- Avoid using double negatives.
- Avoid using leading questions that may encourage the consumer to say what he thinks you want to hear.
- Whenever appropriate, ask open-ended questions rather than questions requiring a "yes" or "no" response.

21-115 PROVISION FOR SERVICES TO APPLICANTS AND RECIPIENTS WHO ARE NON-ENGLISH SPEAKING OR WHO HAVE DISABILITIES 21-115

(Continued)

HANDBOOK CONTINUES

In the example above, one full time Spanish-speaking worker in any program would satisfy the requirements for all programs, provided that the worker would be available to interpret for the other two programs.

HANDBOOK ENDS HERE

.15 When the percentage of non-English cases in a program and/or location is less than five percent, the agency shall ensure that effective bilingual services are provided. This requirement may be met through utilization of paid interpreters, qualified bilingual employees, qualified employees of other agencies or community resources.

.16 Applicants/recipients may provide their own interpreter; however, the CWD shall not require them to do so. Only under extenuating circumstances or at the specific request of the applicant/recipient shall a CWD allow a minor (under the age of 18 years) to temporarily act as an interpreter. This provision does not apply to interpretive services for persons who are deaf.

.2 Forms and other written material required for the provision of aid or services shall be available and offered to the applicant/recipient in the individual's primary language when such forms and other written material are provided by CDSS. When such forms and other written material contain spaces (other than "for agency use only") in which the CWD is to insert information, this inserted information shall also be in the individual's primary language.

.3 Each CWD shall ensure that administrative practices do not have the effect of denying non-English speaking persons and individuals with disabilities equal access to and participation in the available programs and activities.

.4 Auxiliary Aids

.41 CWDs shall provide auxiliary aids and services to persons who are deaf or hearing impaired, or persons with impaired speech, vision or manual skills where necessary to afford such persons an equal opportunity to participate in, and enjoy the benefits and services of programs or activities. Auxiliary aids and services may include brailled material, taped text, qualified interpreters, large print materials, telecommunication devices for the deaf (TDDs) and other effective aids and services for persons with impaired hearing, speech, vision or manual skills. Compliance with this section can be accomplished through use of volunteer services from community organizations and individuals who are able to provide prompt effective services without undue delays using qualified interpreters.

.42 CWDs shall provide an opportunity for individuals with disabilities to request auxiliary aids and services of their choice. CWDs shall give primary consideration to the requests of individuals with disabilities.

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY ARNOLD SCHWARZENEGGER, Governor

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS

June 30, 2006

ALL COUNTY LETTER NO. 06-20

TO: ALL COUNTY WELFARE DIRECTORS
ALL COUNTY CIVIL RIGHTS COORDINATORS

SUBJECT: INTERPRETIVE SERVICES

The purpose of this All-County Letter (ACL) is to remind counties of their continued obligation to comply with the California Department of Social Services (CDSS) Manual of Policies and Procedures (MPP) Division 21 regulations regarding the provision of effective language services to all applicants/recipients in their primary language. The provision of effective language services shall be prompt, without undue delay. These requirements apply regardless of whether the county provides an interpreter (qualified bilingual employees, paid interpreters, qualified employees of other agencies, or use of community resources) or the applicant/recipient chooses to provide his/her own interpreter.

Counties must comply with MPP Section 21-107 regarding the dissemination of information and ensure that applicants/recipients are advised of their right to free interpretive services. It is always the county's obligation to affirmatively offer interpretive services (Section 21-115.15). Once the county has been informed that the applicant/recipient needs an interpreter, the county must offer and provide an interpreter at each client contact. The county's obligation to provide interpretive services may be met using a variety of methods, which may include bilingual staff, county interpreters, and contracted interpreters (including language line).

Applicants/recipients may use their own interpreter, but must not be compelled or encouraged to do so (Section 21-115.16). Before applicants/recipients decide to use their own interpreter, the county is required to advise them at initial intake and at each redetermination of (1) the right to free interpretive services; (2) potential problems of using the client’s own interpreter, including the possibility of ineffective communication, inaccurate interpretation, and the need to disclose private information to the interpreter; (3) the availability of county-provided interpretive services, whether or not a client chooses to provide his own interpreter; and (4) the right to accept county-provided interpretive services at any time, even when a client-provided interpreter is present.

If the applicant/recipient chooses to provide his or her own interpreter, but at any time informs the county that he or she wishes to utilize the county-provided interpreter, the county must provide free interpretive services, without undue delay. The county shall not conduct substantive, program-related conversations with the applicant/recipient until qualified interpretive services are available.

The county may allow a minor to temporarily act as interpreter only at the request of the applicant/recipient, or under other extenuating circumstances. The county must document the use of a minor and the reason(s) for it in the case record. Examples of extenuating circumstances warranting the temporary use of a minor as interpreter include, but are not limited to:

- The County Welfare Department (CWD) telephones or visits the applicant/recipient's home for initial contact and finds a non-English or limited-English speaking client, while a minor in the home speaks English. Under these circumstances, the CWD contact may use the minor as an interpreter only to determine the language of the client and to schedule a date and time to return with a county provided interpreter. When the matter is time sensitive, the county is encouraged to use a telephone interpreter.

- A non-English or limited-English speaking applicant/recipient enters the CWD with a minor child who speaks English and the county does not immediately have access to a county provided interpreter in the applicant/recipient's primary language. Under these circumstances, the minor may only be used as a temporary interpreter to schedule a date and time to return to the CWD when a county provided interpreter will be available. When the matter is time sensitive, the county is encouraged to use a telephone interpreter.

- When a CWD employee encounters a health and safety issue such as a car accident or crime scene, where immediate communication is imperative, a minor may be used temporarily until a qualified interpreter arrives at the scene or communicates with the applicant/recipient via telephone, cell phone, etc.

In all instances, the use of a minor as the applicant's/recipient's interpreter should be temporary, only until a county interpreter is made available.

In addition to providing free interpretive services, the county must document the following in the case record file for each contact with the applicant/recipient:

- The county offered free interpretive services;

- Who provided the interpretive services;

- The county informed the applicant/recipient of potential problems for ineffective communication when using the applicant’s/recipient's own interpreter;

- The county offered county-provided interpretive services if the applicant/recipient provided interpreter is not available;

- A minor temporarily acting as an interpreter did so at the specific request of the applicant/recipient or there were other extenuating circumstances, with an explanation of those circumstances;

- The applicant/recipient signed a consent for the release of information when using his or her own interpreter;

- The county informed the applicant/recipient of his/her right to accept county-provided interpretive services at any time, even when a client provided interpreter is present. (Section 21-115.16; 116.22 through .24)

If you have any questions regarding this letter, you may contact the Civil Rights Bureau at (916) 654-2107, or toll free at 1-866-741-6241.

Sincerely,

TOM LEE
Acting Deputy Director
Human Rights and Community Services Division

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY Gray Davis, Governor

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS - Policy Clarification

October 29, 2003

ALL COUNTY LETTER NO. 03-56

TO: ALL COUNTY WELFARE DIRECTORS
ALL CIVIL RIGHTS COORDINATORS

SUBJECT: REQUIREMENTS FOR LANGUAGE SERVICES

REFERENCE: MANUAL OF POLICIES AND PROCEDURES, DIVISION 21

This ACL serves to clarify the responsibilities of County Welfare Departments under California Department of Social Services (CDSS) regulations in providing effective language services with respect to six areas: 1) Bilingual Staffing, 2) Interpreter Services, 3) Minors Used as Interpreters, 4) Use of Translated Forms, Notices and Materials, 5) Informing Signs, and 6) Documentation.

1. Bilingual Staffing: Pursuant to Manual of Policies and Procedures (MPP) Division 21-115.1, counties are required to have qualified and certified bilingual public contact staff who speak the languages spoken by a substantial number of clients and who serve those non- or limited-English-speaking clients, including clients who use American or other sign language. A substantial number is five percent of the clients served in a program at an office.

   For example, in the local office of a county where clients are applying for and/or receiving Food Stamps and seven percent of those clients speak Tagalog, seven percent of the public contact staff in each job classification in the Food Stamp Program in that office must be certified Tagalog-speaking staff to serve the Tagalog-speaking clients. Counties may have different percentages of non-English-speaking staff at each separate office, and the number of bilingual staff must be determined for each separate office. In addition, counties must measure the substantial number by individual language, not language groups (i.e., Southeast Asian languages).

2. Interpreter Services: Pursuant to MPP Division 21-115.15 and .16, when a non- or limited-English-speaking client population is less than a substantial number (less than five percent) in a program at a location, counties must offer and provide interpreter services, upon request, in the language the client has specified for oral communication. This means that if a client comes to the office, is contacted by telephone, or is visited in his or her home, and speaks limited or no English, and has requested an interpreter, an interpreter must be provided. For example, in a county with a small Russian-speaking population where bilingual staffing is not required, when a Russian-speaking client's child is removed from her home as a result of alleged abuse, and the client requests an interpreter, the county is required to provide a Russian-speaking interpreter when communicating with the client—by phone or in person.

   Interpreter services can be provided in person or by phone using a bilingual staff person who is acting as an interpreter, a contracted interpreter, an interpreter from an outside agency, or a family member or friend.

3. Minors Used as Interpreters: Pursuant to MPP Division 21-115.16, counties are prohibited from using minor children as interpreters except temporarily under extenuating circumstances or at the specific request of the client. Extenuating circumstances may include using a minor child to determine the language of the adult so that an appropriate interpreter or bilingual staff person could be called, or when the adult is experiencing a medical emergency.

4. Use of Translated Documents: Pursuant to MPP Division 21-115.2, when a county uses a form, notice or other written material required by CDSS in the county's delivery of services, benefits and programs, and that translated form, notice or other written material has been provided by CDSS, the county must use the translated form, notice or material when serving a non- or limited-English-speaking client.

   This rule regarding use of translated written materials provided by CDSS applies regardless of the number of non- or limited-English-speaking clients who are served by the county. For example, in a county with less than 5 percent Chinese-speaking clients, the Application for Social Services (SOC 295) that has been translated into Chinese by CDSS must be provided in Chinese to the Chinese-speaking applicants. The same rule applies whether Chinese is less than 5 percent or 5 percent or more: When the translated document is a required form and is provided by CDSS, counties must provide the translated form.

   In addition, if using a translated notice of action, any added information that is unique to the recipient of the notice must be in the language of the client. This means that an explanation of the action that is not printed on the notice must be in the language of the notice. If the notice of action is translated into a non-English language, the informing notice on the reverse side (NA Back) must also be in the translated language.

5. Informing Signs: Pursuant to MPP 21-107.211 and .212, counties must post a sign that informs clients that they may request assistance in their primary language. That requirement can be met by using the Pub 86 poster "Everyone is Different, but Equal Under the Law." However, counties are encouraged to also post separate "I Speak" posters inviting non-English-speaking clients to easily identify their language.

   In addition to the signs offering translation services, if a particular county office serves a substantial number of clients who speak a non-English language, all directional and instructional signs must be translated and posted in that particular language. For example, if a county office that serves a substantial number of Spanish-speaking clients posts a sign stating "Employment Classes Every Thursday at 6 p.m.," the county must also have a sign in Spanish stating "Clases de Empleo Cada Jueves a las 6 p.m."

6. Documentation: Pursuant to MPP Division 21-116.2, counties are required to ask clients their preferred language for oral and written communication and document the preferred language(s) in the client's file. Once known, the county is then required to document the following information or actions regarding language services in a client's file:

   a. Client's acceptance or refusal of written material in his/her language after asking the client's preference.
   b. How bilingual services are provided. If, for example, a bilingual staff person is used, it must be documented in the file.
   c. Temporary use of a minor as an interpreter, and the circumstances requiring temporary use of the minor.
   d. That the county informed a client providing his or her own interpreter of the potential problems for ineffective communication.
   e. Client consent to the release of information to the interpreter if the county uses an interpreter other than a county employee.

   This documentation is assessed when the Civil Rights Bureau does its periodic compliance review. In addition, if a client complains that he or she did not receive appropriate language services, this documentation could provide evidence of the client's preferred language for oral and written communication and that language services were provided.

Each of these important areas related to effective language services is addressed in the civil rights compliance reviews which take place according to MPP Division 21-201. Staff and manager interviews, site visits and case file reviews are performed to determine full compliance with the requirements of state regulations.

If you have questions about translated forms, notices, or materials, you may contact Language Services, at (916) 445-6778, or go to the Language Services web page at http://www.dss.cahwnet.gov/cdssweb/FormsandPu_274.htm. If you have questions regarding this letter, you may contact Christine Webb-Curtis, Chief, Civil Rights Bureau, at (916) 654-2107.

Sincerely,

JEANNE RODRIGUEZ
Deputy Director
Human Resources Management Division

bc:	JR File	17-04
	JR Chron	17-04
	CRB File	15-70
	CRB Chron	15-70

Fact Sheet: Taking Care of YOU: Self-Care for Family Caregivers

First, Care for Yourself

On an airplane, an oxygen mask descends in front of you. What do you do? As we all know, the first rule is to put on your own oxygen mask before you assist anyone else. Only when we first help ourselves can we effectively help others. Caring for yourself is one of the most important – and one of the most often forgotten – things you can do as a caregiver. When *your* needs are taken care of, the person you care for will benefit, too.

Effects of Caregiving on Health and Well Being

We hear this often: "My husband is the person with Alzheimer's, but now I'm the one in the hospital!" Such a situation is all too common. Researchers know a lot about the effects of caregiving on health and well-being. For example, if you are a caregiving spouse between the ages of 66 and 96 and are experiencing mental or emotional strain, you have a risk of dying that is 63 percent higher than that of people your age who are not caregivers.[1] The combination of loss, prolonged stress, the physical demands of caregiving, and the biological vulnerabilities that come with age place you at risk for significant health problems as well as an earlier death.

Older caregivers are not the only ones who put their health and well being at risk. If you are a baby boomer who has assumed a caregiver role for your parents while simultaneously juggling work and raising adolescent children, you face an increased risk for depression, chronic illness and a possible decline in quality of life.

But despite these risks, family caregivers of any age are less likely than non-caregivers to practice preventive healthcare and self-care behavior. Regardless of age, sex, and race and ethnicity, caregivers report problems attending to their own health and well-being while managing caregiving responsibilities. They report:

- Sleep deprivation
- Poor eating habits
- Failure to exercise
- Failure to stay in bed when ill
- Postponement of or failure to make medical appointments.

Family caregivers are also at increased risk for excessive use of alcohol, tobacco and other drugs and for depression. Caregiving can be an emotional roller coaster. On the one hand, caring for your family member demonstrates love and commitment and can be a very rewarding personal experience. On the other hand, exhaustion, worry, inadequate resources and continuous care demands are enormously stressful. Studies show that an estimated 46 percent to 59 percent of caregivers are clinically depressed.

Taking Responsibility for Your Own Care

You cannot stop the impact of a chronic or progressive illness or a debilitating injury on someone for whom you care. But there is a great deal that you can do to take responsibility for your personal well-being and to get your own needs met.

Identifying Personal Barriers

Many times, attitudes and beliefs form personal barriers that stand in the way of caring for yourself. Not taking care of yourself may be a lifelong pattern, with taking care of others an easier option. However, as a family caregiver you must ask yourself, "What good will I be to the person I care for if I become ill? If I die?" Breaking old patterns and overcoming obstacles is not an easy proposition, but it can be done – regardless of your age or situation. The first task in removing personal barriers to self-care is to identify what is in your way. For example,

- Do you feel you have to prove that you are worthy of the care recipient's affection?
- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help? Why?

Sometimes caregivers have misconceptions that increase their stress and get in the way of good self-care. Here are some of the most commonly expressed:

- I am responsible for my parent's health.
- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.

"I never do anything right," or "There's no way I could find the time to exercise" are examples of negative "self-talk," another possible barrier that can cause unnecessary anxiety. Instead, try positive statements: "I'm good at giving John a bath." "I can exercise for 15 minutes a day." Remember, your mind believes what you tell it.

Because we base our behavior on our thoughts and beliefs, attitudes and misconceptions like those noted above can cause caregivers to continually attempt to do what cannot be done, to control what cannot be controlled. The result is feelings of continued failure and frustration and, often, an inclination to ignore your own needs. Ask yourself what might be getting in your way and keeping you from taking care of yourself.

Moving Forward

Once you've started to identify any personal barriers to good self-care, you can begin to change your behavior, moving forward one small step at a time. Following are some effective tools for self-care that can start you on your way.

Tool #1: Reducing Personal Stress

How we perceive and respond to an event is a significant factor in how we adjust and cope with it. The stress you feel is not only the result of your caregiving situation but also the result of your perception of it – whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.

Your level of stress is influenced by many factors, including the following:

- Whether your caregiving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predicts how you will cope now. Identify your current coping strengths so that you can build on them.
- Your caregiving situation. Some caregiving situations are more stressful than others. For example, caring for a person with dementia is often more stressful than caring for someone with a physical limitation.
- Whether support is available.

Steps to Managing Stress

1. *Recognize warning signs early*. These might include irritability, sleep problems, and forgetfulness. Know your own warning signs, and act to make changes. Don't wait until you are overwhelmed.
2. *Identify sources of stress*. Ask yourself, "What is causing stress for me?" Sources of stress might be too much to do, family disagreements, feelings of inadequacy, inability to say no.
3. *Identify what you can and cannot change*. Remember, we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration. Ask yourself, "What do I have some control over? What can I change?" Even a small change can make a big difference. The challenge we face as caregivers is well expressed in words from the Serenity Prayer:
   …Grant me the serenity to
   Accept the things I cannot change,
   Courage to change the things I can,
   And the wisdom to know the difference.
4. *Take action*. Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation, having coffee with a friend. Identify some stress reducers that work for you.

Tool #2: Setting Goals

Setting goals or deciding what you would like to accomplish in the next three to six months is an important tool for taking care of yourself. Here are some sample goals you might set:

- Take a break from caregiving.
- Get help with caregiving tasks like bathing and preparing meals.
- Feel more healthy.

Goals are generally too big to work on all at once. We are more likely to reach a goal if we break it down into smaller action steps. Once you've set a goal, ask yourself, "What steps do I take to reach my goal?" Make an action plan by deciding which step you will take first, and when. Then get started!

Example: Goal and Action Steps

Goal: Feel healthier.

Possible action steps:

1. Make an appointment for a physical check-up.
2. Take a half-hour break once during the week.
3. Walk three times a week for 10 minutes.

Tool #3: Seeking Solutions

Seeking solutions to difficult situations is, of course, one of the most important tools in caregiving. Once you've identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one, giving you more confidence in your abilities.

Steps for Seeking Solutions

1. *Identify the problem*. Look at the situation with an open mind. The real problem might not be what first comes to mind. For example, you think that the problem is simply that you are tired all the time, when the more basic difficulty is your belief that "no one can care for John like I can." The problem? Thinking that you have to do everything yourself.
2. *List possible solutions*. One idea is to try a different perspective: "Even though someone else provides help to John in a different way than I do, it can be just as good." Ask a friend to help. Call Family Caregiver Alliance or the Eldercare Locator (see Resources List) and ask about agencies in your area that could help provide care.
3. *Select one solution from the list*. Then try it!
4. *Evaluate the results*. Ask yourself how well your choice worked.
5. *Try a second solution*. If your first idea didn't work, select another. But don't give up on the first; sometimes an idea just needs fine tuning.
6. *Use other resources*. Ask friends, family members and professionals for suggestions.
7. *If nothing seems to help, accept that the problem may not be solvable now*. You can revisit it at another time.

Note: All too often, we jump from step one to step seven and then feel defeated and stuck. Concentrate on keeping an open mind while listing and experimenting with possible solutions

Tool #4: Communicating Constructively

Being able to communicate constructively is one of a caregiver's most important tools. When you communicate in ways that are clear, assertive and constructive, you will be heard and get the help and support you need. The box below shows basic guidelines for good communication.

Communication Guidelines

- *Use "I" messages rather than "you" messages*. Saying "I feel angry" rather than "You made me angry" enables you to express your feelings without blaming others or causing them to become defensive.
- *Respect the rights and feelings of others*. Do not say something that will violate another person's rights or intentionally hurt the person's feelings. Recognize that the other person has the right to express feelings.
- *Be clear and specific*. Speak directly to the person. Don't hint or hope the person will guess what you need. Other people are not mind readers. When you speak directly about what you need or feel, you are taking the risk that the other person might disagree or say no to your request, but that action also shows respect for the other person's opinion. When both parties speak directly, the chances of reaching understanding are greater.
- *Be a good listener*. Listening is the most important aspect of communication.

Tool #5: Asking for and Accepting Help

When people have asked if they can be of help to you, how often have you replied, "Thank you, but I'm fine." Many caregivers don't know how to marshal the goodwill of others and are reluctant to ask for help. You may not wish to "burden" others or admit that you can't handle everything yourself.

Be prepared with a mental list of ways that others could help you. For example, someone could take the person you care for on a 15-minute walk a couple of times a week. Your neighbor could pick up a few things for you at the grocery store. A relative could fill out some insurance papers. When you break down the jobs into very simple tasks, it is easier for people to help. And they do want to help. It is up to you to tell them how.

Help can come from community resources, family, friends and professionals. Ask them. Don't wait until you are overwhelmed and exhausted or your health fails. Reaching out for help when you need it is a sign of personal strength.

Tips on How to Ask

- *Consider the person's special abilities and interests*. If you know a friend enjoys cooking but dislikes driving, your chances of getting help improve if you ask for help with meal preparation.
- *Resist asking the same person repeatedly*. Do you keep asking the same person because she has trouble saying no?
- *Pick the best time to make a request*. Timing is important. A person who is tired and stressed might not be available to help out. Wait for a better time.
- *Prepare a list of things that need doing*. The list might include errands, yard work, a visit with your loved one. Let the "helper" choose what she would like to do.
- *Be prepared for hesitance or refusal*. It can be upsetting for the caregiver when a person is unable or unwilling to help. But in the long run, it would do more harm to the relationship if the person helps only because he doesn't want to upset you. To the person who seems hesitant, simply say, "Why don't you think about it." Try not to take it personally when a request is turned down. The person is turning down the task, not you. Try not to let a

refusal prevent you from asking for help again. The person who refused today may be happy to help at another time.

- *Avoid weakening your request*. "It's only a thought, but would you consider staying with Grandma while I went to church?" This request sounds like it's not very important to you. Use "I" statements to make specific requests: "I would like to go to church on Sunday. Would you stay with Grandma from 9 a.m. until noon?"

Tool #6: Talking to the Physician

In addition to taking on the household chores, shopping, transportation, and personal care, 37 percent of caregivers also administer medications, injections, and medical treatment to the person for whom they care. Some 77 percent of those caregivers report the need to ask for advice about the medications and medical treatments. The person they usually turn to is their physician.

But while caregivers will discuss their loved one's care with the physician, caregivers seldom talk about their own health, which is equally important. Building a partnership with a physician that addresses the health needs of the care recipient *and* the caregiver is crucial. The responsibility of this partnership ideally is shared between you the caregiver, the physician, and other healthcare staff. However, it will often fall to you to be assertive, using good communication skills, to ensure that everyone's needs are met – including your own.

Tips on Communicating with Your Physician

- *Prepare questions ahead of time*. Make a list of your most important concerns and problems. Issues you might want to discuss with the physician are changes in symptoms, medications or general health of the care recipient, your own comfort in your caregiving situation, or specific help you need to provide care.
- *Enlist the help of the nurse*. Many caregiving questions relate more to nursing than to medicine. In particular, the nurse can answer questions about various tests and examinations, preparing for surgical procedures, providing personal care, and managing medications at home.
- *Make sure your appointment meets your needs*. For example, the first appointment in the morning or after lunch and the last appointment in the day are the best times to reduce your waiting time or accommodate numerous questions. When you schedule your appointment, be sure you convey clearly the reasons for your visit so that enough time is allowed.
- *Call ahead*. Before the appointment, check to see if the doctor is on schedule. Remind the receptionist of special needs when you arrive at the office.
- *Take someone with you*. A companion can ask questions you feel uncomfortable asking and can help you remember what the physician and nurse said.
- *Use assertive communication and "I" messages*. Enlist the medical care team as partners in care. Present what you need, what your concerns are, and how the doctor and/or nurse can help. Use specific, clear "I" statements like the following: "I need to know more about the diagnosis; I will feel better prepared for the future if I know what's in store for me." Or "I am feeling rundown. I'd like to make an appointment for myself and my husband next week."

Tool #7: Starting to Exercise

You may be reluctant to start exercising, even though you've heard it's one of the healthiest things you can do. Perhaps you think that physical exercise might harm you or that it is only for people who are young and able to do things like jogging. Fortunately, research suggests that you can maintain or at least partly restore endurance, balance, strength and flexibility through everyday physical activities like walking and gardening. Even household chores can improve your health. The key is to increase your physical activity by exercising and using your own muscle power.

Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time for exercise is a problem, incorporate it into your daily activity. Perhaps the care recipient can walk or do stretching exercise with you. If necessary, do frequent short exercises instead of those that require large blocks of time. Find activities you enjoy.

Walking, one of the best and easiest exercises is a great way to get started. Besides its physical benefits, walking helps to reduce psychological tension. Walking 20 minutes a day, three times a week, is very beneficial. If you can't get away for that long, try to walk for as long as you can on however many days you can. Work walking into your life. Walk around the mall, to the store or a nearby park. Walk around the block with a friend.

Tool #8: Learning from Our Emotions

It is a strength to recognize when your emotions are controlling you (instead of you controlling your emotions). Our emotions are messages we need to listen to.

They exist for a reason. However negative or painful, our feelings are useful tools for understanding what is happening to us.

Even feelings such as guilt, anger and resentment contain important messages. Learn from them, then take appropriate action.

For example, when you cannot enjoy activities you previously enjoyed, and your emotional pain over-shadows all pleasure, it is time to seek treatment for depression – especially if you are having thoughts of suicide. Speaking with your physician is the first step. (Please refer to the Fact Sheet on Caregiving and Depression, listed below.)

Caregiving often involves a range of emotions. Some feelings are more comfortable than others. When you find that your emotions are intense, they might mean the following:
- That you need to make a change in your caregiving situation.
- That you are grieving a loss.
- That you are experiencing increased stress.
- That you need to be assertive and ask for what you need.

Summing Up

Remember, it is not selfish to focus on your own needs and desires when you are a caregiver – it's an important part of the job. You are responsible for your own self-care. Focus on the following self-care practices:

- Learn and use stress-reduction techniques.
- Attend to your own healthcare needs.
- Get proper rest and nutrition.
- Exercise regularly.
- Take time off without feeling guilty.
- Participate in pleasant, nurturing activities.
- Seek and accept the support of others.
- Seek supportive counseling when you need it, or talk to a trusted counselor or friend.
- Identify and acknowledge your feelings.
- Change the negative ways you view situations.
- Set goals.

It's up to you!

Credits

1 Shultz, Richard and Beach, Scott (1999). *Caregiving as A Risk for Mortality: The Caregiver Health Effects Study*. JAMA, December 15, 1999 - Vol. 282, No.23

A special thank you to Legacy Caregiver Services, Legacy Health System, Portland, OR., for permission to use information from *The Caregiver Helpbook: Powerful Tools for Caregiving* and the *Powerful Tools for Caregivers Class Leaders Guide.*

The Caregiver Helpbook, written by Vicki Schmall, Ph.D., Marilyn Cleland, R.N. and Marilynn Sturdevant, RN, MSW, LCSW, (2000) is highly recommended reading for caregivers. The book can be ordered directly from Legacy Health Systems, (530) 413–6578. caregiver@lhs.org or www.legacyhealth.org

For More Information

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National Center on Caregiving
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
(415) 434–3388
(800) 445–8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

Family Caregiver Alliance Fact Sheet on Caregiving and Depression

Family Caregiver Alliance Fact Sheet on Dementia, Caregiving and Controlling Frustration
Because We Care: A Guide for People Who Care

Administration on Aging
Washington, DC 20201
Phone: (202) 619–0724
www.aoa.gov

Area Agency on Aging
For caregiver support groups, respite providers, and other caregiving services. Eldercare Locator:
(800) 677–1116
www.eldercare.gov

ARCH National Respite Network and Resource Center
Call to find local respite providers.
(800) 473–1727
www.chtop.com/ARCH

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U.S. Department of Health and Human Services
Administration on Aging

National Family Caregiver Support Program Resources

Care Receiving: Creating Partnerships in Self Care

Introduction

The relationship of the caregiver and care receiver has an important effect on the care process. A strong positive partnership between caregivers and care receivers can lessen caregiver stress and result in better quality-of-care for the care-receiver. Limited attention has been paid to the role of care receivers and the challenges they face in this role. Most of us fear losing our abilities for self-care and having to receive help from others. At various points in our lives we all need help and assistance.

Facing Feelings And Values

Most of us never thought we would be in a position to need help. It is important to acknowledge that while we now need assistance with our lives, we also have much to give. The following is advice on coping with the emotional components of receiving care:

- Allow yourself to accept the assistance of others.
- Accept assistance graciously. Frequent expressions of guilt make caregiving more difficult.
- Acknowledge feelings of guilt and/or anger at having to receive care. Don't allow these feelings to affect your relationship with your caregiver.
- Focus on the positive aspects of your life; on the things you can do.
- Keep your sense of humor
- Live in the present; focus on life now and what you are able to do. Celebrate accomplishments.
- Be creative in exploring and developing interests and activities that enhance your self esteem.
- Keep in frequent contact with friends.

Being An Effective Partner

All partnerships require give and take. The partnership you have with your caregiver requires active participation and compromise in order for it to be rewarding and enduring. Below are suggestions for creating a successful partnership:

- Do what you are able to do for yourself. Small efforts are recognized and appreciated.
- Provide moral support; listen to your caregiver.
- Have fun together. Share ideas. Be a good friend.
- Plan as much in advance as possible. Provide your caregiver as much advance notice as possible regarding doctor's appointments, etc.
- Accept help from other sources to give your caregiver needed time off.
- Compromise and problem solve with your caregiver.
- Look for things, small or large, that you can do for your caregiver or family.

Communicating Well

Open, honest communication is essential to create and maintain a successful partnership. Below are strategies that current care receivers suggest:

- Listen to your caregiver's concerns. What are their joys, successes, and problems? What is going on in their lives?
- Be kind. Show affection. Express love.
- Express gratitude but don't overdo it.
- Speak up for yourself; make your needs known.
- Respect your caregiver's scheduling and time limitations.
- Be fully involved in decision-making about your care.

Participating In Self-Care

You are the best source of knowledge about your own health. Participating in your self-care can be an important ingredient in maintaining positive feelings of independence.

- Learn new ways to function. Use mechanical devices such as walkers and wheelchairs to increase mobility.
- Learn as much as you can about your own emotional/physical condition.
- Participate in care by taking an active role with health care providers. Exercise and follow diet recommendations.

Relating To Professional Caregivers

Partnerships with professional caregivers such as doctors, nurses, and social workers involve some of the same issues as partnerships with family or friends. There are also important differences. The following are suggestions for dealing effectively with professional caregivers and agencies:

- Learn all you can about your own physical and/or emotional situation: ask questions, read, attend classes. Do not hesitate to ask professionals to repeat or rephrase what they have said.
- Learn all you can about the beliefs and attitudes of the professional with whom you are dealing.
- Learn about service agencies and how to use them.
- Speak up for yourself. Be sure you understand what is being said.
- Don't hesitate to change doctors if you feel you are not receiving the care you need.
- Become an advocate for yourself and others in the same situation.
- Be persistent about your needs – don't give up.
- Two can be better than one when dealing with professional caregivers. Bring your caregiver or friend to appointments.
- Advocate for yourself with professional caregivers. Be assertive. Take the time you need to explain your problems.

Information provided in this fact sheet was adapted from materials submitted by the Institute of Gerontology, University of Denver, Denver, CO.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

CAREGIVER BURNOUT

By Dr. M. Ross Seligson

Being able to cope with the strains and stresses of being a Caregiver is part of the art of Caregiving. In order to remain healthy so that we can continue to be Caregivers, we must be able to see our own limitations and learn to care for ourselves as well as others.

It is important for all of us to make the effort to recognize the signs of burnout. In order to do this we must be honest and willing to hear feedback from those around us. This is especially important for those caring for family or friends. Too often Caregivers who are not closely associated with the healthcare profession get overlooked and lost in the commotion of medical emergencies and procedures. Otherwise close friends begin to grow distant, and eventually the Caregiver is alone without a support structure. We must allow those who do care for us, who are interested enough to say something, to tell us about our behavior, a noticed decrease in energy or mood changes.

Burnout isn't like a cold. You don't always notice it when you are in its clutches. Very much like Post Traumatic Stress Syndrome, the symptoms of burnout can begin surfacing months after a traumatic episode. The following are symptoms we might notice in ourselves, or others might say they see in us. Think about what is being said, and consider the possibility of burnout.

- Feelings of depression.
- A sense of ongoing and constant fatigue.
- Decreasing interest in work.
- Decrease in work production.
- Withdrawal from social contacts.
- Increase in use of stimulants and alcohol.
- Increasing fear of death.
- Change in eating patterns.
- Feelings of helplessness.

Strategies to ward off or cope with burnout are important. To counteract burnout, the following specific strategies are recommended

- Participate in a support network.
- Consult with professionals to explore burnout issues.
- Attend a support group to receive feedback and coping strategies.
- Vary the focus of caregiving responsibilities if possible (rotate responsibilities with family members).
- Exercise daily and maintain a healthy diet.
- Establish "quiet time" for meditation.
- Get a weekly massage
- Stay involved in hobbies.

By acknowledging the reality that being a Caregiver is filled with stress and anxiety, and understanding the potential for burnout, Caregivers can be forewarned and guard against this debilitating condition. As much as it is said, it can still not be said too often, the best way to be an effective Caregiver is to take care of yourself.

CAREGIVING ISSUES FACING THE MULTI-GENERATIONAL FAMILY

By Helen Hunter, ACSW, CMSW

There are many family situations today where you can find three, four or even five generations living under one roof. While the circumstances that result in multi-generational living vary from financial to health-related to simple family closeness, those who live in these types of households deal with many issues. Serving as the main caregiver for an older relative, dealing with grandchildren and having one of their own children living back at home after several years on his/her own can be a challenge for the best of families.

In dealing with your older relative, the most critical aspect is not just tending to their physical needs, but providing them with the emotional support they require as well. Often, it is coping with these emotional needs that is most time consuming and stressful. Family members often ask "How do I talk to my relative about. . . "(You fill in the blank). The answer is "Not easily." Remember, your job is to help your older relative make informed, reasonable decisions for themselves, not to make the decision for them. It is also important to realize that they may be frightened about their overall condition, and that this frightened state is relayed through anger toward YOU, the main caregiver. It is crucial to keep the lines of communication open between the generations so that both of you can express your fears and concerns as honestly as possible. You may also wish to gain as much knowledge as possible regarding the older person's condition so that you know what to expect of them now and in the future. In that way, you can let them maintain their sense of independence and well-being and provide the needed care when it becomes necessary.

Children, even at an early age, can be asked to take on family responsibilities. They can be very helpful and resourceful. They can perform everyday chores like cleaning and help in preparation of meals and laundry. They can also help Grandma or Grandpa by sitting with them, reading together or watching TV, among other things. By involving children, you are giving them an honest look into the daily care giving process and you open the door to start a dialogue about aging issues in general. The relationship between an older relative and a child is invaluable in that the older person provides educational and historical information that is passed on to another generation and the child can give new and fresh insight on things for the older person.

When an older relative begins to fail, either mentally or physically, it can be very confusing and sometimes frightening for a child. There are many resources geared specifically for children that explain the aging process. Children are seen as extremely therapeutic assets as families deal with the daily issues associated with the care of a relative.

Older relatives can also be an invaluable resource to their grandchildren. They can serve as educators, story tellers and, in many instances, serve as the primary providers of care to their grandchildren. Many older people end up "raising" their grandchildren due to a variety of circumstances. These older relatives struggle not only with the daily demands of care needed by their grandchildren, but also with the concerns and struggles that their own children (the grandchildren's parents) face and their own health and financial issues.

Those who are in the “sandwich generation” often are faced with the daily demands of care needed by their parents or older relatives AND are responsible for the raising of their own children. In addition, they may have to deal with their own health and financial worries. Other responsibilities faced by this generation include the demands of a work schedule and their relationship with a spouse or significant other, in addition to their ongoing relationship with siblings and close friends.

Regardless of their age, there are many instances where the main caregiver in the family refuses to acknowledge that they can’t handle the load. They are too caught up in the daily grind that they don’t recognize the warning signals, which can include extreme fatigue, lack of rest, irritability, and frustration over lack of free time. Letting others know your feelings and that you need help is crucial to the caregiver’s mental and physical well-being.

It is also important to negotiate the exact roles of each family member in terms of providing care. Some may feel more comfortable with hands-on duties – others may want to only focus on household chores or helping with transportation or financial and legal issues.

There are many instances where the care receiver is very stubborn and resistant to any help, even from family members. In these cases you need to be FIRM in expressing the reality of the situation and that the person needs assistance. It is particularly important for those living in multi-generational households who often are providing 24 hours a day/7 days a week care to have an occasional respite break.

With family members living longer, many individuals are faced with the prospect of being a caregiver for a significant number of years. More and more families are opting to live in a mutli-generational household for a variety of reasons, including providing care for a loved one. It is important for the family to recognize that, in many cases, they will not be able to tend to all the needs of their relative, and that they will have to rely on others for occasional support. The support is available – just ask.

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PARENTING CHILDREN WITH DISABILITIES

What are the Effects of Disability on Children?
A serious disability affects a child's ability to participate in common daily activities and might make it difficult to go to school, make friends, and generally have a normal life. It can be physically painful, frightening and might make the child angry or withdrawn. It can make the child feel different and isolated. The situation is compounded when other children talk about a child looking different or being afraid of "catching" the disability. Some children cope well with the pressures of a chronic illness while others need special support.

How Do Children Cope with a Disability?
How a child copes with a disability is dependent on a number of things:

- The severity of the disability
- The child’s age when diagnosed
- The outward appearance of the child including facial or body deformity and/or dependence on a medical device
- The child’s personality and upbringing and ability to handle stress
- The family dynamics

Over time, the child’s reactions might change and the child often feels loss anew when their peers are attaining new abilities or developmental milestones that they do not.

How Do Parents of a Disabled Child React?
Part of the psychological preparation during pregnancy involves the dreaming and visualization of a perfect, beautiful baby. Parents often have many expectations for the "idealized" child. The birth of a child with a chronic illness or the discovery that a child has a disability has profound effects on a family.

When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress. During this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents’ ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties – health, programmatic, and financial.

Parents’ Grieving
Following the diagnosis or birth of the child, parents often go through a period of mourning the loss of the anticipated, perfect child. All their dreams and expectations for their child will have to change to match the reality of the new situation. Parents will experience a range of emotions, most notably, shock, denial, magical thinking, sadness, guilt, anger, disappointment, lack of control and resentment related to the chronic illness or disability of their child. These feelings usually lessen over time, though critical events, as when their child is missing a developmental milestone, may bring them up again.

What Do Parents Worry About?

Seeing their child be disabled is very hard on parents as well as all other family members. There are a number of things that parents worry about: not being in control, not being able to help their child, and concern over not making the right treatment decisions. Some specific issues include:

- The struggle with their own emotions – anger, guilt – physical and mental exhaustion
- Stress on the marriage
- Figuring out how to support their child; feeling alone in fighting every resource (schools, agencies, the health care team, insurance or Medi-Cal, social worker) for the care they deem their child needs
- Stress over making medical decisions for their child and not understanding what is going on
- Fear of medical treatments and their outcome
- Hoping with every new encounter that it was a misdiagnosis or that a new treatment might be the "magic pill"
- Worrying that everyone is evaluating how they deal with their child
- Fear of an emergency situation and knowing when to get help
- Not having access to a doctor who is knowledgeable about their child's condition
- Knowing how to parent a chronically ill child
- What to tell friends and family
- Monitoring their child's symptoms and knowing a condition may be worsening
- Learning how to meet a child's needs at home
- Meeting the needs of the entire family while caring for a sick child
- Trying to define a "new normal"

Some advice you can give the parents of a child with a disability:

- <u>Take care of yourself so you can take care of your child</u> – It is important for the parents to have the personal energy and emotional stamina in order to take care of his/her child.

- <u>Balance</u> – It is common for parents to focus nearly all attention on the disabled child at the expense of that child's siblings and the parents' relationship. Parents should be encouraged to get the help they need so that the family system can thrive. This can take the form of a family outing with the non-disabled child, leaving the disabled child with a family member or a relief provider. Praise should be given to the siblings for jobs well done. Siblings are at the risk of losing their childhood because of the needs of the disabled child; the siblings' role in the family and in sharing caretaking of the disabled child should be appropriate to the age of the sibling.

- <u>Reach out and seek information</u> – Parents should be encouraged to learn what they can so they can be an advocate for their child's needs. If they have information from good sources, they will be credible when discussing their child's needs. They should be encouraged to reach out to friends and family for support.

- <u>Be realistic about meeting everyone's needs</u> – Personal expectations may need to be altered with the need to deal with care issues of their child. Understand that control of the situation is not possible and that everything will constantly shift. This will help decrease the stress of trying to make things 'perfect.'

- Build a support system – If not family then in the community (friends, church, formal support groups, neighbors). If the parent finds that it is getting increasingly difficult to manage her sick child at home, she should arrange for some respite care.

- Focus on the big picture – Parents should be encouraged to look for progress and accomplishments one day at a time. Seeing the overview of the situation may help decrease frustration with the day-to-day challenges.

- Focus on the child as a person and not the illness – Even children with a chronic illness or disability needs support and discipline. The parent should be encouraged to keep perspective on what to expect from the child and his/her personal needs without only looking at their healthcare needs. If the parent needs help in setting appropriate boundaries for the child with a disability, he/she might benefit from parenting classes or assistance from the regional center; ignored inappropriate behavior from a toddler will only become a more significant behavior problem as the child grows.

How do Parents Cope when their Child is Disabled?

The parents' lives change dramatically once a child is diagnosed with a chronic condition. They will learn a new vocabulary and develop a new way of living. Many parents indicate that while discovering their child may have a lifelong condition is a bit like the "loss of a dream," it also provides the opportunity to see life in a new light and focus on the other good things that can be valued. Focusing on the child as a person and not the illness and being as positive as possible helps the parent, the child with the disability, and the family cope.

It is very helpful for the parent to talk to people who are supportive and reliable, and who will be there for them now and in the future. This can be a family member, friend, or support group. Some friends or family members might not cope well with the news, but it is important to find those who can be an effective support for the parents. Parents should also be encouraged to learn as much as they can about the condition.

Speaking with other parents whose children have gone through something similar can also be beneficial, because they can share their experience. There are support groups dealing with most disabling conditions. Often the health care team makes referrals to such support groups. Support groups can also be located on the internet. This is a great venue for asking questions, expressing concerns, and learning from the experiences of others. Health care professionals associated with the hospital who are trained in counseling, such as child life specialists and social workers, can often provide some support.

Through all this, it is important for the parents to look after themselves by managing their emotions, eating well, and finding some time to exercise and relax. And it is equally important to stay engaged with the rest of the family. They should be encouraged to continue to nurture their relationship with each other and any other children they have.

How to Raise a Child with Chronic Illness

Raise them the same way you would another child. They need boundaries, opportunities, encouragement, and support. Overprotecting and spoiling them does not instill confidence and will not prepare them well for the future. Cultivating independence and having expectations of a child as he grows speaks to future wellness and the child's overall capability. Having structure also contributes to a sense of security. Also, by giving the child opportunities to make decisions, the parents give him a sense of being in control of his life when so much of it is beyond his control.

How Can Parents Support their Child with a Disability?

It is critical to explain to the child, as best and as simply as possible, the origins of the illness or disability. Many children feel guilty, believing that they are sick because they did something "bad." They also feel angry that they may not be able to do all the things their peers can do or not being able to "get well."

Parents can support their child by letting them know what is going on and what lies ahead in terms of treatment. They should help provide as many opportunities for choice as possible. By staying calm, the parents model calmness to their child. If the child is young, the parent should make sure he has a favorite toy to comfort him.

Parents should communicate often so the child has a chance to express his emotions about the disability. If he is young, he should be encouraged to express himself through play. If he is old enough, he should be taught problem solving skills and deep breathing techniques to cope with the effects of the condition on his life. He should be encouraged to develop special interests that take the focus off the condition and give him something to be proud of. Above all, parents need to express love and make their child a key player in the family's activities.

How Can Parents Help the Child Get Used to Being Different?

Parents should talk with their child about the issues that are important to him/her. Communication will help ease stress. It will also serve to dispel misinformation that the parent or his/her child may be focused on. Parents should encourage the child to live life to the fullest within the context of his illness. They should help him/her develop strengths and areas of interest, things he/she can be proud of. Helping him grow as a person will build his self-esteem. Sometimes self-esteem takes a hit in a child with chronic illness if they feel they did something to deserve being sick or if the disability stops them from doing certain things. Building self-esteem can have beneficial effects in all areas of life, including making friends, fitting in, and doing well at school. On top of that, people with good self-esteem and a positive outlook also tend to be healthier and take better care of themselves.

It also helps for parents to prepare their child for questions from peers and others about his/her condition, as well as possible teasing or bullying, which affects children who stand out as being "different." The child will also need to be prepared to encounter ignorance from people who do not understand their condition. They may think, for example, that the child's condition is contagious. It helps if parents educate the child and inform others as necessary.

There are also health care professionals who can help the child adjust. These include social workers, child life specialists, and doctors who specialize in pediatric or adolescent medicine. There may also be support groups or camps for kids with the disability that connect children with common illnesses. In addition, there are lots of wonderful books for children that reinforce the positives of being different.

How Can Parent Help the Child Deal with Teasing or Bullying?

Children often tease if they feel threatened by or are misinformed about someone. They also feel stronger themselves if they can pick on someone who seems weaker or different in some way. Often they pick up this attitude at home. Strategies for dealing with confrontation include:

- Ignoring it
- Refusing to express distress
- Meeting it head on, looking the person in the eye and saying "I refuse to be treated like this," and forcing the confronter to respond
- Defusing the situation with humor
- If in a public place, simply walking away
- If there is threat of assault, alerting people nearby by yelling "fire!" which gets more attention than "help!"

How Do Parents Help Siblings Cope?

When a child is disabled, it affects everyone in a family – parents, siblings, grandparents. Often, siblings get lost in the shuffle. All the attention is focused on the sick brother or sister. Everything seems to be about them: they get the visitors and the toys. Sometimes special occasions are forgotten when medical emergencies arise. All this can make siblings feel isolated and ignored. When parents are sad and frightened about a child, this can also affect the family dynamic.

Siblings may not get a chance to discuss their feelings and what they think about their sibling's illness. As a result, they may act out or be very dramatic (sometimes even faking illness or acting younger than they are, for example) to get their parent's attention. They can also be very emotional – angry, jealous, sad, fearful, guilty. There may also be some embarrassment when their peers start making comments about their sick sibling.

Studies show that without proper attention, these children are at increased risk of health problems, as well as psychosocial difficulties. They may suffer depression, anxiety, or other disorders. This can stem from the pressure of the uncertainty of the sibling's condition, the fact that life may be upside down, and the realization that responsibilities will increase in order to manage the household.

There are things that can be done however, and the good news is that sometimes illness brings families closer together. One key thing parents can do is explain to their other children the condition that the disabled child has and explain why it requires so much time away from home at appointments are in the hospital.

Parents should maintain structure at home, while also being flexible. They should be as organized as possible, and have a schedule so siblings know who is at the hospital and when, and who is fixing dinner, picking the kids up from school. Parents should strive to be flexible but strive to maintain a sense of balance in the family.

Parents should schedule special "family time" together and make a conscious effort not to focus on the sick child's condition during family time. They should communicate often and meaningfully to reinforce the family relationship. In terms of attention, the disabled child should be taught to share his toys with his siblings, and relatives should be asked to focus equally on all the children in the family.

Parents should try to be hopeful and encourage their kids to have positive thoughts. If they are old enough, they should be taught stress management. If a child really seems to not be coping well with their sibling's disability, get them some help by way of a counselor. This is particularly important if they are demonstrating destructive or self-destructive behaviors.

How Can Parents and Siblings of a Child with a Disability Decrease Stress?

Parents of a chronically disabled child and the child's siblings need to learn how to lessen the stress they are feeling. The following are things that can be done to decrease stress:

1. **Do not ignore stress you are experiencing** – eliminate stressors, pay attention to stress and do not let it take control of you.
2. **Keep stressful situations in perspective** – look at the big picture, weigh the importance of a situation, do not over-react.
3. **Work at controlling your expectations** – keep expectations within reality, give up control of outcomes, do not look at things as black and white.
4. **Do not be a perfectionist** – learn to go with the flow, do not be so hard on yourself, and respect hard work even if it is not perfect.
5. **Develop problem solving skills** – look for ways to take control of problems, do not let problems run your life and learn to make decisions.
6. **Watch how you spend your time** – prioritize how you spend your time; use time to meet your needs and learn to say 'no'.
7. **Do not procrastinate** – letting things pile up just makes stress worse; do not waste energy worrying about something – just do it!
8. **Get organized** – set realistic goals for yourself and keep to them; disorganization wastes energy and time and increases stress.
9. **Learn to relax** – learn relaxation techniques and find time to be quiet and focus on yourself; find time to have fun.
10. **Get enough sleep or rest** – find ways to get help so you can sleep, take naps during the day to re-energize; fatigue decreases your ability to cope with stressful situations.
11. **Eat a healthy diet** – good nutrition will help you feel better and give you the energy to deal with the stress in your daily life.
12. **Get regular exercise** – exercise helps by increasing energy, allowing time to regenerate and helps clear the mind to make it easier to relax.
13. **Focus on the positive** – a negative attitude will only reinforce the stress and create a negative environment; focusing on the positive will help you see the good in things you may otherwise see as negative.
14. **Develop a support system** – you cannot do it alone; find friends, family or a support group of others dealing with similar issues.
15. **Keep a sense of humor** – everything is easier to handle with a good sense of humor and a laugh.

NICHCY

Interim Update — June 1996

Briefing Paper

Respite Care

Raising a child with disability or chronic illness poses many challenges. As families meet these challenges, time off can become a necessity for the caretakers. In recent years, the growth of respite care services—short-term specialized child care—has begun to provide families with some temporary relief.

This Briefing Paper *is adapted from a 1989 NICHCY publication called "Respite Care: A Gift of Time." It discusses the emergence and diversity of respite care services, with particular emphasis on the benefits of respite care for families of children with disabilities or special health care needs. Tips and advice for parents who are seeking respite care are also presented. This issue concludes with a current listing of readings and organizations that can provide parents and others with additional information on the subject of respite care.*

The birth of a child with a disability or chronic illness, or the discovery that a child has a disability, has profound effects on a family. When parents learn that their child has a disability or special health care need, they begin a process of continuous, lifelong adjustment. Adjustment is characterized by periods of stress, and during this time, family members' individual feelings of loss can be overwhelming, shutting out almost all other feelings. Coping with uncertainty about the child's development may interfere with the parents' ability to provide support to each other and to other family members. Even when the diagnosis is clear, there are still many uncertainties — health, programmatic, and financial.

Social and community support can reduce the stress experienced by families. The support of relatives, friends, service providers, and the community can help families ease the adjustment period. Over the years, there has been a growing awareness that adjustment to the special needs of a child influences all family members. This awareness has generated interest and has led to the development of support services for families to assist them throughout the lifelong adjustment process. Within the diversity of family support services, respite care consistently has been identified by families as a priority need (Cohen & Warren, 1985).

The following was written by a parent of a child with a chronic illness.

Of the first six months of my child's life, three and a half months were spent in the hospital. We lived in a world of intensive care, with cardiac monitors, oxygen tents, tubes in every orifice and IV's in every extremity of my daughter's body.

The weeks my daughter was home were completely taken up with her care: two hours to get a meal in her, so for six hours a day I was feeding her; up many nights holding her

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so she could sleep on my shoulder so that she could breathe if she had a respiratory infection. Respiratory infections were frequent because of her disabilities, and many nights my husband and I would have to get our older child up, take him to our neighbor's house and take my daughter to the hospital where she could have oxygen if her breathing got too labored. After getting her admitted, we would go back home, and get up again the next morning to get our son off to school and to return to the hospital. This after being awakened in the middle of the night with a phone call from the hospital saying that they were transferring her to intensive care so she could be watched more closely.

Did we need respite? You bet we did! This was important particularly with a disabled and medically fragile child who needed expert care.

During that time, either my husband or I always had to be with our daughter while the other ran to the grocery, the bank, the pediatrician for our son's health care needs, or just to sleep for a few hours. Our friends disappeared from our lives, and our relatives lived far away. The world of normal family life in which family members live, work, and play together and take joy in each other's accomplishments, activities, and outings vanished.

Our daughter had major surgery scheduled at six months and she would be hospitalized for at least 10 days. I approached my daughter's doctors with our family's need for a rest. Would they and the nurses care for her for seven days while our family went away? We wouldn't leave for three days after surgery to make sure she was on the road to recovery. We felt safe leaving her in their hands, and we could truly relax.

The week that our family stayed at the beach was the most wonderful gift during those six months. It was truly a blessing, not only for us but for our daughter, for it gave us the opportunity to stand outside the situation and view it from a distance. It enabled us to review what had gone on before, to put things into perspective, to think and plan. We were also physically restored, and we were able to go on with much more strength for the next 12 months caring for our daughter. Respite care was unavailable 11 years ago when we needed to cope with the challenges my daughter presented to our family. I had to make it happen. Ω

All parents need a break now and then, to have time for themselves away from the responsibilities of caring for their children. This is true for families of children with disabilities or chronic health care needs too, only for these families it may be more difficult to arrange.

"Parents...are clearly the experts about the need and importance of respite care."

While respite may be a new word for some people, it is not a new phenomenon; it emerged in the late 1960's with the deinstitutionalization movement. One of the most important principles of this movement was the belief that the best place to care for a child with special needs is in the child's home and community. Families with a child who has a disability or chronic illness know the commitment and intensity of care necessary for their children. The level of dedication and care becomes part of daily life, part of the family routine, but this same commitment can make stress routine too. Parents can become accustomed to having no time for themselves. According to Salisbury and Intagliata (1986), "the need of families for support in general and for respite care in particular has emerged as one of the most important issues to be addressed in the 1980's by policymakers, service providers, and researchers in the field of developmental disabilities," (p. *xiii*).

Respite care is an essential part of the overall support that families may need to keep their child with a disability or chronic illness at home. United Cerebral Palsy Associations, Inc. (UCPA) defines respite care as "a system of temporary supports for families of developmentally disabled individuals which provides the family with relief. 'Temporary' may mean anything from an hour to three months. It may also mean 'periodically or on a regular basis.' It can be provided in the client's home or in a variety of out-of-home settings," (Warren and Dickman, 1981, p. 3). Respite services are intended to provide assistance to the family, and to prevent "burn-out" and family disintegration. Since not all families have the same needs, respite care should always be geared to individual family needs by identifying the type of respite needed and matching the need to the services currently available, or using this information to develop services where none exist. Once identified, it is also important for families to have ready access to that type of respite, in an affordable form.

Regardless of the type of respite program utilized, the emphasis should be on orienting services toward the entire family. The birth of a child with a disability or the discovery that a child has a disability or chronic illness is obviously a difficult time for the entire family, including siblings, grandparents and other relatives. Families need to adjust to major changes in their daily lifestyles and in their dreams. Extended family and friends will also need to adjust to these changes. These changes will take planning and time. We are accustomed to typical family life; a child with a significant disability or chronic illness is not typical. Therefore, plans for an untypical lifestyle call for creativity and flexibility. It is also important to bear in mind that the child will change as he or she grows and develops into an individual with his or her own personality and ideas.

Many families will find these changes difficult to handle. Many communities may be limited in their resources or in their interest in meeting the special needs such families present. These combined factors can leave the immediate family with the full-time care of their child and can lead to feelings of isolation from other family members, friends, community activities, religious and social functions. Even performing the basic necessities of daily life, such as grocery shopping or carpooling, can become difficult to impossible.

It is obvious to anyone who has lived this life that respite care becomes a vital service—a necessity, not a luxury. Parents, of course, are clearly the experts about the need and importance of respite care. Just as families differ, so will the necessity for respite care. Basically, however, all families require some relaxation, diversion, and the security of knowing that their children are safe and happy. The most difficult problem for the family with a child who has a disability is finding the quality of care and expertise the child needs.

As one parent put it, "Families need an uncomplicated, easily accessible means of arranging respite care to suit their wants and needs. When a potential pleasure becomes more trouble than it's worth, then I give it up. I always measure the event against the complications involved in making it happen. Time off is no relaxation if I spend the entire time worrying if the kids are OK. I can't enjoy myself if I think they are unhappy, and certainly I can't relax if I'm not confident about the reliability of the person watching my children. I think many professionals are under the misconception that time away from the cares of rearing a child with a disability is what I need to maintain my sanity. I need much more than time—I need the security that comes from *knowing* that the person I've left my son with is as capable as I am of providing for his needs. You simply can't relax and enjoy yourself and worry at the same time. It's peace of mind I need — not just time."

> *"The child or youth with a disability also benefits from respite care, gaining the opportunity to build new relationships and to move toward independence."*

Benefits of Respite Care

In addition to providing direct relief, respite has added benefits for families, including:

Relaxation. Respite gives families peace of mind, helps them relax, and renews their humor and their energy;

Enjoyment. Respite allows families to enjoy favorite pastimes and pursue new activities;

Stability. Respite improves the family's ability to cope with daily responsibilities and maintain stability during crisis;

Preservation. Respite helps preserve the family unit and lessens the pressures that might lead to institutionalization, divorce, neglect and child abuse;

Involvement. Respite allows families to become involved in community activities and to feel less isolated;

Time Off. Respite allows families to take that needed vacation, spend time together and time alone; and

Enrichment. Respite makes it possible for family members to establish individual identities and enrich their own growth and development.

Often, we hear the question, "Who takes care of the caretakers?" Caretakers can include not only parents, but also brothers and sisters, grandparents, and extended family and friends. Respite gives caretakers the opportunity to have a rest, to take care of personal matters, to enjoy some leisure time, and occasionally to be relieved of the constant need to care for a child with a disability or chronic illness.

The child or youth with disabilities also benefits from respite care, gaining the opportunity to build new relationships and to move toward independence. In many families, it is common for children to attend day care or after-school care, interact with peers and adults outside the family, and stay with a child care provider while their parents enjoy an evening out. Respite provides these same opportunities for children with special needs.

For older individuals with a disability, respite can assist in building skills needed for independent living. Since the most appropriate living situation for many adults with a disability is in a group home or other supported environment, out-of-home respite care can enable families to test this option, explore community resources and prepare themselves and their family member with a disability for this change.

States and communities are recognizing that respite care also benefits them. On average, the costs for respite services are 65 to 70 percent less than the costs of maintaining people in institutions (Salisbury and Intagliata, 1986). The cost-effectiveness of respite services allows scarce tax dollars to be used for additional community-based services. During the previous decade, over 30 states passed legislation for in-home family support services, including respite care, using either direct services or voucher systems (Agosta and Bradley, 1985).

With the 1986 passage of the Children's Justice Act (Public Law 99-401) and its amendment, the Children's with Disabilities Temporary Care Reauthorization Act (P.L. 101-127), respite care has gained support at the Federal level. This legislation authorized funding to states to develop and implement affordable respite care programs and crisis nurseries. Unfortunately, while this Federal funding provides relief for some families, access and affordability continue to be issues for many families in need. As Brill (1994) observes:

> Families soon discovered that the law fell short of providing national guidelines for respite care. Every state dispensed different versions of the services, and individual agencies devised their own criteria for length of time and funding allotments. (p. 49)

Thus, in spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families. However, charging for respite services can limit their availability to those families who can afford the fees (Cohen and Warren, 1985).

> *"In spite of the availability of government funding in some areas, many respite care programs must charge for their services. This practice reduces expenses for providers and makes it possible to serve more families."*

For children and youth with disabilities, their families and communities, and Federal, state and local governments, the benefits of respite care are enormous. However, the need for maintaining and expanding the levels of available respite services is tremendous.

Respite Care Suggestions for Parents

Parents deciding to leave their child who has special needs in the care of someone else, either in or outside their home, may experience a variety of hesitations. They can have feelings of guilt, anxiety, even a sense of loss of control.

Jeanne Borfitz-Mescon (1988) suggests that a number of fears and concerns are common to parents in this situation: that the child may not get as much attention, or that the care may not be as good; that something may be missed; that the caretaker or staff may not be able to comfort their child, and that he or she might be left crying. The anxiety resulting from these very normal and real concerns or fears can in fact cause parents to believe that respite is just not worth it.

It is important that as a parent you become comfortable with your decision and develop the trust critical to maintaining the peace of mind necessary for relaxation and enjoyment. One way to accomplish this goal is to begin now to think about respite care and whether you, your family, and your child with special needs would benefit from it. The following suggestions may help.

How can you tell if your family could benefit from respite care?

Ask yourself the following questions:

1. Is finding temporary care for your child a problem?
2. Is it important that you and your spouse enjoy an evening alone together, or with friends, without the children?
3. If you had appropriate care for your child with special needs, would you use the time for a special activity with your other children?
4. Do you think that you would be a better parent if you had a break now and then?
5. Are you concerned that in the event of a family emergency there is no one with whom you would feel secure about leaving your child?
6. Would you be comfortable going to a trained and reputable respite provider to arrange for care for your child?

If you have answered "Yes" to several of these questions, you and your family could benefit from respite care and should investigate the resources in your community.

Many agencies and organizations have information on respite care services. (For a referral, contact the National Respite Locator Service, operated by the ARCH National Resource Center: 1-800-773-5433). In general, seek out groups or professionals who work with children your child's age. For example, if your child is in preschool, contact the school and discuss the need for respite care with the staff. If there is a parent group associated with your school, or if there is a local parent group concerned with children who have needs similar to your child's, ask them. If your child is an adolescent, talk to the staff at his or her school or, again, identify parent groups in your area with needs similar to yours.

The following list presents some of the types of groups you may want to contact in seeking services. Many will be listed in your telephone book. If you experience difficulty locating the organization in your community, often a state contact can be made. For further information and assistance, contact NICHCY, and be sure to ask for a NICHCY *State Resource Sheet* for your state. Additional resources are listed at the end of this *Briefing Paper*.

State and Local Government Agencies

- State Department of Mental Retardation
- State Developmental Disabilities Council
- State Program for Children with Special Health Care Needs (formerly Crippled Children's Services)
- Departments of Health and Human Services, or Social Services
- Department of Mental Health
- State and local Departments of Education
- State Protection and Advocacy Agency

State and Local Disability or Support Groups

- The Arc
- United Cerebral Palsy Associations, Inc.
- Autism Society of America
- Brain Injury Association
- Mental Health Association and CASSP
- Spina Bifida Association
- National Easter Seal Society
- Parent Training and Information Center
- Parent-to-Parent
- University Affiliated Program(s)
- Community Services Board
- YMCA/YWCA
- Churches
- Recreation Centers

What should you know when seeking respite care services in your community?

Ask yourself the following questions. The information will be helpful to you when contacting agencies in your local community about respite care (Bradley, 1988).

1. What kind of services do I need? (Long-term, short-term, or both? Why?)
2. Do I prefer services in my home, a cooperative, or in an outside setting? (This will depend on the type of service you need.)
3. Can I donate my time to a cooperative, or is it better for me to obtain help from a respite agency?
4. Does this agency provide the types of service I need?
5. Is there a cost for the service?
6. Am I able to afford this service?
7. If I can't afford the service, are there funds available to assist me?
8. Who is responsible for the direct payment to the provider?
9. How are respite providers selected?
10. Are the providers trained?
11. How many hours of training have they had?
12. Do these providers have training in First Aid and CPR?
13. What other areas are covered in their training?
14. For out-of-home care, does anyone monitor the facility for safety and health measures?
15. Will I be able to have a prior meeting with the care provider?
16. Will I have an opportunity to provide written care instructions to the provider?
17. Will I have an opportunity to assist in training the provider with reference to my son's/daaughter's needs?
18. What is the policy that covers emergency situations?
19. Will I have to carry additional insurance to cover the provider while he/she is in my home?
20. Is there a policy which deals with mismatches between providers and the family?
21. Can I request a specific care provider and have the same person with my child each time?
22. Will the respite care provider care for my other children too?

A Final Word...

Caring for a child with disabilities or severe health problems can be a full-time job. It is easy to become overwhelmed with the care needs of a child with a disability or chronic illness. Often, families who would not hesitate to call for relief from the constant care of their typical children hesitate to call for relief from the care of their child with a disability or special health care need. That is why respite, as the word implies, is truly an interval of rest. Respite can be your answer to renewed energies and a new perspective. If respite care is not available in your community, make it happen. The best advocate for your family and your child is you. One of the most important goals to strive for is family unity and well-being. It is important to remember that you, too, can have the gift of time that respite care represents.

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Additional Resources

ARCH National Resource Center. (1995). *ARCH national directory of crisis nurseries and respite care programs*. Chapel Hill, NC: Author. (Available from ARCH National Resource Center, Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: 1-800-473-1727; (919) 490-5577.)

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Organizations

CLEARINGHOUSES AND TECHNICAL ASSISTANCE:

ARCH National Resource Center for Crisis Nurseries and Respite Care Services — Chapel Hill Training-Outreach Project, 800 Eastowne Drive, Suite 105, Chapel Hill, NC 27514. Telephone: (800) 473-1727; (919) 490-5577. The mission of the ARCH National Resource Center is to provide support to service providers through training, technical assistance, evaluation, and research. The Center provides a central contact point for the identification and dissemination of relevant materials to crisis nurseries and respite care programs. Numerous fact sheets and general resource sheets (including state contact sheets) are available about respite care and crisis nursery care. ARCH also operates the National Respite Locator Service who's mission is to help parents locate respite care services in their area. Please contact them at 1-800-773-5433.

OTHER ORGANIZATIONS:

The Arc (formerly the Association for Retarded Citizens of the United States) — 500 E. Border Street, Suite 300, Arlington, TX 76010. Telephone: (800) 433-5255; (817) 261-6003; (817) 277-0553 (TT).

Association for the Care of Children's Health (ACCH) — 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814. Telephone: (800) 808-2224; (301) 654-6549.

Association for Persons with Severe Handicaps (TASH)— 29 W. Susquehanna Avenue, Suite 210, Baltimore, MD 21204. Telephone: (410) 828-8274; (410) 828-1306 (TT)

Autism Society of America — 7910 Woodmont Avenue, Suite 650, Bethesda, MD 20814. Telephone: (800) 3-AUTISM; (301) 657-0881.

Brain Injury Association (formerly the National Head Injury Foundation) — 1776 Massachusetts Avenue N.W., Suite 100, Washington, DC 20036. Telephone: (800) 444-6443; (202) 296-6443.

Epilepsy Foundation of America — 4351 Garden City Drive, Landover, MD 20785. Telephone: (800) 332-1000 (outside of MD); (301)459-3700.

National Down Syndrome Congress — 1605 Chantilly Drive, Suite 250, Atlanta, GA 30324. Telephone: (800) 232-6372; (404) 633-1555.

National Down Syndrome Society — 666 Broadway, New York, NY 10012-2317. Telephone: (800) 221-4602; (212) 460-9330.

National Easter Seal Society — 230 West Monroe Street, Suite 1800, Chicago, IL 60606. Telephone: (800) 221-6827; (312) 726-6200; (312) 726-4258 (TT).

Sick Kids (need) Involved People (SKIP) — 545 Madison Avenue, 13th Floor, New York, NY 10022. Telephone: (212) 421-9160.

Spina Bifida Association of America — 4590 MacArthur Boulevard N.W., Suite 250, Washington, DC 20007. Telephone: (800) 621-3141; (202) 944-3285.

United Cerebral Palsy Associations, Inc. (UCPA) — 1660 L Street N.W., Suite 700, Washington, DC 20036. Telephone: (800) 872-5827; (202) 842-1266.

Zero to Three/National Center for Clinical Infant Programs — 734 15th Street, NW, Suite 1000, Washington, DC 20005-1013. Telephone: (202)638-1144. (Voice); 1-800-899-4301 (Publications).

FAMILY SUPPORT PROJECTS:

American Association of University Affiliated Programs (AAUAP) — The AAUAP represents the national network of University Affiliated Programs (UAPs) in the United States. The UAPs provide interdisciplinary training for professionals and paraprofessionals and offer programs and services for children with disabilities and their families. Individual UAPs have staff with expertise in a variety of areas and can provide information, technical assistance, and inservice training to agencies, service providers, parent groups, and others. For information on a UAP in your area, write: AAUAP,8630 Fenton Street, Suite 410, Silver Spring, MD 20910. Telephone: (301) 588-8252.

The Beach Center on Families and Disability — This center conducts research and training, and disseminates information relevant to families who have members with developmental disabilities or serious emotional disturbances. Write: The Beach Center on Families and Disability,The University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045. Telephone: (913) 864-7600.

Children and Adolescent Service System Programs (CASSP) — CASSPs are federally-funded programs located throughout several states and localities, designed to improve service delivery for children and adolescents with emotional disorders. CASSP provides funding to states for research and training centers and for technical assistance activities. To contact a CASSP in your area, or to obtain a publications list and additional information, write: National Technical Assistance Center for Children's Mental Health, 3307 M Street, NW, Suite 401, Washington, DC 20007. Telephone: (202) 687-5000.

National Clearinghouse on Family Support and Children's Mental Health — The Center provides research and training, and disseminates information relative to serious emotional disorders and family support issues, including a newsletter. Write: National Clearinghouse on Family Support and Children's Mental Health, Portland State University, P.O. 751, Portland, OR 97207-0751. Telephone: 1-800-628-1696; (503) 725-4040.

NICHCY Briefing Paper is published several times a year in response to questions from individuals and organizations that contact the Clearinghouse. In addition, NICHCY disseminates other materials and can respond to individual requests for information. For further information and assistance, or to receive a NICHCY *Publications Catalog*, contact NICHCY, P.O. Box 1492, Washington, DC 20013. Telephone: 1-800-695-0285 (Voice/TT) and (202) 884-8200 (Voice/TT). E-mail: nichcy@aed.org Web Site: www.nichcy.org

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U.S. Department of Health and Human Services
Administration on Aging

National Family Caregiver Support Program Resources

Communicating Better with Health Professionals

Introduction

Sometimes it can seem like health professionals speak a different language. When we feel worried about a loved one's health condition, it can be hard to keep up with everything being said by a doctor or nurse. It's important to communicate clearly with health professionals. Good communication helps you be a more effective caregiver, leads to better care, helps family members feel like part of the healthcare team, and helps clear up confusion quickly.

Four Keys To Effective Communication

We can all improve our communication skills. Researchers have found four key ways that we can strengthen communication in healthcare:

1. Be fully present

- Before entering the health setting, take a moment to calm your mind. Breathe deeply.
- Make eye contact.
- Focus on the present moment – don't worry about yesterday or tomorrow.
- Set a positive tone.
- Maintain a strong sense of yourself.

2. Participate

- Be prepared.
- Clearly state your purpose.
- Offer information about your loved one's condition.
- Ask questions.
- Assert yourself. When you assert yourself you ask questions, clearly state what you want, offer compromises, and set limits about what is acceptable in a care plan.

3. Build understanding

- Really listen – with your full attention.
- If you hear something you don't understand, ask the health professional to clarify the point.
- Show that you understand what someone is saying by repeating it back in your own words.
- Avoid assumptions. Don't jump to conclusions. Allow others to finish speaking.
- State difficulties and concerns. Ask for help in understanding the reasons for treatment choices and recommendations.

4. Encourage working together

- Focus on goals that you, your loved one, and the health professional can agree upon.
- Be clear about who is responsible for what and get extra help with certain tasks, if needed.
- Speak openly and honestly.
- Help with problem solving. Share information that you have that can help the health team make good decisions about care.
- Express appreciation. Saying "thank you" to health professionals who gave you help means more than you can imagine.

Family Caregivers As Team Members

The role of the family caregiver is to serve as an effective member of the healthcare team, along with the patient, doctor, nurse, social worker, therapists, and other team members. Your goal is to help your loved one navigate the healthcare system and get the best quality care possible. Here is a list of key activities for you as a team member:

- Set up a file with detailed records of important medical information.
- Go to appointments with your loved one and speak up for him or her, as needed.
- Write down notes during appointments.
- Ask questions about anything that is not clear or sounds complicated.
- If you disagree or have a concern, speak up.
- Ask others to listen to your loved one's concerns in his or her own words.
- Provide progress reports to health professionals.
- If your loved one's needs are not being met by his or her team of health professionals, find a new team.

How To Support Treatment Plans

- Make sure your loved one follows medical instructions. If you have any questions or doubts about what is to be done, call and ask.
- Come prepared. Bring complete information about your loved one's current symptoms, condition, medication, and therapies.
- Be a good reality check. Help your loved one not to exaggerate, dramatize, or under-report symptoms.
- Reach out for help if something changes. Don't attempt to play doctor yourself.
- Tell the doctor when you seek a second opinion. It's okay. Health professionals are used to this and usually find a second opinion to be helpful.
- Educate yourself about the particular disorder your loved one has. Share what you learn with health professionals. They won't always have all the answers or know the latest research about a particular disorder.

Respect Health Professionals' Limits

- Be respectful of health professionals' time and emotional limits
- Be patient; most health care offices are busy and see many patients every day
- Learn the office routine – including the best time to call with medical questions, how to make appointments, and the name of the person who handles billing information.

Information provided in this fact sheet was adapted from materials submitted by the National Family Caregivers Association, Kensington, MD. For more information, visit their website at www.nfcacares.org.

FOR MORE INFORMATION

AoA recognizes the importance of making information readily available to consumers, professionals, researchers, and students. Our website provides information for and about older persons, their families, and professionals involved in aging programs and services. For more information about AoA, please contact: US Dept of Health and Human Services, Administration on Aging, Washington, DC 20201; phone: (202) 401-4541; fax (202) 357-3560; Email: aoainfo@aoa.gov; or contact our website at: www.aoa.gov

FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving

FACT SHEET: DEMENTIA, CAREGIVING AND CONTROLLING FRUSTRATION

The Stresses of Caregiving

Caring for an individual with Alzheimer's disease or a related dementia can be challenging and, at times, overwhelming. Frustration is a normal and valid emotional response to many of the difficulties of being a caregiver. While some irritation may be part of everyday life as a caregiver, feeling extreme frustration can have serious consequences for you or the person you care for. Frustration and stress may negatively impact your physical health or cause you to be physically or verbally aggressive towards your loved one. If your caregiving situation is causing you extreme frustration or anger, you may want to explore some new techniques for coping.

When you are frustrated, it is important to distinguish between *what is and what is not within your power to change*. Frustration often arises out of trying to change an uncontrollable circumstance. As a caregiver of someone with dementia, you face many uncontrollable situations. Normal daily activities—dressing, bathing and eating—may become sources of deep frustration for you. Behaviors often associated with dementia, like wandering or asking questions repeatedly, can be frustrating for caregivers but are uncontrollable behaviors for people with dementia. Unfortunately, you cannot simply change the behavior of a person suffering from dementia.

When dealing with an uncontrollable circumstance, you do control one thing: *how you respond to that circumstance*.

In order to respond without extreme frustration, you will need to:

- learn to recognize the warnings signs of frustration;
- intervene to calm yourself down physically;
- modify your thoughts in a way that reduces your stress;
- learn to communicate assertively;
- learn to ask for help.

Warning Signs of Frustration

If you can recognize the warning signs of frustration, you can intervene and adjust your mood before you lose control. Some of the common warning signs of frustration include:

- shortness of breath
- knot in the throat
- stomach cramps
- chest pains
- headache
- compulsive eating
- excessive alcohol consumption
- increased smoking

- lack of patience
- desire to strike out

Calming Down Physically

When you become aware of the warning signs of frustration, you can intervene with an immediate activity to help you calm down. This gives you time to look at the situation more objectively and to choose how to respond in a more controlled way.

When you feel yourself becoming frustrated, try counting from one to ten slowly and taking a few deep breaths. If you are able, take a brief walk or go to another room and collect your thoughts. It is better to leave the situation, even for a moment, than to lose control or react in a way you will regret. If you think someone may be offended when you leave the room, you can tell that person you need to go to the restroom. You can also try calling a friend, praying, meditating, singing, listening to music or taking a bath. Try experimenting with different responses to find out what works best for you and the person you care for.

The regular practice of relaxation techniques can also help prepare you for frustrating circumstances. If possible, try the following relaxation exercise for at least ten minutes each day:

Sit in a comfortable position in a quiet place. Take slow, deep breaths and relax the tension in your body. While you continue to take slow, deep breaths, you may want to imagine a safe and restful place and repeat a calming word or phrase.

Modifying Your Thoughts

As you take time out to collect your thoughts, try rethinking your situation in ways that reduce frustration. How you think often affects how you feel. Of course, feelings of frustration arise from difficult circumstances. If, however, you analyze your response to a frustrating situation, you will usually find some form of *maladaptive*—or negative—thinking that has the effect of increasing your frustration, preventing you from looking at your situation objectively, or finding a better way to deal with it.

Below are six major types of unhelpful thought patterns common among caregivers. Following each unhelpful thought pattern is an example of an *adaptive*—or more helpful—thought that can be used as self-defense against frustration. Familiarizing yourself with the unhelpful thought patterns and the adaptive responses can help you control your frustration.

Over-generalization: You take one negative situation or characteristic and multiply it. For example, you're getting ready to take the person in your care to a doctor's appointment when you discover the car battery has died. You then conclude, "This always happens; something always goes wrong."

Adaptive response: "This does not happen all the time. Usually my car is working just fine. At times things don't happen the way I would like, but sometimes they do."

Discounting the positive: You overlook the good things about your circumstances and yourself. For example, you might not allow yourself to feel good about caregiving by thinking, "I could do more" or "anyone could do what I do."

Adaptive response: "Caregiving is not easy. It takes courage, strength, and compassion to do what I do. I am not always perfect, but I do a lot and I am trying to be helpful."

Jumping to conclusions: You reach a conclusion without having all the facts. You might do this in two ways:

- *Mindreading*: We assume that others are thinking negative thoughts about us. For example, a friend doesn't return a phone call, and we assume that he or she is ignoring us or doesn't want to talk to us.

  Adaptive response: "I don't know what my friend is thinking. For all I know, she didn't get the message. Maybe she is busy or just forgot. If I want to know what she is thinking, I will have to ask her."

- *Fortune-telling*: You predict a negative outcome in the future. For example, you will not try adult day care because you assume the person in your care will not enjoy it. You think, "He will never do that. Not a chance!"

  Adaptive response: "I cannot predict the future. I don't think he is going to like it, but I won't know for sure unless I try."

"Should" statements: You try to motivate yourself using statements such as "I should call mother more often" or "I shouldn't go to a movie because Mom might need me." What you think you "should" do is in conflict with what you want to do. You end up feeling guilty, depressed or frustrated.

Adaptive response: "I would like to go to a movie. It's okay for me to take a break from caregiving and enjoy myself. I will ask a friend or neighbor to check in on Mom."

Labeling: You identify yourself or other people with one characteristic or action. For example, you put off doing the laundry and think, "I am lazy."

Adaptive response: "I am not lazy. Sometimes I don't do as much as I could, but that doesn't mean I am lazy. I often work hard and do the best that I can. Even I need a break sometimes."

Personalizing: You take responsibility for a negative occurrence that is beyond your control. For example, you might blame yourself when the person in your care requires hospitalization or placement in a facility.

Adaptive response: "Mom's condition has gotten to the point where I can no longer take care of her myself. It is her condition and not my shortcomings that require her to be in a nursing home."

Using the "Triple-Column Technique": Unhelpful thought patterns are usually ingrained reactions or habits. To modify your negative thoughts, you will have to learn to recognize them, know why they are false, and talk back to them.

One helpful way to practice using more adaptive thinking processes is to use the "triple-column technique." Draw two lines down the center of a piece of paper to divide the paper into thirds. When you are feeling frustrated, take a personal "time out" and write your negative thoughts in the first column.

Negative Thoughts	Thought Patterns	Adaptive Thoughts
(Caregiver burns dinner.) "I can't do anything right!"	Over-generalization	I'm not perfect, but nobody is perfect. Sometimes I make mistakes, and sometimes I do things well.
(Caregiver has coffee with a friend and spouse has accident at home.) "I'm selfish and rotten! If I had been home, he wouldn't have fallen."	Labeling; personalizing	I'm not selfish or rotten. I do a lot to take care of my husband, but I need to take care of myself as well. He might have fallen even if I had been home.
(Brother does not show up to take your Dad to the doctor.) "I knew I couldn't trust him. I should just do it myself next time."	Jumping to conclusions; should statements	I don't know why he didn't come, but I need his help, so we'll have to find ways for him to share the burden of Dad's care.

In the second column, try to identify the type of unhelpful pattern from the six examples above. In the third column, talk back to your negative thoughts with a more positive point of view. See below for examples.

Communicating Assertively

Good communication can reduce frustration by allowing you to express yourself while helping others to understand your limits and needs. *Assertive* communication is different from passive or aggressive communication. When you communicate passively, you may be keeping your own needs and desires inside to avoid conflict with others. While this may seem easier on the surface, the long-term result may be that others feel they can push you around to get their way.

When you communicate aggressively, you may be forcing your needs and desires onto others. While this allows you to express your feelings, aggressive communication generally makes others more defensive and less cooperative.

When you communicate assertively, you express your own needs and desires while respecting the needs and desires of others. Assertive communication allows both parties to engage in a dignified discussion about the issue at hand.

Keys to assertive communication are:

- Respecting your own feelings, needs and desires.
- Standing up for your feelings without shaming, degrading or humiliating the other person.
- Using "I" statements rather than "you" statements. For example, say, "I need a break" or "I would like to talk to you and work this out" instead of "You are irresponsible" or "You never help out!"
- Not using "should" statements. For example, say, "It's important to me that promises be kept," instead of "You should keep your promise."

The Critical Step: Asking for Help

You cannot take on all the responsibilities of caregiving by yourself. It is essential that you ask for and accept help. Discuss your needs with family members and friends who might be willing to share caregiving responsibilities. People will not realize you need help if you do not explain your situation and ask for assistance. Remember, you have the right to ask for help and express your needs.

When to say Yes

Don't be afraid to say "Yes" if someone offers to help. Say "Yes" at the moment a person offers to help rather than saying "maybe" and waiting until you are in a fix. Have a list handy of errands or tasks you need help with. Keep in mind that people feel useful and gratified when they are able to help others.

When to say "No"

Often, caregivers are pulled in multiple directions. In addition to the demands of caregiving, you may feel compelled to meet the demands of your immediate and extended family, your friends and your employer. Learn how to say "No" to the demands of others when you are overwhelmed or need a break. It is your right to say "No" to extra demands on your time without feeling guilty.

Learning Effective Communication Techniques for Dementia Caregiving

Many families find it frustrating to communicate with a loved one who has dementia. The person with dementia may repeat questions over and over or mistake you for someone else. It is important to remember that the person with dementia cannot control behavior caused by their disease. They do not need to be corrected or grounded in "reality." You can distract them or just agree with them as a way to reduce your frustration.

It can be helpful, however, to learn more about dementia and effective communication techniques which will ease your frustration. For example, use simple, direct statements, and place yourself close when speaking to a person with a cognitive disorder. Try not to argue about unimportant things such as what the date is. Allow extra time to accomplish tasks such as dressing. Remember, people with dementia often react more to our feelings than our words. Finding ways to be calm can help you to gain cooperation.

Self-Care to Prevent Frustration

Caregiving can be tiring and stressful. When you're caring for others, it's easy to forget to care for yourself. While it may be difficult to find time to focus on yourself and your needs, it is very important that you do so to prevent frustration and burnout.

Here are three steps to taking better care of YOU:

Make Time for Yourself

You may feel guilty about needing or wanting time out for rest, socialization and fun. However, everyone deserves regular and ongoing breaks from work, including caregivers. "Respite" providers can give you the opportunity to take the breaks you need. Respite breaks may be provided by in-home help, adult day care, "friendly visitor" programs, friends and neighbors, or other means. The important point is to allow yourself to take a break from caregiving. See "Resources" at the end of this fact sheet for organizations that might help you give yourself time off from caregiving.

Take Care of Yourself

Although caregiving may make it difficult to find time for yourself, it is important to eat well, exercise, get a good night's sleep and attend to your own medical needs.

When you do not take care of yourself, you are prone to increased anxiety, depression, frustration and physical distress that will make it more difficult to continue providing care.

Seek Outside Support

Sharing your feelings with a counselor, pastor, a support group, or with another caregiver in a similar situation can be a great way to release stress and get helpful advice. You may want to contact the organizations under "Resources" at the end of this Fact Sheet or look in the community services section at the front of the *Yellow Pages*, under "Counseling" or "Senior Services" to find services to help you get some caregiver support.

Credits

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Parrish, Monique, L.C.S.W., Dr. PH., (2000). *"Stress: What is it? What can be done about it?" Stress Reduction Instruction Manual*, written for John Muir Mount Diablo Medical Center, Concord, CA.

For More Information

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National Center on Caregiving
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San Francisco, CA 94104
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(800) 445–8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating disorders that strike adults.

Family Caregiver Alliance Fact Sheet on Behavior Management Strategies (Dementia)

Family Caregiver Alliance Fact Sheet on Hiring-In-Home Help

Family Caregiver Alliance Fact Sheet on Taking Care of YOU: Self-Care for Family Caregivers

Alzheimer's Association
225 N. Michigan Ave., Ste. 1700
Chicago, IL 60601–7633
(800) 272–3900
www.alz.org

Eldercare Locator
Call to find your local Area Agency on Aging and services for the elderly and caregivers, including respite care providers.
(800) 677–1116
www.eldercare.gov

Faith in Action
Call to find volunteer caregiving assistance.
(877) 324–8411
www.fiavolunteers.org

ARCH National Respite Network and Resource Center
Call to find local respite providers.
(800) 473–1727
www.archrespite.org/index.htm

Prepared by Family Caregiver Alliance. Funded by the California Department of Mental Health.

FACT SHEET: CAREGIVER'S GUIDE TO UNDERSTANDING DEMENTIA BEHAVIORS

Caring for a loved one with dementia poses many challenges for families and caregivers. People with dementia from conditions such as Alzheimer's and related diseases have a progressive *brain* disorder that makes it more and more difficult for them to remember things, think clearly, communicate with others, or take care of themselves. In addition, dementia can cause mood swings and even change a person's personality and behavior. This Fact Sheet provides some practical strategies for dealing with the troubling behavior problems and communication difficulties often encountered when caring for a person with dementia.

Ten Tips for Communicating with a Person with Dementia

We aren't born knowing how to communicate with a person with dementia—but we can learn. Improving your communication skills will help make caregiving less stressful and will likely improve the quality of your relationship with your loved one. Good communication skills will also enhance your ability to handle the difficult behavior you may encounter as you care for a person with a dementing illness.

1. **Set a positive mood for interaction.** Your attitude and body language communicate your feelings and thoughts stronger than your words. Set a positive mood by speaking to your loved one in a pleasant and respectful manner. Use facial expressions, tone of voice and physical touch to help convey your message and show your feelings of affection.

2. **Get the person's attention.** Limit distractions and noise—turn off the radio or TV, close the curtains or shut the door, or move to quieter surroundings. Before speaking, make sure you have her attention; address her by name, identify yourself by name and relation, and use nonverbal cues and touch to help keep her focused. If she is seated, get down to her level and maintain eye contact.

3. **State your message clearly.** Use simple words and sentences. Speak slowly, distinctly and in a reassuring tone. Refrain from raising your voice higher or louder; instead, pitch your voice lower. If she doesn't understand the first time, use the same wording to repeat your message or question. If she still doesn't understand, wait a few minutes and rephrase the question. Use the names of people and places instead of pronouns or abbreviations.

4. **Ask simple, answerable questions.** Ask one question at a time; those with yes or no answers work best. Refrain from asking open-ended questions or giving too many choices. For example, ask, *"Would you like to wear your white shirt or your blue shirt?"* Better still, show her the choices—visual prompts and cues also help clarify your question and can guide her response.

5. **Listen with your ears, eyes and heart.** Be patient in waiting for your loved one's reply. If she is struggling for an answer, it's okay to suggest words. Watch for nonverbal cues and body language, and respond appropriately. *Always strive to listen for the meaning and feelings that underlie the words.*

6. **Break down activities into a series of steps.** This makes many tasks much more manageable. You can encourage your loved one to do what he can, gently remind him of steps he tends to forget, and assist with steps he's no longer able to accomplish on his own. Using visual cues, such as showing him with your hand where to place the dinner plate, can be very helpful.

7. **When the going gets tough, distract and redirect.** When your loved one becomes upset, try changing the subject or the environment. For example, ask him for help or suggest going for a walk. *It is important to connect with the person on a feeling level, before you redirect.* You might say, *"I see you're feeling sad—I'm sorry you're upset. Let's go get something to eat."*

8. **Respond with affection and reassurance.** People with dementia often feel confused, anxious and unsure of themselves. Further, they often get reality confused and may recall things that never really occurred. *Avoid trying to convince them they are wrong.* Stay focused on the feelings they are demonstrating (which are real) and respond with verbal and physical expressions of comfort, support and reassurance. Sometimes holding hands, touching, hugging and praise will get the person to respond when all else fails.

9. **Remember the good old days.** Remembering the past is often a soothing and affirming activity. Many people with dementia may not remember what happened 45 minutes ago, but they can clearly recall their lives 45 years earlier. Therefore, *avoid asking questions that rely on short-term memory*, such as asking the person what they had for lunch. Instead, try asking general questions about the person's distant past—this information is more likely to be retained.

10. **Maintain your sense of humor.** *Use humor whenever possible, though not at the person's expense.* People with dementia tend to retain their social skills and are usually delighted to laugh along with you.

Handling Troubling Behavior

Some of the greatest challenges of caring for a loved one with dementia are the personality and behavior changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor.

To start, consider these ground rules:
We cannot change the person. The person you are caring for has a brain disorder that shapes who he has become. When you try to control or change his behavior, you'll most likely be unsuccessful or be met with resistance. It's important to:

- *Try to accommodate the behavior, not control the behavior*. For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.

- *Remember that we* ***can*** *change our behavior or the physical environment.* Changing our own behavior will often result in a change in our loved one's behavior.

Check with the doctor first. Behavioral problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

Behavior has a purpose. People with dementia typically cannot tell us what they want or need. They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is fulfilling a need to be busy and productive. *Always consider what need the person might be trying to meet with their behavior—and, when possible, try to accommodate them.*

Behavior is triggered. It is important to understand that all behavior is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behavior or it could be a change in the physical environment. *The root to changing behavior is disrupting the patterns that we create.* Try a different approach, or try a different consequence.

What works today, may not tomorrow. The multiple factors that influence troubling behaviors and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Get support from others. You are not alone—there are many others caring for someone with dementia. Call your local Area Agency on Aging, the local chapter of the Alzheimer's Association, a Caregiver Resource Center or one of the groups listed below in *Resources* to find support groups, organizations and services that can help you. Expect that, like the loved one you are caring for, you will have good days and bad days. Develop strategies for coping with the bad days (see the FCA Fact Sheet, *Dementia, Caregiving and Controlling Frustration*).

The following is an overview of the most common dementia-associated behaviors with suggestions that may be useful in handling them. You'll find additional resources listed at the end of this Fact Sheet.

Wandering

People with dementia walk, seemingly aimlessly, for a variety of reasons, such as boredom, medication side effects or to look for "something" or someone. They also may be trying to fulfill a physical need—thirst, hunger, a need to use the toilet or exercise. Discovering the triggers for wandering are not always easy, but they can provide insights to dealing with the behavior.

- Make time for regular exercise to minimize restlessness.
- Consider installing new locks that require a key. Position locks high or low on the door; many people with dementia will not think to look beyond eye level. Keep in mind fire and safety concerns for all family members; the lock(s) must be accessible to others and not take more than a few seconds to open.

- Try a barrier like a curtain or colored streamer to mask the door. A "*stop*" sign or "*do not enter*" sign also may help.
- Place a black mat or paint a black space on your front porch; this may appear to be an impassable hole to the person with dementia.
- Add "child-safe" plastic covers to doorknobs.
- Consider installing a home security system or monitoring system designed to keep watch over someone with dementia. Also available are new digital devices that can be worn like a watch or clipped on a belt that use global positioning systems (GPS) or other technology to track a person's whereabouts or locate him if he wanders off..
- Put away essential items such as the confused person's coat, purse or glasses. Some individuals will not go out without certain articles.
- Have your relative wear an ID bracelet and sew ID labels in their clothes. Always have a current photo available should you need to report your loved one missing. Consider leaving a copy on file at the police department or registering the person with the Alzheimer's Association Safe Return program (see *Resources*).
- Tell neighbors about your relative's wandering behavior and make sure they have your phone number.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Sometimes accidents result from environmental factors; for example, someone can't remember where the bathroom is located or can't get to it in time. If an accident occurs, your understanding and reassurance will help the person maintain dignity and minimize embarrassment.

- Establish a routine for using the toilet. Try reminding the person or assisting her to the bathroom every two hours.
- Schedule fluid intake to ensure the confused person does not become dehydrated. However, avoid drinks with a diuretic effect like coffee, tea, cola, or beer. Limit fluid intake in the evening before bedtime.
- Use signs (with illustrations) to indicate which door leads to the bathroom.
- A commode, obtained at any medical supply store, can be left in the bedroom at night for easy access.
- Incontinence pads and products can be purchased at the pharmacy or supermarket. A urologist may be able to prescribe a special product or treatment.
- Use easy-to-remove clothing with elastic waistbands or Velcro^{Ò} closures, and provide clothes that are easily washable.

Agitation

Agitation refers to a range of behaviors associated with dementia, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behavior problems progress with the stages of dementia, from mild to more severe. Agitation may be triggered by a variety of things, including environmental factors, fear and fatigue. Most often, agitation is triggered when the person experiences "control" being taken from him.

- Reduce caffeine intake, sugar and junk food.
- Reduce noise, clutter or the number of persons in the room.

- Maintain structure by keeping the same routines. Keep household objects and furniture in the same places. Familiar objects and photographs offer a sense of security and can suggest pleasant memories.
- Try gentle touch, soothing music, reading or walks to quell agitation. Speak in a reassuring voice. Do not try to restrain the person during a period of agitation.
- Keep dangerous objects out of reach.
- Allow the person to do as much for himself as possible—support his independence and ability to care for himself.
- Acknowledge the confused person's anger over the loss of control in his life. Tell him you understand his frustration.
- Distract the person with a snack or an activity. Allow him to forget the troubling incident. Confronting a confused person may increase anxiety.

Repetitive Speech or Actions (perseveration)

People with dementia will often repeat a word, statement, question or activity over and over. While this type of behavior is usually harmless for the person with dementia, it can be annoying and stressful to caregivers. Sometimes the behavior is triggered by anxiety, boredom, fear or environmental factors.

- Provide plenty of reassurance and comfort, both in words and in touch.
- Try distracting with a snack or activity.
- Avoid reminding them that they just asked the same question. Try ignoring the behavior or question and distract the person into an activity.
- Don't discuss plans with a confused person until immediately prior to an event.
- You may want to try placing a sign on the kitchen table, such as, "*Dinner is at 6:30*" or "*Lois comes home at 5:00*" to remove anxiety and uncertainty about anticipated events.
- Learn to recognize certain behaviors. An agitated state or pulling at clothing, for example, could indicate a need to use the bathroom.

Paranoia

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree. This, too, is part of the dementia—try not to take it personally.

- If the confused person suspects money is "missing," allow her to keep small amounts of money in a pocket or handbag for easy inspection.
- Help them look for the object and then distract them into another activity. Try to learn where the confused person's favorite hiding places are for storing objects, which are frequently assumed to be "lost." Avoid arguing.
- Take time to explain to other family members and home-helpers that suspicious accusations are a part of the dementing illness.
- Try nonverbal reassurances like a gentle touch or hug. Respond to the feeling behind the accusation and then reassure the person. You might try saying, "I see this frightens you; stay with me, I won't let anything happen to you."

Sleeplessness/Sundowning

Restlessness, agitation, disorientation and other troubling behavior in people with dementia often get worse at the end of the day and sometimes continue throughout the night. Experts believe this behavior, commonly called *sundowning,* is caused by a combination of factors, such as exhaustion from the day's events and changes in the person's biological clock that confuse day and night.

- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.
- Watch out for dietary culprits, such as sugar, caffeine and some types of junk food. Eliminate or restrict these types of foods and beverages to early in the day. Plan smaller meals throughout the day, including a light meal, such as half a sandwich, before bedtime.
- Plan for the afternoon and evening hours to be quiet and calm; however, *structured, quiet activity is important*. Perhaps take a stroll outdoors, play a simple card game or listen to soothing music together.
- Turning on lights well before sunset and closing the curtains at dusk will minimize shadows and may help diminish confusion. At minimum, keep a nightlight in the person's room, hallway and bathroom.
- Make sure the house is safe: block off stairs with gates, lock the kitchen door and/or put away dangerous items.
- As a last resort, consider talking to the doctor about medication to help the agitated person relax and sleep. Be aware that sleeping pills and tranquilizers may solve one problem and create another, such as sleeping at night but being more confused the next day.
- It's essential that you, the caregiver, get enough sleep. If your loved one's nighttime activity keeps you awake, consider asking a friend or relative, or hiring someone, to take a turn so that you can get a good night's sleep. Catnaps during the day also might help.

Eating/Nutrition

Ensuring that your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste "funny." The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation.

- Make meal and snack times part of the daily routine and schedule them around the same time every day. Instead of three big meals, try five or six smaller ones.
- Make mealtimes a special time. Try flowers or soft music. Turn off loud radio programs and the TV.
- Eating independently should take precedence over eating neatly or with "proper" table manners. Finger foods support independence. Pre-cut and season the food. Try using a straw or a child's "sippy cup" if holding a glass has become difficult. Provide assistance only when necessary and allow plenty of time for meals.
- Sit down and eat with your loved one. Often they will mimic your actions and it makes the meal more pleasant to share it with someone.

- Prepare foods with your loved one in mind. If they have dentures or trouble chewing or swallowing, use soft foods or cut food into bite-size pieces.
- If chewing and swallowing are an issue, try gently moving the person's chin in a chewing motion or lightly stroking their throat to encourage them to swallow.
- If loss of weight is a problem, offer nutritious high-calorie snacks between meals. Breakfast foods high in carbohydrates are often preferred. On the other hand, if the problem is weight gain, keep high-calorie foods out of sight. Instead, keep handy fresh fruits, veggie trays and other healthy low-calorie snacks.

Bathing

People with dementia often have difficulty remembering "good" hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes. From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both caregivers and their loved ones.

- Think historically of your loved one's hygiene routine – did she prefer baths or showers? Mornings or nights? Did she have her hair washed at the salon or do it herself? Was there a favorite scent, lotion or talcum powder she always used? Adopting—as much as possible—her past bathing routine may provide some comfort. Remember that it may not be necessary to bathe every day—sometimes twice a week is sufficient.
- If your loved one has always been modest, enhance that feeling by making sure doors and curtains are closed. Whether in the shower or the bath, keep a towel over her front, lifting to wash as needed. Have towels and a robe or her clothes ready when she gets out.
- Be mindful of the environment, such as the temperature of the room and water (older adults are more sensitive to heat and cold) and the adequacy of lighting. It's a good idea to use safety features such as non-slip floor bath mats, grab-bars, and bath or shower seats. A hand-held shower might also be a good feature to install. Remember—people are often afraid of falling. Help them feel secure in the shower or tub.
- Never leave a person with dementia unattended in the bath or shower. Have all the bath things you need laid out beforehand. If giving a bath, draw the bath water first. Reassure the person that the water is warm—perhaps pour a cup of water over her hands before she steps in.
- If hair washing is a struggle, make it a separate activity. Or, use a dry shampoo.
- If bathing in the tub or shower is consistently traumatic, a towel bath provides a soothing alter-native. A *bed* bath has traditionally been done with only the most frail and bed-ridden patients, soaping up a bit at a time in their beds, rinsing off with a basin of water and drying with towels. A growing number of nurses in and out of facilities, however, are beginning to recognize its value and a variation—the "*towel* bath"—for others as well, including people with dementia who find bathing in the tub or shower uncomfortable or unpleasant. The towel bath uses a large bath towel and washcloths dampened in a plastic bag of warm water and no-rinse soap. Large bath-blankets are used to keep the patient covered, dry and warm while the dampened towel and washcloths are massaged over the body. For more information, see the book *Bathing*

Without a Battle, (details in the *Recommended Reading* section below), or visit www.bathingwithoutabattle.unc.edu/main_page.html.

Additional Problem Areas

- Dressing is difficult for most dementia patients. Choose loose-fitting, comfortable clothes with easy zippers or snaps and minimal buttons. Reduce the person's choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time, in the order it is to be worn. Remove soiled clothes from the room. Don't argue if the person insists on wearing the same thing again.
- Hallucinations (seeing or hearing things that others don't) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses. State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person their perceptions are wrong. Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medication.
- Sexually inappropriate behavior, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behavior, may occur during the course of the illness. Remember, this behavior is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behavior occurs, i.e., what you will say and do if the behavior happens at home, around other adults or children. If you can, identify what triggers the behavior.
- Verbal outbursts such as cursing, arguing and threatening often are expressions of anger or stress. React by staying calm and reassuring. Validate your loved one's feelings and then try to distract or redirect his attention to something else.
- "Shadowing" is when a person with dementia imitates and follows the caregiver, or constantly talks, asks questions and interrupts. Like sundowning, this behavior often occurs late in the day and can be irritating for caregivers. Comfort the person with verbal and physical reassurance. Distraction or redirection might also help. Giving your loved one a job such as folding laundry might help to make her feel needed and useful.
- People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid or confused by what you are asking of them. Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

Credits and Recommended Reading

Bathing Without a Battle, by Ann Louise Barrick, Joanne Rader, Beverly Hoeffer and Philip Sloane, (2002), Springer Publishing, (877) 687–7476.

Caring for a Person with Memory Loss and Confusion: An Easy Guide for Caregivers, (2002), Journeyworks Publishing, Santa Cruz, CA, (800) 775–1998.

Communicating Effectively with a Person Who Has Alzheimer's, (2002), Mayo Clinic Staff, www.mayoclinic.com/invoke.cfm?id=AZ00004

Steps to Enhancing Communication: Interacting with Persons with Alzheimer's Disease,(1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

***Steps to Understanding Challenging Behaviors: Responding to Persons with Alzheimer's Disease*, (1996), Alzheimer's Association, Chicago, IL, (800) 272–3900.

The Validation Breakthrough: Simple Techniques for Communicating with People with "Alzheimer's-Type Dementia," Naomi Feil , 2nd Edition 2002, Health Professions Press, Baltimore, MD, (410) 337–8539.

Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses, A. Robinson, B. Spencer, and L.White, (2001), Eastern Michigan University, Ypsilanti, MI, (734) 487–2335.

For More Information

Family Caregiver Alliance
180 Montgomery St., Suite 1100
San Francisco, CA 94104
(415) 434–3388
(800) 445–8106
www.caregiver.org
info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating health conditions that strike adults.

FCA Publications
***Practical Skills Training for Family Caregivers*,** Mary A. Corcoran, 2003, Family Caregiver Alliance, 180 Montgomery Street, Suite 1100, San Francisco, CA 94104, (800) 445–8106.
www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=954
FCA Fact Sheets. All Family Caregiver Alliance Fact Sheets are available free online. Printed versions are $1.00 for each title—send your requests to FCA Publications, 180 Montgomery St., Suite 1100, San Francisco, CA 94104. For the full list, see:
www.caregiver.org/caregiver/jsp/publications.jsp?nodeid=345
FCA Fact Sheet:* *Dementia, Caregiving and Controlling Frustration
FCA Fact Sheet:* *Taking Care of YOU: Self-Care for Family Caregivers
FCA Fact Sheet:* *Hiring In-Home Help
FCA Fact Sheet:* *Community Care Options

Alzheimer's Disease Education and Referral (ADEAR) Center
(800) 438-4380
www.alzheimers.org
This service of the National Institute on Aging offers information and publications on diagnosis, treatment, patient care, caregiver needs, long-term care, education and research related to Alzheimer’s disease.

Eldercare Locator
(800) 677–1116
www.eldercare.gov
This service of the Administration on Aging offers information about and referrals to respite care and other home and community services offered by state and Area Agencies on Aging.

Alzheimer’s Association Safe Return Program
(800) 272–3900
www.alz.org/SafeReturn
A nationwide program that identifies people with dementia who wander away and returns them to their homes. For a $40 registration fee, families can register their loved one in a national confidential computer database. They also receive an identification bracelet or necklace and other identification and educational materials.

This fact sheet was prepared by Family Caregiver Alliance in cooperation with California’s statewide system of Caregiver Resource Centers. Reviewed by Beth Logan, M.S.W., Education and Training Consultant and Specialist in Dementia Care. Funded by the California Department of Mental Health. © 2004 Family Caregiver Alliance. All rights reserved. FS-CGTU20050610.

Department of SOCIAL SERVICES CDSS

Coordinated Care Initiative (CCI)

VOLUNTARY (OPTIONAL) PROVIDER TRAINING CURRICULUM*

This curriculum is a compilation of training resources developed by the CCI Voluntary Provider Training Workgroup in accordance with Welfare & Institutions Code Section 12330. The usage of these and other training resources, by providers, is optional and can help provide consistency, accountability, and increased quality of care for In-Home Supportive Services (IHSS) consumers.

Acknowledgements

Topic 1: Introduction to In-Home Supportive Services

Overview of the IHSS Program; Properly Communicating IHSS Authorized Tasks/Hours; Properly Completing Timesheets; Provider Requirements and Responsibilities; Confidentiality and Mandated Reporting

Topic 2: Working with the IHSS Consumer

Professional/Ethical Caregiving; Building and Keeping Good Relationships; Consumer Rights and Responsibilities; Setting Appropriate Boundaries

Topic 3: Communication Skills

Building Trust; Cultural Competency; Communication Differences for Family and Non-Family Providers; Potential Barriers; Dealing with Challenging Situations; The Health Insurance Portability and Accountability Act (HIPAA) and Confidentiality; Talking About Disabilities (Level of Control, Level of Independence); Communicating with Deaf and Hard of Hearing Consumers; Communicating with Consumers with Speech Impediments; Conflict Resolution

Topic 4: Care for the Caregiver

Proper Ergonomics/Body Mechanics; Correctly Lifting, Bending, and Moving to Continue Providing Care for the Consumer; Alternative Resources and Respite Care to Prevent Caregiver Burnout; Handling Loss and Grief as a Care Provider; Setting Appropriate Boundaries

Topic 5: Injury and Fall Prevention

Consumer Ergonomics/Body Mechanics; Safety in the Home; Transfers

Topic 6: Universal Precautions

Infection Control; Understanding Common Communicable Diseases; Sanitation (Soiled Clothes and Linens; Hands); Resources for Providers

Topic 7: Personal Care

Bowel, Bladder, and Menstrual Care; Bed Baths; Partial Sitting Baths; Tub Baths and Showers; Oral Care; Dressing; Shaving a Consumer; Repositioning

Topic 8: Paramedical Services

Tube Feedings; Suctioning/Tracheotomy Care; Stoma Care; Injections; Medication Management; Ostomy Care; Catheter Care; Cleaning of Equipment; Preventing Pressure Sores; Wound Care; Range of Motion

Topic 9: Food and Nutrition

General Nutrition Considerations (Meals, Medication, Observing Changes); Food Sanitation; Feeding/Choking Risks; Cultural Considerations; Hydration and Hydration Considerations; Use of Assistive Devices; Special Diets

Topic 10: Medication Management

Common Medication Side Effects; Setting Up Medi-Sets/Organization; Pain Management; Natural Medications; Medication Abuse and What To Do About It; Precautions for Providers

Topic 11: Use of Durable Medical Equipment (DME) in the Home

Assistive Devices Available to Consumers; Variations of Equipment; Respect for, Cleaning of, and Limitations of the Equipment; Use of Wheelchair Van Lifts and Other Adaptive Vehicles; Medical Supplies

Topic 12: Working with Consumers with Physical and Mental Health Disabilities

The Ten Most Common Physical Disabilities; The Ten Most Common Mental Health Disabilities; Tips for Effectively Dealing with Consumers' Disabilities

Topic 13: Emergency Procedures

Emergency Preparedness; In the Event of an Emergency; Emergency Contacts

Topic 14: Recognizing, Preventing, and Reporting Abuse and Neglect

Types of Abuse and Neglect; Getting Help

Topic 15: Cardio-Pulmonary Resuscitation (CPR) and First Aid - Layperson Responders

Where to Obtain Training (Optional)

**This Voluntary (Optional) Provider Training was developed through a stakeholder workgroup process and is intended to provide you with information and resources regarding best practices and interventions in your role as an IHSS provider. Please note, however, some material contained in this Voluntary (Optional) Provider Training Curriculum was included to help you understand the broad needs of many IHSS consumers, including needs met by sources outside the scope of the IHSS program. Certain information is intended for providers of services outside the scope of the IHSS program and/or services that require special training to be performed safely. IHSS providers must not perform services which are not authorized by the IHSS program and/or require special training.*

Sample Cover Letter to Accompany the SOC 321

<date>

< name, MD>
<address>

Dear Dr. :

Your patient, __________________, has applied for or is receiving In-Home Supportive Services (IHSS), which is unskilled home care provided by someone selected by the IHSS recipient. Your patient indicates that s/he needs assistance in performing some services which are considered by the IHSS program to be paramedical in nature. The State allows payment for paramedical services through IHSS if those services are authorized by, and provided under the direction of, the patient's doctor. These services are defined in State regulations as "activities which include the administration of medications, puncturing the skin, or inserting a medical device into a body orifice, activities requiring sterile procedures, or other activities requiring judgment based on training given by a licensed health care professional." [MPP 30-757.19(c)]

Some examples of paramedical services are:

- colostomy irrigation
- catheter insertion
- injections
- sterile treatments of decubitus ulcers
- tube feeding
- diabetic glucose level testing

Attached is a form to authorize payment for the receipt of such service through the IHSS Program. If you authorize these services, your office is responsible to assure that the unlicensed provider has received training and direction on how to perform these services. I have included an envelope for the return of a completed form.

Sincerely,

IHSS Social Worker

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757
(Continued)

.19 Paramedical services, under the following conditions:

.191 The services shall have the following characteristics:

(a) are activities which persons would normally perform for themselves but for their functional limitations,

(b) are activities which, due to the recipient's physical or mental condition, are necessary to maintain the recipient's health.

(c) are activities which include the administration of medications, puncturing the skin, or inserting a medical device into a body orifice, activities requiring sterile procedures, or other activities requiring judgment based on training given by a licensed health care professional.

.192 The services shall be provided when ordered by a licensed health care professional who is lawfully authorized to do so. The licensed health care professional shall be selected by the recipient. The recipient may select a licensed health care professional who is not a Medi-Cal provider, but in that event shall be responsible for any fee payments required by the professional.

.193 The services shall be provided under the direction of the licensed health care professional.

.194 The licensed health care professional shall indicate to social services staff the time necessary to perform the ordered services.

.195 This service shall be provided by persons who ordinarily provide IHSS. The hourly rate of provider compensation shall be the same as that paid to other IHSS providers in the county for the delivery method used.

.196 The county shall have received a signed and dated order for the paramedical services from a licensed health care professional. The order shall include a statement of informed consent saying that the recipient has been informed of the potential risks arising from receipt of such services. The statement of informed consent shall be signed and dated by the recipient, or his/her guardian or conservator. The order and consent shall be on a form developed or approved by the department.

.197 In the event that social services staff are unable to complete the above procedures necessary to authorize paramedical services during the same time period as that necessary to authorize the services described in .11 through .18, social services staff shall issue a notice of action and authorize those needed services which are described in .11 through .18 in a timely manner as provided in Section 30-759. Paramedical services shall be authorized at the earliest possible subsequent date.

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757
(Continued)

.198 In no event shall paramedical services be authorized prior to receipt by social services staff of the order for such services by the licensed health care professional. However, the cost of paramedical services received may be reimbursed retroactively provided that they are consistent with the subsequent authorization and were received on or after the date of application for the paramedical services.

NOTE: Authority cited: Sections 10553, 10554, 12300, 12301.1 and 12301.21, Welfare and Institutions Code; and Chapter 939, Statutes of 1992. Reference: Peremptory Writ of Mandate, Disabled Rights Union v. Woods, Superior Court, Los Angeles County, Case #C 380047; Miller v. Woods/Community Services for the Disabled v. Woods, Superior Court, San Diego County, Case Numbers 468192 and 472068; and Sections 12300, 12300(c)(7), 12300(f), 12300(g), 12300.1, and 12301.2, Welfare and Institutions Code.

30-758 TIME PER TASK AND FREQUENCY GUIDELINES 30-758

Repealed by Manual letter No. SS-06-02, effective 9/1/06

NOTE: Authority cited: Sections 10553, 10554, 12300, and 12301.2, Welfare and Institutions Code; and Chapter 939, Statutes of 1992. Reference: Peremptory Writ of Mandate, Disabled Rights Union v. Woods, Superior Court, Los Angeles County, Case #C 380047; and Sections 12300, and 12301.2, Welfare and Institutions Code.

30-759 APPLICATION PROCESS 30-759

.1 Each request or application for services shall have been made in accordance with Section 30-009.22.

.11 Recipient information including ethnicity and primary language (including sign language) shall be collected and recorded in the case file.

.2 Applications shall be processed, including eligibility determination and needs assessment, and notice of action mailed no later than 30 days following the date the written application is completed. An exception may be made for this requirement when a disability determination in accordance with Section 30-771 has not been received in the 30-day period. Services shall be provided, or arrangements for their provision shall have been made, within 15 days after an approval notice of action is mailed.

.3 Pending final determination, a person may be considered blind or disabled for purposes of non-PCSP IHSS eligibility under the following conditions:

.31 For a disabled applicant, eligibility may be presumed if the applicant is not employed and has no expectation of employment within the next 45 days, and if in the county's judgment the person appears to have a mental or physical impairment that will last for at least one year or end in death.

.32 For a blind applicant, eligibility may be presumed if in the county's judgment the person appears to meet the requirements of Section 30-771.2.

REQUEST FOR ORDER AND CONSENT - PARAMEDICAL SERVICES

PATIENT'S NAME

MEDI-CAL IDENTIFICATION NUMBER

TO:

Dear Doctor:

This patient has applied for In-Home Supportive Services (IHSS) and stated that he/she needs certain paramedical services in order for him/her to remain at home. You are asked to indicate on this form what specific services are needed and what specific condition necessitates the services.

In-Home Supportive Services is authorized to fund the provision of paramedical services, if you order them for this patient. For the purpose of this program, paramedical services are activities which, due to the recipient's physical or mental condition, are necessary to maintain the recipient's health and which the recipient would perform for himself/herself were he/she not functionally impaired. These services will be provided by In-Home Supportive Services providers who are not licensed to practice a health care profession and will rarely be training in the provision of health care services. Should you order services, you will be responsible for directing the provision of the paramedical services.

Your examination of this patient is reimbursable through Medi-Cal as an office visit provided that all other applicable Medi-Cal requirements are met.

If you have any questions, please contact me.

SIGNED	TITLE	TELEPHONE NUMBER	DATE

TO BE COMPLETED BY LICENSED PROFESSIONAL

NAME OF LICENSED PROFESSIONAL	OFFICE TELEPHONE

OFFICE ADDRESS (IF NOT LISTED ABOVE)

TYPE OF PRACTICE

TYPE OF PRACTICE

☐ Physician/Surgeon ☐ Podiatrist ☐ Dentist

CONTINUED ON BACK

RETURN TO: (COUNTY WELFARE DEPARTMENT)

Does the patient have a medical condition which results in a need for IHSS paramedical services?" ☐ YES ☐ NO
Is YES, list the condition(s) below:

List the paramedical services which are needed and should be provided by IHSS in your professional judgement.

TYPE OF SERVICE	TIME REQUIRED TO PERFORM THE SERVICE EACH TIME PERFORMED	FREQUENCY*		HOW LONG SHOULD THIS SERVICE BE PROVIDED?
		# OF TIMES	TIME PERIOD	

* Indicate the number of times a service should be provided for a specific time period: (Example: two times daily, etc.)

Additional comments:

☐ IF CONTINUED ON ANOTHER SHEET, CHECK HERE

CERTIFICATION

I certify that I am licensed to practice in the State of California as specified above and that this order falls within the scope of my practice. In my judgement the services which I have ordered are necessary to maintain the recipient's health and could be performed by the recipient for himself/herself were he/she not functionally impaired.

I shall provide such direction as is needed, in my judgement, in the provision of the ordered services.

I have informed the recipient of the risks associated with the provision of the ordered services by his/her IHSS provider.

SIGNATURE ▶ DATE

PATIENT'S INFORMED CONSENT

I have been advised of risks associated with provision of the services listed above and consent to provision of these services by my In-Home Supportive Services provider.

SIGNATURE ▶ DATE

30-763 SERVICE AUTHORIZATION (Continued) 30-763

.44 When the recipient is under eighteen years of age and is living with the recipient's parent(s), who has a legal duty pursuant to the Family Code to provide for the care of his/her child, IHSS may be purchased from a provider other than the parent(s) when no parent is able and available to provide the IHSS services for any of the following reasons, and services must be provided during the inability or unavailability of the parent(s):

.441 When the parent(s) is unavailable because of employment or is enrolled in an educational or vocational training program.

.442 If the parent(s) is physically or mentally unable to provide the needed IHSS services.

.443 When the parent is unavailable because of on-going medical, dental or other health-related treatment.

.444 When the parent(s) must be unavailable to perform shopping and errands essential to the family, search for employment, or for essential purposes related to the care of the recipient's minor siblings, IHSS may be purchased from a provider other than the parent(s) for up to eight hours per week to perform IHSS tasks necessary during the unavailability of the parent(s).

.45 When the recipient is under eighteen years of age and is living with the recipient's parent(s), who has a legal duty under the Family Code to provide for the care of his/her child, the IHSS specified in Section 30-763.456 may be purchased from a parent under the following condition:

.451 The parent has left full-time employment or is prevented from obtaining full-time employment because no other suitable provider is available and the inability of the parent to perform supportive services may result in inappropriate placement or inadequate care.

(a) For the purposes of this section, full-time employment means working an average of 40 or more hours per week regardless of worksite location. A parent providing IHSS-funded care to his/her own child is not full-time employment.

.452 For the purposes of Section 30-763.451, a suitable provider is any person who is willing, able, and available to provide the needed IHSS. A suitable provider who is a person having a duty pursuant to the Family Code need only be able and available to provide the needed IHSS; the person is only considered to be unavailable if that unavailability occurs during a time the recipient must receive a specific service, for the following reasons: employment, enrollment in an educational or vocational training program, or employment searches.

30-763 SERVICE AUTHORIZATION (Continued) **30-763**

HANDBOOK BEGINS HERE

.453 Example: Both parents are employed full-time. Their minor child is eligible to receive IHSS. One parent leaves his full-time job in order to provide IHSS to the child; the other parent retains full-time employment. If the other requirements in Section 30-763.451 are met, IHSS may be purchased from the parent who left his job since he left full-time employment to provide IHSS to the child.

.454 Example: When one parent is employed full-time and the other parent, who has never been employed, is at home, able and available to provide IHSS.

(a) When the employed parent left his/her job to provide IHSS to his/her child, IHSS could not be purchased from that parent since the conditions pursuant to Section 30-763.451 are not met because the other parent is a suitable provider.

(b) When the employed parent did not leave full-time employment, the non-working parent may qualify as a paid provider only if that parent is prevented from obtaining full-time employment in order to provide IHSS to the child and other requirements pursuant to Section 30-763.451 are met. When the non-working parent cannot be employed full-time for reasons other than the need to provide IHSS to the child, the non-working parent does not qualify as a paid provider.

HANDBOOK ENDS HERE

.455 A parent provider who meets the requirements in Section 30-763.451 shall be paid for performing authorized services regardless of the presence of the other parent in the home, including non-work hours, weekends, and holidays.

.456 The IHSS provided shall be limited to:

(a) Related services, as specified in Section 30-757.13.

(b) Personal care services, as specified in Section 30- 757.14.

(c) Accompaniment when needed during necessary travel to health-related appointments or to alternative resource sites, as specified in Section 30 757.15.

(d) Protective supervision, as specified in Section 30-757.17, limited to protective supervision needed because of the functional limitations of the recipient. This service shall not include routine child care or supervision.

(e) Paramedical services, as specified in Section 30-757.19.

30-763 SERVICE AUTHORIZATION (Continued) **30-763**

.457 A recipient's parent(s) is not eligible to be an IHSS provider to his/her minor child under the Personal Care Services Program pursuant to Welfare and Institutions Code section 14132.95(f).

.46 When the recipient is a parent living with his/her child(ren) who is under fourteen years of age and who is not eligible or does not need IHSS.

.461 The recipient's need for domestic and heavy cleaning services in common living areas, and for related services shall be assessed as if the child(ren) did not live in the home.

.462 The child(ren)'s needs shall not be considered when assessing the need for services, including domestic or heavy cleaning in areas used solely by the child(ren).

.47 Live-in Providers:

.471 Domestic and heavy cleaning services shall not be provided in areas used solely by the provider. The need for related services may be prorated between the provider and the recipient, if the provider and the recipient agree. All other services shall be assessed based on the recipient's individual need, except as provided in Sections 30-763.33 and .34.

.5 Having estimated the need according to Sections 30-763.1 and .2, and after making the adjustments identified in Sections 30-763.3 and .4 as appropriate, the remaining list of services and hours per service is the total need for IHSS services.

.6 Identification of Available Alternative Resources

.61 Social services staff shall explore alternative in-home services supportive services which may be available from other agencies or programs to meet the needs of the recipient as assessed in accordance with Section 30-761.26.

.611 Social services staff shall arrange for the delivery of such alternative resources as necessary in lieu of IHSS program-funded services when they are available and result in no cost to the IHSS program or the recipient except as provided in Section 30-763.613.

IHSS PROGRAM CATEGORIES

Program Title	Characteristics	Payment Source
CFCO **2K**	All CFCO participants must be eligible for Full-Scope, Federal Financial Participation (FS FFP) Medi-Cal [as in the Personal Care Services Program (PCSP) and IHSS Plus Option (IPO) programs], and meet CFCO Nursing Facility Level Of Care (NF LOC) eligibility.	Federal, State, and County Hours max 283
IHSS Plus Option (IPO) **2L**	Covers consumers who are eligible for Full Scope Federal Financial Participation (FFP) Medi-Cal, but not eligible for Personal Care Services (PCSP) due to one or more of the following: • Consumer has a spouse for a provider; **or** • Consumer is a minor child with a parent for a provider; **or** • Consumer receives Advance Pay; **or** • Consumer receives Restaurant Meal Allowance.	Federal, State, and County Hours max 195 for NSI **Note**: IPO services are eligible for FFP as a Section 1915(j) State Plan Option.
Personal Care Services Program (PCSP) **2M**	Covers consumers who are eligible for Full Scope FFP Medi-Cal. Services include: Domestic and Related Services, Personal Care Services, Protective Supervision, Heavy Cleaning, Transportation, Yard Hazard Abatement, and Paramedical. **Note**: If one of the four IPO conditions listed above exists, the case would be an IPO case rather than PCSP. If the consumer is not eligible for FFP Medi-Cal, the consumer would be in the Residual Program.	Federal, State, and County Hours max 283 **Note:** Cases with Protective Supervision and cases with only Domestic and Related Services were added to the PCSP Program in 2004.
Residual Program **2N**	Covers consumers who are not eligible for Full Scope FFP Medi-Cal and who meet the IHSS eligibility criteria (MPP 30-755).	State and County Hours max 195 for NSI and 283 for SI

COMMUNITY FIRST CHOICE OPTION (CFCO)
ELIGIBILITY CRITERIA

All CFCO participants must be eligible for Full-Scope, Federal Financial Participation (FS FFP) Medi-Cal [as in the Personal Care Services Program (PCSP) and IHSS Plus Option (IPO) programs], and meet CFCO Nursing Facility Level Of Care (NF LOC) eligibility based on one of the following criteria:

1. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) of 195 or more IHSS hours per month.
2. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) under 195 IHSS hours per month and:
    - Have 3 or more of the following services with the designated Functional Index (FI) Ranks:
        - Eating, FI Rank of 3-6
        - Bowel and bladder, FI Rank of 3-6
        - Menstrual care, FI Rank of 3-6
        - Bathing/grooming, FI Rank of 4-5
        - Dressing, FI Rank of 4-5
        - Mobility inside, FI Rank of 4-5
        - Transferring, FI Rank of 4-5
        - Respiration, FI Rank of 5-6
        - Paramedical, (FI Rank not applicable)

      OR
    - Have a combined FI Rank of 6 or higher in mental functioning (memory, orientation, and judgment)
3. Have an impairment level of "Severely Impaired" (SI). A recipient is deemed SI when he/she has a combined "Individual Assessed Need" of 20 hours or more per week in one or more of the following services:
        - Preparation of meals
        - Meal clean-up (if preparation of meals and feeding are assessed needs)
        - Respiration
        - Bowel and bladder care
        - Feeding
        - Routine bed baths
        - Dressing
        - Menstrual care
        - Ambulation
        - Transfer
        - Bathing, oral hygiene, grooming
        - Repositioning and rubbing skin
        - Care and assistance with prosthesis
        - Paramedical services

The above criteria were developed by the Department of Health Care Services (DHCS) in consultation with the California Department of Social Services (CDSS).

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757
(Continued)

.198 In no event shall paramedical services be authorized prior to receipt by social services staff of the order for such services by the licensed health care professional. However, the cost of paramedical services received may be reimbursed retroactively provided that they are consistent with the subsequent authorization and were received on or after the date of application for the paramedical services.

NOTE: Authority cited: Sections 10553, 10554, 12300, 12301.1 and 12301.21, Welfare and Institutions Code; and Chapter 939, Statutes of 1992. Reference: Peremptory Writ of Mandate, Disabled Rights Union v. Woods, Superior Court, Los Angeles County, Case #C 380047; Miller v. Woods/Community Services for the Disabled v. Woods, Superior Court, San Diego County, Case Numbers 468192 and 472068; and Sections 12300, 12300(c)(7), 12300(f), 12300(g), 12300.1, and 12301.2, Welfare and Institutions Code.

30-758 TIME PER TASK AND FREQUENCY GUIDELINES 30-758

Repealed by Manual letter No. SS-06-02, effective 9/1/06

NOTE: Authority cited: Sections 10553, 10554, 12300, and 12301.2, Welfare and Institutions Code; and Chapter 939, Statutes of 1992. Reference: Peremptory Writ of Mandate, Disabled Rights Union v. Woods, Superior Court, Los Angeles County, Case #C 380047; and Sections 12300, and 12301.2, Welfare and Institutions Code.

30-759 APPLICATION PROCESS 30-759

.1 Each request or application for services shall have been made in accordance with Section 30-009.22.

.11 Recipient information including ethnicity and primary language (including sign language) shall be collected and recorded in the case file.

.2 Applications shall be processed, including eligibility determination and needs assessment, and notice of action mailed no later than 30 days following the date the written application is completed. An exception may be made for this requirement when a disability determination in accordance with Section 30-771 has not been received in the 30-day period. Services shall be provided, or arrangements for their provision shall have been made, within 15 days after an approval notice of action is mailed.

.3 Pending final determination, a person may be considered blind or disabled for purposes of non-PCSP IHSS eligibility under the following conditions:

.31 For a disabled applicant, eligibility may be presumed if the applicant is not employed and has no expectation of employment within the next 45 days, and if in the county's judgment the person appears to have a mental or physical impairment that will last for at least one year or end in death.

.32 For a blind applicant, eligibility may be presumed if in the county's judgment the person appears to meet the requirements of Section 30-771.2.

20CFR§ 416.934
PRESUMPTIVE DISABILITY
FOR MEDI-CAL

§ 416.934 Impairments which may warrant a finding of presumptive disability or presumptive blindness.

We may make findings of presumptive disability and presumptive blindness in specific impairment categories without obtaining any medical evidence. These specific impairment categories are—

(a) Amputation of a leg at the hip;

(b) Allegation of total deafness;

(c) Allegation of total blindness;

(d) Allegation of bed confinement or immobility without a wheelchair, walker, or crutches, due to a longstanding condition, excluding recent accident and recent surgery;

(e) Allegation of a stroke (cerebral vascular accident) more than 3 months in the past and continued marked difficulty in walking or using a hand or arm;

(f) Allegation of cerebral palsy, muscular dystrophy or muscle atrophy and marked difficulty in walking (e.g., use of braces), speaking, or coordination of the hands or arms.

(g) Allegation of Down syndrome.

(h) Allegation of severe mental deficiency made by another individual filing on behalf of a claimant who is at least 7 years of age. For example, a mother filing for benefits for her child states that the child attends (or attended) a special school, or special classes in school, because of mental deficiency or is unable to attend any type of school (or if beyond school age, was unable to attend), and requires care and supervision of routine daily activities.

(i) Allegation of amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease).

[45 FR 55621, Aug. 20, 1980, as amended at 50 FR 5574, Feb. 11, 1985; 53 FR 3741, Feb. 9, 1988; 56 FR 65684, Dec. 18, 1991; 67 FR 58046, Nov. 19, 2001; 68 FR 51693, Aug. 28, 2003]

CHILDREN'S CASES (MPP §30-763.4-.457)

PROGRAM TYPES			
IHSS-RESIDUAL (IHSS-R) 2N	**IHSS Plus Option (IPO) 2L**	**Personal Care Services Program (PCSP) 2M**	**Community First Choice Options (CFCO) 2K**
• If case is not eligible for CFCO, PCSP or IPO then check for IHSS-R eligibility • Some reasons for IHSS-R eligibility include: o a child is eligible for Medi-Cal through a State-only, non-FFP Medi-Cal program o Adoption Assistance Program (AAP). This type of case can either be State-only (aid code 04) or Federal-only (aid code 03 FFP). • Hours are limited to 195 NSI or 283 SI If the Share of Cost (SOC) exceeds services for an IHSS-R case then we would deny IHSS.	• Has a limit of 195 for NSI and 283 for SI • Has either: – a Parent Provider – Restaurant Meal Allowance or – Advance Pay • Children make up less than 1% of the IPO population • Does not meet criteria for CFCO (Parent defined as natural or adoptive)	• Receives full- scope FFP Medi-Cal • DOES NOT have: – a Parent-Provider – Does not receive Restaurant Meal Allowance – Does not receive Advance Pay • **Does not meet criteria for CFCO** • Hours max 283 (Parent defined as natural or adoptive)	All CFCO participants must be eligible for full-scope, Federal Financial Participation (FFP) Medi-Cal, and meet CFCO Nursing Facility Level of Care eligibility based on one of the following criteria: 1. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) of 195 or more IHSS hours per month. 2. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) under 195 IHSS hours per month and: • Have 3 or more of the following services with the designated Functional Index (FI) Ranks: o Eating, FI Rank of 3-6 o Bowel and bladder, FI Rank of 3-6 o Menstrual care, FI Rank of 3-6 o Bathing/grooming, FI Rank of 4-5 o Dressing, FI Rank of 4-5 o Mobility inside, FI Rank of 4-5 o Transferring, FI Rank of 4-5 o Respiration, FI Rank of 5-6 o Paramedical, (FI Rank not applicable) **OR** • Have a combined FI Rank of 6 or higher in mental functioning (memory, orientation, and judgment) 3. Have an impairment level of "Severely Impaired" (SI). A recipient is deemed SI when he/she has a combined "Individual Assessed Need" of 20 hours or more per week in one or more of the following services: – Preparation of meals – Meal clean-up (if preparation of meals and feeding are assessed needs) – Respiration – Bowel and bladder care – Feeding – Routine bed baths – Dressing – Menstrual care – Ambulation – Transfer – Bathing, oral hygiene, grooming – Repositioning and rubbing skin – Care and assistance with prosthesis – Paramedical services **Most minor cases fall under this program.** Hours max 283

REGULATIONS THAT APPLY

MPP §30-763

.44 When the recipient is under eighteen years of age and is living with the recipient's parent(s), who have a legal duty pursuant to the Family Code to provide for the care of his/her child, IHSS may be purchased from a provider other than the parent(s) when no parent is able and available to provide the IHSS services for any of the following reasons, and services must be provided during the inability and /or unavailability of the parent(s):

.441 When the parent (s) is unavailable because of employment or is enrolled in an educational or vocational training program.

.442 If the parent(s) is physically or mentally unable to provide the needed IHSS services.

.443 When the parent is unavailable because of on-going medical, dental or other health-related treatment.

.444 When the parent (s) must be unavailable to provide shopping and errands essential to the family, search for employment, or for essential purposes related to the care of the recipient's minor siblings, IHSS may be purchased from a provider other than the parent (s) for up to eight hours per week to perform IHSS tasks necessary during the unavailability of the parent(s).

.45 When the recipient is under eighteen years of age and is living with the recipient's parent(s), who have a legal duty under the Family Code to provide for the care of his/her child, the IHSS specified in Section 30-763.456 may be purchased from a parent under the following conditions:

.451 The parent has left full-time employment or is prevented from obtaining full-time employment because no other suitable provider is available and the inability of the parent to perform supportive services may result in inappropriate placement or inadequate care.

(a) For the purpose of this section, full-time employment means working an average of 40 or more hours per week regardless of worksite location. A parent providing IHSS-funded care to his/her own child is not full-time employment.

.452 For the purposes of Section 30-763.451, a suitable provider is any person who is willing, able, and available, to provide the needed IHSS. A suitable provider who is a person having a duty pursuant to the Family Code need only be able and available to provide the needed IHSS; the person is only considered to be unavailable if that unavailability occurs during a time the recipient must receive a specific service, for the following reasons: employment, enrollment in an educational or vocational training program, or employment searches.

.453 Example: Both parents are employed full-time. Their child is eligible to receive IHSS. One parent leaves his full-time job in order to provide IHSS to the child; the other parent retains full-time employment. If the other requirements in Section 30—763.451 are met, IHSS may be purchased from the parent who left his job since he left full-time employment to provide IHSS to the child.

.454 Example: When one parent is employed full-time and the other parent, who has never been employed, is at home, able and available to provide IHSS.

(a) When the employed parent left his/her job to provide IHSS to his/her child, IHSS could not be purchased from that parent since the conditions pursuant to Section 30-763.451 are not met because the other parent is a suitable provider.

(b) When the employed parent did not leave full-time employment, the non-working parent may qualify as a paid provider only if that parent is prevented from obtaining full-time employment in order to provide IHSS to the child and other requirements pursuant to Section 30-763.451 are met. When the non-working parent cannot be employed full-time for reasons other than the need to provide IHSS to the child, the non-working parent does not qualify as a paid provider.

CHILDREN'S CASES (MPP §30-763.4-.457)

.455 A parent provider who meets the requirements in Section 30-763.451 shall be paid for performing authorized services regardless of the presence of the parent in the home, including non-work hours, weekends, and holidays.

.456 The IHSS provided shall be limited to:

- (a) Related services, as specified in Section 30-757.13.
- (b) Personal care services, as specified in Section 30-757.14.
- (c) Accompaniment when needed during necessary travel to health-related appointments or to alternative resource sites as specified in Section 30-757.15.
- (d) Protective Supervision, as specified in Section 30-757.17, limited to protective supervision needed because of the functional limitations of the recipient. This service shall not include routine child care or supervision.
- (e) Paramedical services, as specified in Section 30-757.19.

.457 A recipient's parent(s) is not eligible to be IHSS provider to his/her minor child under the Personal Care Services Program pursuant to Welfare and Institutions Code section 14132.95(f).

CHILDREN'S CASES (MPP §30-763.4-.457)

TIPS

- ✓ Parents have a legal duty pursuant to the Family Code to provide for the care of their child.
- ✓ If a parent works full-time or attends school or vocational rehab or is disabled or receiving on going treatment, then a non-parent provider can be paid.
- ✓ If the parent has left full-time employment or is prevented from obtaining full-time employment because no other suitable provider is available and (parent's choice) the inability of the parent to perform supportive services may result in inappropriate placement or inadequate care the **parent CAN BE PAID.** (Full-time employment means working an average of 40 or more hours per week regardless of worksite location)
- ✓ Up to eight hours per week may be purchased from a provider (other than the parent) to perform IHSS tasks necessary during the unavailability of the parent(s), because the parent(s) are providing shopping and errands essential to the family, searching for employment, or for essential purposes related to the care of the recipient's minor siblings. **(These hours are taken from the already authorized to purchase hours**).
- ✓ Can a parent work out of the home and still be an IPO, CFCO or IHSS - R provider?
  Yes, as long as they are not employed full-time. MPP § 30-763.451(a)
- ✓ A parent provider who meets the requirements in Section 30-763.451, shall be paid for performing authorized services regardless of the presence of a non-provider parent/employed parent in the home, including non-work hours, weekends, and holidays.
- ✓ When the parent is the provider - ALL RULES IN MPP § 30-763.44 concerning the parent's work status and eligibility apply.
- ✓ **When the client is an Institutionally Deemed DDS WAIVER (6v) and (6W) case, a non–parent provider may provide PCSP services EVEN if the parent is in the home.**
- ✓ All cases must meet program criteria for disability. See MPP §30-759.3 for IHSS-R and MPP §30-780.2(b) for CFCO, IPO and PCSP.

What is Institutional Deeming?

- Deeming is defined as “Procedures by which the income and resources of certain relatives, living in the same household as the client, are determined to be available to the client for the purposes of establishing eligibility and share of cost.”

- An individual living in an institution does not have income or resources of a parent or spouse considered in the person’s Med-Cal eligibility determination.

- When consumers on certain Department of Developmental Services (DDS) waivers are “deemed” or considered eligible for institutionalization, (Institutionally Deemed) all income and resources of a parent or spouse are **excluded** by county Medi-Cal when determining their Medi-Cal eligibility and share of cost.

- Through Institutional Deeming, under the DDS Waiver, minor children meeting the criteria above may be determined as Medi-Cal eligible regardless of the parent’s resources or income.

- Institutionally Deemed Cases will have either an aid code 6V indicating no share of cost or an aid code **6W** indicating that there is a share of cost.

- Institutionally Deemed DDS Waiver cases are eligible for Independence Plus Option (IPO), PCSP and CFCO as long as the recipient meets **all** criteria.

- DDS Waiver cases are eligible for Personal Care Services Program (PCSP**) only** if the recipient meets **all** PCSP eligibility requirements. Specifically, the parent of the minor child **may not** be paid as the provider of services in the PCSP. Nor may the case be in advance pay status in the event that the parent is not the provider.

- When the client is an Institutionally Deemed DDS **Waiver case, a non–parent provider may provide PCSP services even if the parent is in the home.**

- Institutionally Deemed persons **may not qualify for IHSS RESIDUAL** program because the income and resources of the parent or spouse must be considered in determining eligibility.

- All cases must meet all other IHSS eligibility requirements before being eligible for services.

Reference: ACL 00-83, ACIN 1-28-06

In-Home Operations
QUICK REFERENCE GUIDE
California Department of Health Care Services
Long-Term Care Division
In-Home Operations (IHO) Branch

WEBSITE:
For general information about In-Home Operations
or to view a copy of IHO's Home and Community Based Waivers

http://www.dhcs.ca.gov/services/Pages/IHO.aspx

E-mail: IHOwaiver@dhcs.ca.gov

IHO BRANCH CONTACT INFORMATION

NORTHERN REGION	SOUTHERN REGION
P.O. Box 997437, MS 4502	311 South Spring Street, Suite 313
Sacramento, CA 95899-7437	Los Angeles, CA 90013
Phone (916) 552-9105	Phone (213) 897-6774
FAX (916) 552-9150	FAX (213) 897-7355
(916) 552-9151	(213) 897-9314

IN-HOME OPERATIONS
QUICK-REFERENCE GUIDE

THIS IS ONLY A REFERENCE GUIDE. PLEASE CALL ABOVE LISTED PHONE NUMBERS FOR ANY CLARIFICATION

HCBS WAIVER SERVICES

Eligibility	Full-scope Medi-Cal eligible and medically eligible beneficiary. Priority enrollment for an applicant who has been authorized for Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services for at least six months prior to his/her 21st birthday who meet medical eligibility criteria; and for an applicant currently in an acute hospital who is eligible for placement in an HCBS Waiver.
Available Services	Home and Community-Based Services (HCBS) waivers are designed to assist in supporting a participant in his/her home as an alternative to care in a licensed health care facility. HCBS waiver services include: Case management, transitional case management; community transition: private duty nursing; family training; environmental accessibility adaptations; waiver personal care; life sustaining medical equipment operation expenses, habilitation; respite care; and personal emergency response systems.
Criteria for Services	HCBS waiver services may be authorized when medically necessary at a cost that is not greater than what may be provided in a licensed health care facility. **These services must be prior authorized.**
Place of Services	The participant's home or community setting.
Service Providers	HCBS waiver services providers include: licensed and certified home health agencies; congregate living facilities; licensed registered nurses; licensed vocational nurses; licensed clinical social workers; marriage & family therapists; licensed psychologists; nonprofit organizations; professional corporations; personal care or employment agencies; and unlicensed caregivers.
Requests for Service	A HCBS Waiver application (available upon request – see contact information including: **website, e-mail, and phone number** on cover page) must be completed and returned to In-Home Operations (IHO).
Required Documentation	Medical records **(Including but not limited to):** Medical information that supports the request for services; assessment and identification of skilled nursing care needs; home safety evaluation; Plan of Treatment (POT) signed by the physician, beneficiary/participant & caregivers; and a TAR requesting the services.

IN-HOME OPERATIONS

In-Home Operations (IHO) is part of the California Department of Health Care Services (DHCS). IHO has statewide responsibility for reviewing and authorizing home and community-services through the Medi-Cal Nursing Facility/Acute Hospital (NF/AH) Waiver.

IHO has two offices in California – the Northern Regional Headquarters office, located in Sacramento, and a Southern Regional office, located in Los Angeles.

The Northern Regional office is responsible for reviewing all new statewide requests for HCBS waiver services. Upon receipt and review of the NF/AH Waiver Application, the request for the NF/AH waiver services is then forwarded to the appropriate regional office for completing the intake process and ongoing administrative case management.

Home and Community-Based Services (HCBS) Waivers

Home- and Community-Based Services (HCBS) waivers are creative alternatives, allowed under federal law, for states participating in Medicaid (Medi-Cal in California), to be implemented in the home or community for certain Medi-Cal beneficiaries to avoid hospitalization or nursing facility placement. HCBS waivers are not part of the Medi-Cal State Plan benefit. Services provided under a waiver are not typically part of the benefit package available under federal Medicaid. California currently has the following seven HCBS waivers: Developmentally Disabled Waiver; Multi-Purpose Senior Services Program Waiver; Acquired Immune Deficiency Syndrome Waiver; Pediatric Palliative Care Waiver; Assisted Living Waiver; In-Home Operations (IHO) Waiver; and the Nursing Facility/Acute Hospital (NF/AH) Waiver.

The authorization and management of IHO and NF/AH waiver services are the responsibility of the IHO Branch. Under IHO, the current facility alternatives for these two HCBS waivers are: Acute Hospital; Adult or Pediatric Sub-Acute; Skilled Nursing Facility (SNF or NF level B); and, Intermediate Care Facility (ICF or NF level A).

Requests for waiver services can come from Medi-Cal providers, associated agencies, beneficiaries, families, friends, or advocates. Requests may be faxed, e-mailed, and telephoned to IHO. Upon receipt of the request for HCBS waiver services, IHO will send an HCBS Waiver application to the individual. Assessment for HCBS waiver services begins upon the receipt of the completed HCBS Waiver application by IHO.

Once a Medi-Cal home program is established for the Medi-Cal waiver participant, medically necessary waiver services are authorized by IHO that will assist the waiver participant in remaining safely at home. Additional Medi-Cal services authorized by IHO when medically appropriate for HCBS Waiver participants include equipment, supplies, therapies, and transportation. For information on these waivers please call (916) 552-9105 or visit our website at: http://www.dhcs.ca.gov/services/Pages/IHO.aspx

Nursing Facility Acute Hospital (NF/AH) Waiver

- Services are subject to prior authorization.
- The NF/AH waiver is designed:

- For a person who has a long-term medical condition(s) and who meet the acute hospital, subacute nursing facility, skilled nursing facility B (skilled) or A (intermediate) level of care with the option of returning to and/or remaining in his/her home or home-like setting in the community in lieu of institutionalization;
- To facilitate a safe and timely transition of medically needy Medi-Cal eligible beneficiaries from a medical facility to his/her home and community; and,
- To offer Medi-Cal eligible beneficiaries who reside in the community but are at risk of being institutionalized within the next 30 days, the option of utilizing NF/AH Waiver services to develop a home program that will assist in safely meeting his/her home medical care needs.

- Participant must be Medi-Cal eligible. This can be established in one of two ways:
  - Community deeming rules/requirements, i.e., the regular financial rules for Medi-Cal eligibility; or,
  - Institutional deeming rules/requirements, i.e., the individual is assessed to be Medi-Cal eligible "as if" he/she were in a long-term care facility.

- Authorized services must be cost-neutral to the Medi-Cal program. This means that the total cost of providing waiver services and all other medically necessary Medi-Cal services to the participant must cost the same or less than the services would cost if incurred by the Medi-Cal program for providing care to the waiver participant in a comparable level facility.

- NF/AH waiver services include: Case management, transitional case management, community transition services, private duty nursing (including shared nursing services); family training; minor environmental accessibility adaptations; personal care services; medical equipment operating expenses; habilitation; respite care; and personal emergency response systems (including installation and testing).

- Services are provided in the participant's home that has been assessed to be a safe environment by an IHO Nurse Evaluator or an IHO designee.

- Services are authorized through appropriate licensed and certified home health agencies; congregate living facilities; licensed registered nurses; licensed vocational nurses; licensed clinical social workers; marriage & family therapists; licensed psychologists; nonprofit organizations; professional corporations; personal care or employment agencies; and unlicensed caregivers.
- Implementation of NF/AH waiver services also involves the active participation of the family and/or primary caregiver in the home care program. Participants must have an identified support network system available to them in the event the HCBS provider of direct care services is not able to provide the total number of hours approved and authorized by IHO. A family member and/or a primary caregiver should be proficient in the tasks necessary to care for the participant at home to ensure care is not interrupted. This proficiency requirement may be satisfied by training, as necessary to safely carry out the plan of treatment and/or by providing direct care to the participant on an ongoing basis. The involvement of the family and/or the primary caregiver helps to ensure a safe home program for the participant.

- Services are prescribed by the participant's community-based primary care physician in accordance with regulations outlined in the CCR, Title 22, Division 3.

ONLINE RESOURCES FOR MEDI-CAL SERVICES

Long-Term Care Division HCBS Waivers and Programs:
http://www.dhcs.ca.gov/services/ltc/Pages/default.aspx

California Code of Regulations, Title 22, Division 3: www.ccr.oal.ca.gov

Medi-Cal Provider Bulletins: www.medi-cal.ca.gov

State Statutes – Health and Safety Code; Welfare and Institutions Code: www.oal.ca.gov

CALIFORNIA CHILDREN'S SERVICES: PROGRAM OVERVIEW

PROGRAM DESCRIPTION

The CCS program provides diagnostic and treatment services, medical case management, and physical and occupational therapy services to children under age 21 with CCS-eligible medical conditions. Examples of CCS-eligible conditions include, but are not limited to, chronic medical conditions such as cystic fibrosis, hemophilia, cerebral palsy, heart disease, cancer, traumatic injuries, and infectious diseases producing major sequelae. CCS also provides medical therapy services that are delivered at public schools.

The CCS program is administered as a partnership between county health departments and the California Department of Health Care Services (DHCS). Currently, approximately 70 percent of CCS-eligible children are also Medi-Cal eligible. The Medi-Cal program reimburses their care. The cost of care for the other 30 percent of children is split equally between CCS Only and CCS Healthy Families. The cost of care for CCS Only is funded equally between the State and counties. The cost of care for CCS Healthy Families is funded 65 percent federal Title XXI, 17.5 percent State, and 17.5 percent county funds.

In addition, Insurance Code Sections 12693.62, 12693.64 and 12693.66, relating to the California's Healthy Families Program, provides that the services authorized by the CCS program to treat a Healthy Families plan's subscriber's CCS-eligible medical condition are excluded from the plan's responsibilities. The participating health plan's responsibility for providing all covered medically necessary health care and case management services changes at the time that CCS eligibility is determined by the CCS program for the plan subscriber. The health plan is still responsible for providing primary care and prevention services not related to the CCS-eligible medical condition to the plan subscriber so long as they are within the Healthy Families program scope of benefits. The health plan also remains responsible for children referred to but not determined to be eligible for the CCS program.

LEGISLATIVE AUTHORITY

Enabling legislation of the CCS program

Health and Safety Code, Section 123800 et seq. is the enabling statute for the CCS program. The explicit legislative intent of the CCS program is to provide necessary medical services for children with CCS medically eligible conditions whose parents are unable to pay for these services, wholly or in part. The statute also requires the DHCS and the county CCS program to seek eligible children by cooperating with local public or private agencies and providers of medical care to bring potentially eligible children to sources of expert diagnosis and treatment.

The CCS program is mandated by the Welfare and Institutions Code and the California Code of Regulations (Title 22, Section 51013) to act as an “agent of Medi-Cal” for Medi-Cal beneficiaries with CCS medically eligible conditions. Medi-Cal is required to refer all CCS-eligible clients to CCS for case management services and authorization for treatment. The statute also requires all CCS applicants who may be eligible for the Medi-Cal program to apply for Medi-Cal.

PROGRAM ADMINISTRATION

In counties with populations greater than 200,000 (independent counties), county staff perform all case management activities for eligible children residing within their county. This includes determining all phases of program eligibility, evaluating needs for specific services, determining the appropriate provider(s), and authorizing for medically necessary care. For counties with populations under 200,000 (dependent counties), the Children's Medical Services (CMS) Branch provides medical case management and eligibility and benefits determination through its regional offices located in Sacramento, San Francisco, and Los Angeles. Dependent counties interact directly with families and make decisions on financial and residential eligibility. Some dependent counties have opted to participate in the Case Management Improvement Project (CMIP) to partner with regional offices in determining medical eligibility and service authorization. The regional offices also provide consultation, technical assistance, and oversight to independent counties, individual CCS paneled providers, hospitals, and the Special Care Centers within their region.

FUNDING DESCRIPTION

The funding source for a county CCS program is a combination of monies appropriated by the county, State General Funds, and the federal government. AB 948, the realignment legislation passed in 1992, mandated that the State and county CCS programs share in the cost of providing specialized medical care and rehabilitation to physically handicapped children through allocations of State General Fund and county monies. The amount of State money available for the CCS program is determined annually through the Budget Act.

Directory of Regional Centers

California has 21 regional centers with more than 40 offices located throughout the state that serve individuals with developmental disabilities and their families.

Regional Centers	Executive Director	Areas Serve
Alta California Regional Center 2241 Harvard Street, Suite 100 Sacramento, CA 95815	**Phil Bonnet** (916) 978-6400	Alpine, Colusa, El Dorado, Nevada, Placer, Sacramento, Sierra, Sutter, Yolo, and Yuba counties
Central Valley Regional Center 4615 North Marty Avenue Fresno, CA 93722-4186	**Robert Riddick** (559) 276-4300	Fresno, Kings, Madera, Mariposa, Merced, and Tulare counties
Eastern Los Angeles Regional Center 1000 South Fremont Alhambra, CA 91802-7916 **Mailing Address:** P.O. Box 7916 Alhambra, CA 91802-7916	**Gloria Wong** (626) 299-4700	Eastern Los Angeles county including the communities of Alhambra and Whittier
Far Northern Regional Center 1900 Churn Creek Road, #319 Redding, CA 96002 **Mailing Address:** P. O. Box 492418 Redding, CA 96049-2418	**Laura Larson** (530) 222-4791	Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity counties
Frank D. Lanterman Regional Center 3303 Wilshire Boulevard, Suite 700 Los Angeles, CA 90010	**Diane Campbell Anand** (213) 383-1300	Central Los Angeles county including Burbank, Glendale, and Pasadena
Golden Gate Regional Center 1355 Market Street, Suite 220 San Francisco, CA 94103	**James Shorter** (415) 546-9222	Marin, San Francisco, and San Mateo counties
Harbor Regional Center 21231 Hawthorne Boulevard Torrance, CA 90503	**Patricia Del Monico** (310) 540-1711	Southern Los Angeles county including Bellflower, Harbor, Long Beach, and Torrance

Inland Regional Center 1365 S. Waterman Ave. San Bernardino, CA 92408 **Mailing Address:** P. O. Box 19037 San Bernardino, CA 92423	**Carol Fitzgibbons** (909) 890-3000	Riverside and San Bernardino counties
Kern Regional Center 3200 North Sillect Avenue Bakersfield, CA 93308	**Duane Law** (661) 327-8531	Inyo, Kern, and Mono counties
North Bay Regional Center 10 Executive Court, Suite A Napa, CA 94558	**Bob Hamilton** (707) 256-1100	Napa, Solano, and Sonoma counties
North Los Angeles County Regional Center 15400 Sherman Way, Suite 170 Van Nuys, CA 91406-4211	**George Stevens** (818) 778-1900	Northern Los Angeles county including San Fernando and Antelope Valleys
Redwood Coast Regional Center 525 Second Street, Suite 300 Eureka, CA 95501	**Clay Jones** (707) 445-0893	Del Norte, Humboldt, Mendocino, and Lake counties
Regional Center of the East Bay 500 Davis Street, Suite 100 San Leandro, CA 94577	**James M. Burton** (510) 618-6100	Alameda and Contra Costa counties
Regional Center of Orange County 1525 North Tustin Avenue Santa Ana, CA 92705	**Larry Landauer** (714) 796-5100	Orange county
San Andreas Regional Center 300 Orchard City Drive, Suite 170 Campbell, CA 95008	**Javier Zaldivar** (408) 374-9960	Monterey, San Benito, Santa Clara, and Santa Cruz counties
San Diego Regional Center 4355 Ruffin Road, Suite 200 San Diego, CA 92123-1648	**Carlos Flores** (858) 576-2996	Imperial and San Diego counties

San Gabriel/Pomona Regional Center 75 Rancho Camino Drive Pomona, CA 91766	**R. Keith Penman** (909) 620-7722	Eastern Los Angeles county including El Monte, Monrovia, Pomona, and Glendora
South Central Los Angeles Regional Center 650 West Adams Boulevard, Suite 200 Los Angeles, CA 90007-2545	**Dexter Henderson** (213) 744-7000	Southern Los Angeles county including the communities of Compton and Gardena
Tri-Counties Regional Center 520 East Montecito Street Santa Barbara, CA 93103-3274	**Omar Noorzad, Ph.D.** (805) 962-7881	San Luis Obispo, Santa Barbara, and Ventura counties
Valley Mountain Regional Center 702 North Aurora Street Stockton, CAÂ 95202	**Paul Billodeau** (209) 473-0951	Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties
Westside Regional Center 5901 Green Valley Circle, Suite 320 Culver City, CA 90230-6953	**Michael Danneker** (310) 258-4000	Western Los Angeles county including the communities of Culver City, Inglewood, and Santa Monica

http://www.dds.ca.gov/RC/RCList.cfm

Updated from website 6/6/14

How do we apply?

Fill out a CCS application and return it to your county CCS office. You can get an application from your county CCS office or download from:
www.dhs.ca.gov/ccs

Fill out your application carefully so CCS will have all the information they need to see if you qualify.

Can a child apply for CCS?

If your child is 18 or older, or an emancipated minor they can apply on their own.

What if I need more information about CCS?

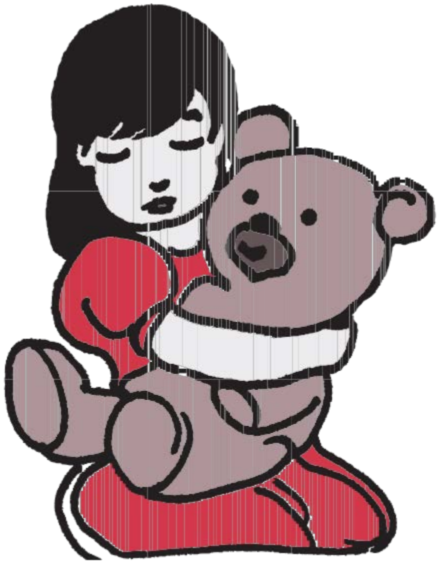
For more information, or help in filling out your application, contact your county CCS office. Find their address and phone number in the government section of your phone book. Look under California Children's Services or County Health Department.

Or, look for your CCS local office at:
www.dhs.ca.gov/ccs

Arnold Schwarzenegger
Governor, State of California

PUB 4 May 2003 English

California Children's Services



Caring for Children with Special Medical Needs

What is California Children's Services (CCS)?

CCS is a state program that helps children with certain diseases, physical limitations, or chronic health problems.

Can our child get CCS?

If you or your child's doctor think that your child has a medical problem that CCS covers, CCS can pay for an exam to see if CCS can cover your child's problem.

If CCS covers your child's problem, CCS pays for or provides services like:

- Doctor visits
- Hospital stays
- Surgery
- Physical and occupational therapy
- Lab tests and X-rays
- Orthopedic appliances and medical equipment.

What else can CCS do for our child?

CCS can manage your child's medical care. This means CCS can get the special doctors and care your child needs.

Sometimes, CCS refers you to other agencies, like public health nursing and regional centers so you can get the services your child needs.

CCS also has a Medical Therapy Program (MTP). MTPs are in public schools and give physical and occupational therapy to eligible children.

Are there other requirements?

To get CCS, your child must:

- Be under 21 years old; and
- Have or may have a medical problem that CCS covers; and
- Be a resident of California; and
- Have a family income under $40,000 (your adjusted gross income on the state tax form).

What if my family's income is more than $40,000?

You can still get CCS if:

- You have Medi-Cal (full scope, no cost);
- You have Healthy Families insurance;
- Your out-of-pocket medical expenses for your child's care is more than 20% of your family income;
- You only want MTP services;
- You need to see a doctor to see if your child is eligible for CCS; or
- You adopted your child with a known medical problem that made them eligible for CCS.

What medical problems does CCS cover?

CCS doesn't cover all problems. CCS covers most problems that are physically disabling or that need to be treated with medicines, surgery, or rehabilitation. There are other factors, too.

CCS covers children with problems like:

- congenital heart disease
- cancers, tumors
- hemophilia, sickle cell anemia
- thyroid problems, diabetes
- serious chronic kidney problems
- liver or intestine diseases
- cleft lip/palate, spina bifida
- hearing loss, cataracts
- cerebral palsy, uncontrolled seizures
- rheumatoid arthritis, muscular dystrophy
- AIDS
- severe head, brain, or spinal cord injuries, severe burns
- problems caused by premature birth
- severely crooked teeth
- broken bones

Can we use any doctor or provider we want?

No. CCS must approve the provider, services and equipment first.

Department of Developmental Services Regional Centers

(Colors correspond to areas served by each Regional Center)

Updated: July 1, 2003

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES

CDSS
WILL LIGHTBOURNE
DIRECTOR

EDMUND G. BROWN JR.
GOVERNOR

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[x] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

August 29, 2014

ALL-COUNTY LETTER NO. 14-60

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: IMPLEMENTATION OF THE COMMUNITY FIRST CHOICE OPTION (CFCO) PROGRAM

REFERENCES: SOCIAL SECURITY ACT (SSA) Section 1915(k) (42 United States Code Section 1396n); WELFARE and INSTITUTIONS CODE (WIC) Section 14132.956; IHSS PROGRAM MANAGERS' LETTER (DECEMBER 2, 2011); COUNTY FISCAL LETTER (CFL) No. 12/13-28 (JANUARY 24, 2013)

This In-Home Supportive Services (IHSS) All-County Letter (ACL) provides counties with additional information regarding implementation of California's CFCO Program.

Background

The federal Patient Protection and Affordable Care Act (ACA) of 2010 (Public Law 111-148) was enacted March 23, 2010 and established CFCO as a new State Plan Option, which allows States to provide Home and Community-Based Attendant Services and Supports.

In December 2011, the California Department of Social Services (CDSS) and the California Department of Health Care Services (DHCS) submitted a State Plan Amendment (SPA) for the CFCO Program to the Centers for Medicare & Medicaid Services (CMS). This SPA allowed California to receive an additional 6% in federal funding for services for CFCO-eligible Personal Care Services Program (PCSP) and IHSS Plus Option (IPO) program recipients, who were moved into CFCO, and for new CFCO-eligible applicants. This initial CFCO SPA was approved by CMS on August 31, 2012, retroactive to December 1, 2011.

The initial SPA was based on the *draft* CFCO federal regulations and was approved with the understanding that a new SPA would be submitted for approval to include

Nursing Facility Level of Care (NF LOC) eligibility criteria as required, per the final CFCO regulations. The new CFCO SPA was approved by CMS on July 31, 2013, with an effective date of July 1, 2013.

California was the first state in the nation to receive approval for implementing the CFCO Program. With this addition, California now operates four IHSS programs: IHSS-Residual (IHSS-R), PCSP, IPO and CFCO.

Development and Implementation Council
As required by 42 Code of Federal Regulations (CFR) Section 441.575 and WIC Section 14132.956, CDSS established a Development and Implementation Council (Council) to collaborate on the implementation of CFCO. The Council is composed of elders and individuals with disabilities, their representatives, and other stakeholders. CDSS, DHCS, and the Council worked together to develop both CFCO SPAs to implement CFCO services and supports. The counties will be notified of any further Council meetings necessary to provide updates on the status of CFCO implementation.

CFCO Eligibility
All CFCO participants must be eligible for Full-Scope, Federal Financial Participation (FS FFP) Medi-Cal (as in the PCSP and the IPO programs), and meet CFCO NF LOC eligibility based on one of the following criteria:

1. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) of 195 or more IHSS hours per month.

2. Have a total assessed need (excluding heavy cleaning and yard hazard abatement) under 195 IHSS hours per month and:

    - Have 3 or more of the following services with the designated Functional Index (FI) Ranks:
        - Eating, FI Rank of 3-6
        - Bowel and bladder/menstrual care, FI Rank of 3-6
        - Bathing/grooming, FI Rank of 4-5
        - Dressing, FI Rank of 4-5
        - Mobility inside, FI Rank of 4-5
        - Transfer, FI Rank of 4-5
        - Respiration, FI Rank of 5-6
        - Paramedical, (FI Rank not applicable)

    OR

- Have a combined FI Rank of 6 or higher in mental functioning (memory, orientation, and judgment). FI Ranks for mental functioning can be either 1, 2, or 5.

3. Have a combined “Individual Assessed Need” total of 20 hours or more per week in one or more of the following services:

    - Preparation of meals
    - Meal clean-up (if preparation of meals and feeding are assessed needs)
    - Respiration
    - Bowel and bladder care
    - Feeding
    - Routine bed baths
    - Dressing
    - Menstrual care
    - Ambulation
    - Transfer
    - Bathing, oral hygiene, grooming
    - Repositioning and rubbing skin
    - Care and assistance with prosthesis
    - Paramedical services

The above NF LOC criteria were developed by DHCS in consultation with CDSS.

The new CFCO eligibility requirements are more stringent than those in effect from December 1, 2011 through June 30, 2013; therefore, individuals with FS FFP Medi-Cal eligibility who were, but are no longer, eligible for CFCO, due to the NF LOC criteria, will be served in the PCSP or IPO programs, effective July 1, 2013.

Please note that, as in the IPO program, recipients in CFCO may also receive Restaurant Meal Allowance, Advance Pay, service(s) provided by a recipient’s spouse, and service(s) provided by a minor recipient’s parent.

Required Services in CFCO

The four required services in CFCO are:

1. Assistance with Activities of Daily Living (ADLs), Instrumental Activities of Daily Living (IADLs), and health-related tasks, which currently include:

    - Personal Care Services
    - Protective Supervision
    - Domestic and Related Services

- Paramedical Services
- Medical Accompaniment
- Heavy Cleaning
- Yard Hazard Abatement

2. Acquisition, maintenance, and enhancement of skills necessary for recipients to perform ADLs, IADLs, and health-related tasks:

    - This service is provided via the IHSS Teaching and Demonstration Service, as described in Manual of Policies and Procedures (MPP) Section 30-757.18. This regulation section contains all the information regarding the Teaching and Demonstration service currently available. (Previously, only IHSS-R recipients were eligible for the Teaching and Demonstration Service.)

    - A recipient training handbook addressing "Teaching and Demonstration" is available online at the IHSS Consumer/Recipient Resources webpage at: http://www.cdss.ca.gov/agedblinddisabled/res/FactSheets/IHSS_Teaching_and_Demonstration_Color.pdf

3. Back-up Systems to ensure continuity of services and supports:

    The back-up system requirements are being met through the use of the Individualized Back-up Plan and Risk Assessment process for all CFCO recipients.

    - Effective December 1, 2011, form SOC 864 (IHSS Program Individualized Back-up Plan and Risk Assessment) is a required form for use during assessments and reassessments. Please refer to the IHSS Program Managers' Letter, dated December 2, 2011, at: http://www.cdss.ca.gov/agedblinddisabled/res/pdf/CFCO-FINAL%20PM's%20Letter%20(12-2-11).pdf

        - Please note form SOC 864 is now automated in the Case Management, Information and Payrolling System (CMIPS) II.

4. Voluntary Recipient Training on Managing Care Providers:

    - Recipients may choose to receive training on how to manage their care providers. Training options include:

- A recipient training handbook available online at the IHSS Consumer/Recipient Resources webpage: http://www.cdss.ca.gov/agedblinddisabled/res/2011_IHSS_Consumer_Training_HB_v2.pdf

- Recipient education videos located at the link below. These videos address how an IHSS consumer/recipient may hire a care provider and includes tips on how to find, interview, and select a care provider. http://www.cdss.ca.gov/agedblinddisabled/PG3154.htm

Although CFCO regulations allow States to provide permissible services and supports, such as expenditures for transition costs, California did not elect to include permissible services.

6% in Federal Medical Assistance Percentage (FMAP)
As previously stated in this ACL, the federal ACA provides an additional 6% in FMAP for CFCO Home and Community-Based Attendant Services and Supports. The required CFCO services eligible for the enhanced FMAP are: (1) assistance with ADLs, IADLs, and health-related tasks and (2) acquisition, maintenance, and enhancement of skills necessary for recipients to perform ADLs, IADLs, and health-related tasks.

The 6% in FMAP was retroactive to December 1, 2011. Counties received their portion of the enhanced FMAP for the period December 1, 2011 through June 30, 2012. After June 30, 2012, the counties' portion of the additional 6% in FMAP was factored into the calculation of the County Maintenance of Effort (MOE). Please see CFL No. 12/13-28 for additional details.

http://www.cdss.ca.gov/lettersnotices/EntRes/getinfo/cfl/2012-13/12-13_28.pdf

Systems and New Aid Code
As a newly established IHSS program, CFCO was assigned the Medi-Cal Secondary Aid Code of 2K in CMIPS II. CMIPS II programming of this Aid Code is expected to be completed by September 1, 2014. Prior to that, CFCO recipients will receive services under CFCO, but will continue to be identified in the system as either a PCSP (Aid Code 2M) or IPO (Aid Code 2L) case.

Effective September 1, 2014, as the movement of IPO recipients into CFCO is completed, those recipients who are considered Non-Severely Impaired (NSI) and receive protective supervision, will be eligible for 195 hours of protective supervision, plus hours for other services, up to a maximum of 283 hours per month.

Quality Assurance (QA)

The CFCO SPA resulted in two notable changes to existing QA requirements for all IHSS programs:

County Annual Quality Assurance/Quality Improvement (QA/QI) Plans:

- The static (i.e. unchanged) data formerly reported in the QA/QI Plans will instead now only be included in county Policies and Procedures (P&P). The CFCO SPA reflects the requirement to review county P&P for that information, in addition to reviewing the QA/QI Plan. Please refer to ACL No. 13-105 (Updated Guidance on County Submission of Annual QA/QI Improvement Plans) for further details.

QA Sample Size

- Previously, county QA was required to conduct 250 desk reviews per allocated QA position every year, with a subset of 50 also receiving home visits. The new methodology results in significantly reduced workloads for counties, while still providing for the review of a representative sample of each county's IHSS caseload, statistically valid to within appropriate parameters.

<u>SOC 824</u>

On a quarterly basis, counties report IHSS program-specific data on form SOC 824 (IHSS QA/QI Quarterly Activities Report), which now includes fields for CFCO program data. Prior to the September 1, 2014 implementation of the CFCO 2K Aid Code, we request that counties enter "0" in the CFCO data columns, as there is no other automated means to capture this data. Beginning September 1, 2014, counties will enter CFCO data on form SOC 824 based on cases with a 2K Aid Code.

For questions regarding this ACL, please contact the Adult Programs Policy and Operations Bureau at (916) 651-5350.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

c: CWDA
Department of Health Care Services

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY ARNOLD SCHWARZENEGGER, Governor

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

April 11, 2006

ALL-COUNTY INFORMATION NOTICE NO. I-28-06

TO: ALL-COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

<u>REASON</u> <u>FOR</u> <u>THIS</u> <u>TRANSMITTAL</u>

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[x] Initiated by CDSS

SUBJECT: IN-HOME SUPPORTIVE SERVICES (IHSS) - QUESTIONS AND ANSWERS REGARDING ELIGIBILITY AND ASSESSMENT

This All-County Information Notice provides counties with additional information regarding IHSS eligibility and assessment eligibility.

If you have any questions, please contact Jan Howland, Manager, IHSS Plus Waiver Unit, Adult Programs Branch at (916) 229-4044.

Sincerely,

JOSEPH M. CARLIN
Acting Deputy Director
Disability and Adult Programs Division

Attachment

This All-County Information Notice (ACIN) is to provide counties with additional instructions regarding eligibility and assessment under the In-Home Supportive Services (IHSS) Plus Waiver (IPW).

GENERAL PROGRAM QUESTIONS

Question 1: In how many Medi-Cal Waivers may an IPW recipient participate?

Answer: The IPW is a Demonstration Project Waiver under Section 1115 of the Social Security Act. A recipient may concurrently participate in one Section 1115 Waiver and in one of several Section1915 Waivers. However, a recipient may not concurrently participate in two Waivers under the Section 1115 authority. The other two Section 1115 Waivers managed by the Department of Health Services are:

- Family Planning, Access, Care and Treatment program which allows federal reimbursement for reproductive health services for medically indigent females and males.
- Senior Care Action Network which provides social and health services to persons age 65 and over and is designed to keep functionally impaired older people living at home as long as possible.

Question 2: Who will remain in the IHSS-Residual (IHSS-R) program? Will these recipients receive State only Medi-Cal?

Answer: Recipients who remain in the IHSS-R program are those who have been determined eligible for IHSS-R services, but who are not eligible for federally funded full-scope Medi-Cal, such as non-citizens under the five year ban. Recipients in the IHSS-R program are eligible for Medi-Cal only if they have had a Medi-Cal eligibility determination by a Medi-Cal eligibility worker and meet Medi-Cal eligibility criteria for coverage under one of the Medi-Cal programs appropriate for their status.

Question 3: Which cases will be automatically moved into the IPW?

Answer: IHSS-R recipients who are eligible for federally funded, full scope Medi-Cal and who meet the IPW criteria were moved automatically into the IPW when the first phase of Case Management, Information and Payrolling System (CMIPS) enhancements were completed on February 27, 2006.

PARENT PROVIDERS

Question 4: Has the Welfare and Institutional Code (W&IC) been amended to allow spouses and/or parents of minor children to provide services under Medi-Cal?

Answer: Yes, W&IC Section 14132.951 was added to allow implementation of the IPW, which allows spouses of minor children to provide in-home care services.

Question 5: Will all services fall under the IPW when the recipient is under 18 years of age, and in-home care services are provided by both parent(s) and non-parent(s)?

Answer: Yes, When both parents and non-parents provide any services in which the child has an authorized need, all services provided fall under the IPW. Parent providers must meet the criteria in Manual Policy and Procedures (MPP) 30-763.45. When services are provided by a non-parent provider only, the case qualifies as an IPW only if the case meets another IPW eligibility criteria, i.e., the child receives Advance Payment or Restaurant Meal Allowance. When the minor recipient is living with a parent(s), a non-parent provider can provide IHSS when the criteria in MPP 30-763.44 is met.

Note: All services authorized for minors, regardless if performed by a parent or non-parent provider, must be assessed based on their disability, not their age (WIC)12300(a).

Question 6: Can a parent work out of the home and still be an IPW provider?

Answer: Yes, as long as they are not working full-time. MPP 30-763.451(a) requires that to be a paid provider, the parent has left full-time employment or is prevented from obtaining full-time employment because of the need to provide in home supportive services to the child.

Question 7: If a recipient is currently receiving services under the IHSS-R because they have a parent or spouse provider, or received Advance Pay or Restaurant Meal Allowance, will they be moved into the IPW?

Answer: Recipients previously receiving services in the IHSS-R, or both IHSS-R and Personal Care Services Program (PCSP) (previously designated as split cases), were moved automatically by CMIPS to the IPW on February 27, 2006 if they receive advance pay, restaurant meal allowance, or have a parent or spouse provider. There are no longer split cases. Medi-Cal does not allow services to be provided by a parent or spouse, nor receipt of Advance Pay or Restaurant Meal Allowance, under PCSP.

Question 8: Can two parents who both work full-time be paid for services in the IPW during the hours they are home in the morning and evening?

Answer: No, two parents both working full-time cannot be paid providers for their minor children under the IPW. In order for parents to be paid providers, they must meet the criteria in MPP 30-763.45. MPP 30-763.451(a) requires that the parent has left full-time employment or is prevented from obtaining full-time employment because of the need to provide IHSS to the child.

Question 9: Is Protective Supervision available for IPW cases, and what rules apply?

Answer: Yes, Protective Supervision is available in the IPW for anyone who is determined eligible for Protective Supervision and who meets IPW criteria: Restaurant Meal Allowance, Advance Pay, or has a parent or spouse as a provider. However, the criteria in MPP 30-757.171 and 30-757.172 must be met.

INSTITUTIONAL DEEMING WAIVER

Question 10: Are Institutional Deeming (ID) Department of Developmental Services (DDS) Waiver cases, which are currently served in PCSP, eligible for the IPW?

Answer: Yes, ID Waiver recipients are eligible for the IPW as long as the recipient meets all IPW eligibility criteria. ID Waiver cases were previously served in the PCSP, as PCSP is a Medi-Cal benefit. With the implementation of the IPW (also a Medi-Cal benefit) on August 1, 2004, these cases may now be covered under either PCSP or the IPW, depending on the eligibility criteria. If ID Waiver cases meet IPW criteria (i.e. parent or spouse provider, receives advance pay or restaurant meal allowance), then the case would be served under the IPW. Spouses and parents of minor children, therefore, can be paid provides under the IPW, regardless of how the recipient qualified for federally funded full-scope Medi-Cal.

Question 11: Can parents of minor children whose Medi-Cal eligibility is through the ID Waiver provide Protective Supervision under the IPW?

Answer: Yes, parents of minor children whose Medi-Cal eligibility is through the ID Waiver are eligible to provide all authorized services, including Protective Supervision under the IPW. To clarify, persons whose Medi-Cal eligibility is through the ID Waiver are eligible to receive Protective Supervision under PCSP also, as long as the parent or spouse are not the provider.

Question 12: Can a non-parent provider provide services under PCSP to an ID Waiver child even if the parent is present in the home?

Answer: Yes, per All-County Letter (ACL) 00-83 under the Assessment Section (page 4), when the recipient is an ID Waiver child, a non-parent provider may provide services under PCSP even if the parent is present in the home.

Question 13: Can a non-parent provider provide services under IPW to an ID Waiver child even if the parent is present in the home?

Answer: No, MPP 30-763.44 states that a non-parent provider can be paid when the parent cannot be present because of employment, education, training, or ongoing medical or health related treatment. However MPP 30-763.44 also allows for an exception when the parent is physically or mentally unable to perform services.

For additional information on PCSP, please see ACL 00-83 on the DDS Home and Community Based Services Waiver-Determining Eligibility for the PCSP.

RESPITE CARE

Question 14: Is “respite care” offered under the IPW?

Answer: Yes, up to 8 hours of services a week, supplied by a provider other than the parent, may be authorized under the IPW for periods when the parent(s) must be absent from the home. The absence from the home must be to perform shopping and errands essential to the family or for essential purposes related to the care of the recipient’s siblings who are minors, per MPP 30-763.444.

MAXIMUM HOURS FOR IHSS-R, PCSP AND IPW, INCLUDING PROTECTIVE SUPERVISION

Question 15: What are the maximum hours allowed under the three IHSS programs, including hours that may be authorized for protective supervision?

Answer:

IHSS-R:

1. Non-Severely Impaired (NSI) recipients may receive up to a total of 195 hours, including any needed protective supervision. [WIC 12303.4(a), MPP 30-765.12].
   - The entire 195 hours can be for protective supervision if no other needed services are paid for by IHSS.*

2. Severely Impaired (SI) recipients may receive up to a total of 283 hours, including any needed protective supervision. [WIC 12303.4(b), MPP 30-765.11].
   - The entire 283 hours can be for protective supervision if no other needed services are paid for by IHSS.*

PCSP:

Under PCSP, there is no NSI/SI distinction; all cases are eligible for a maximum of 283 hours.

1. NSI recipients may receive up to a total of 283 hours. [WIC 14132.95(g)]. If the case meets IHSS-R NSI criteria, only up to 195 hours can be authorized for protective supervision.
   - If 195 hours are authorized for protective supervision, the remaining service needs may be authorized, up to a maximum of 283 hours, for other PCSP services.

2. SI recipients may receive up to a total of 283 hours. [WIC 14132.95(g)].
   - If the case meets IHSS-R SI criteria, the entire 283 hours can be for protective supervision.*

IPW (same as IHSS-R):

1. NSI recipients may receive up to a total of 195 hours, including any needed protective supervision. [WIC 12303.4(a), MPP 30-765.12].
   - The entire 195 hours can be for protective supervision if no other needed services are paid for by IHSS.*

2. SI recipients may receive up to a total of 283 hours, including any needed protective supervision. [WIC 12303.4(b), MPP 30-765.11].
   - The entire 283 hours can be for protective supervision if no other needed services are paid for by IHSS.*

*Although unlikely, this can occur; the 20 hours or more per week assessed in specified areas as required in the SI definition [MPP 30-701(s)(1)], could be provided as an alternative resource.

Clarification:

- There are no longer any split cases. If any of the elements of an IPW case are present, the entire case is an IPW case. (See ACL 05-05, the IPW Waiver Application and associated documents that support the IPW budget neutrality methodology.)
- If a recipient's hours are reduced as a result of moving from PCSP to IPW, counties must adjust their hours are reduced as a result of moving from PCSP to IPW, counties must adjust their hours in CMIPS which will generate a 10-day Notice of Action to the recipient. Because the IPW follows IHSS-R rules, recipients who are authorized for NSI will have fewer maximum hours available.

SHARE OF COST CALCULATIONS

There is no need for an IHSS county staff to calculate an IHSS Share of Cost (SOC) if the case is a zero SOC Medi-Cal case. The Medical eligibility worker will advise the IHSS county staff if there is a change or elimination of the SOC. California Department of Health Services and California Department of Social Services leave it up to county discretion regarding how to communicate this information between the two agencies.

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY GRAY DAVIS, Governor

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

December 7, 2000

ALL-COUNTY LETTER NO. 00-83

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[X] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[X] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

SUBJECT: **THE DEPARTMENT OF DEVELOPMENTAL SERVICES (DDS) HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER – DETERMINING ELIGIBILITY FOR THE PERSONAL CARE SERVICES PROGRAM**

Assembly Bill 2779, Chapter 329, Statutes of 1998, amended the Welfare and Institutions Code Section 14132.95, and the Department of Health Services received approval of a state plan amendment, to allow the provision of Personal Care Services as a covered benefit to medically needy aged, blind, or disabled persons. The purpose of this All County Letter is to inform counties of this change in statute and to provide counties with instructions on evaluating medically needy, Regional Center consumers, who are in the Department of Developmental Services Home and Community-Based Services Waiver (DDS Waiver), for Personal Care Services Program (PCSP) eligibility.

Background

Institutionally deemed children who are approved for the DDS Waiver are those who are under the age of eighteen, living at home, not currently eligible for zero share-of-cost Medi-Cal and who meet the target criteria set forth in the DDS Waiver. Children are evaluated as if they are institutionalized, so institutional deeming rules apply to them. Through institutional deeming, under the DDS Waiver, children meeting the criteria above may be determined as Medi-Cal eligible regardless of their parent's resources or income. The Department of Developmental Services estimates this population to consist of approximately 1300 cases. A list of Regional Center contacts and the areas each center serves is attached. (See Attachment I & II)

The Health Care Financing Administration has recently approved full expansion for six regional centers (Eastern Los Angeles, North Bay, Valley Mountain, Westside, Alta

California, and Kern). Full expansion is expected to occur within other regional centers by the end of the year. Regional Centers that have been federally approved for full expansion may also enroll institutionally deemed persons age eighteen years of age and older in the DDS Waiver. Counties should follow the same Medi-Cal eligibility rules for these persons as are used for persons under the age of eighteen, meaning that no income or resources of a parent or a spouse can be used in determining Medi-Cal eligibility for the DDS waiver for this population.

What is Institutional Deeming?

Deeming, as defined in the Manual of Policies and Procedures 30-701, means "procedures by which the income and resources of certain relatives, living in the same household as the recipient, are determined to be available to the recipient for the purposes of establishing eligibility and share of cost." An individual living in an institution does not have income or resources of a parent or spouse considered in the person's Medi-Cal eligibility determination. Since certain DDS Waiver consumers are deemed or considered eligible for institutionalization, all income and resources of a parent or a spouse are excluded by county Medi-Cal workers when determining their Medi-Cal eligibility and share of cost.

How is institutional deeming applied to IHSS and PCSP?

Institutionally deemed persons may not qualify for the In-Home Supportive Services (IHSS) residual program because the income and resources of the parent or spouse must be considered in determining eligibility. The IHSS residual program services are **not** provided under the Medi-Cal State Plan. As a result, **not all of the IHSS regulations apply to the institutionally deemed waiver population.**

Under the Medi-Cal State Plan personal care service is a Medi-Cal benefit provided through the Personal Care Services Program (PCSP). Under the DDS Waiver the consumer is eligible for full-scope Medi-Cal benefits. Although these consumers may not meet the IHSS program eligibility criteria, they may be eligible for services under PCSP because of their Medi-Cal eligibility status.

The DDS Waiver consumer is eligible for PCSP only if he or she meets **all PCSP eligibility requirements.** Specifically, the parent of the minor child **may not** be paid as the provider of services in the Personal Care Services Program under Welfare & Institutions Code, Section 14132.95(f) nor may there be advance pay status in the event that the parent is not the provider.

Determination of Eligibility

The Regional Centers have been instructed by DDS to inform consumers or the parent/legal guardians or spouse to contact the IHSS Program Manager in their local county welfare department to request an assessment for PCSP eligibility. County Medi-Cal staff should receive a Department of Developmental Services Waiver Referral form directly from the Regional Centers. (See Attachment III) This referral form will alert the county that the consumer is a DDS waiver consumer.

It is important to insure that eligible DDS Waiver consumers are not being denied services they are entitled to receive through PCSP based on parental or spousal income and resources. In determining PCSP eligibility for these regional center consumers the county should:

- First, the county Medi-Cal worker will determine Medi-Cal eligibility and share of cost as specified under Medi-Cal Procedures Section 19 D. If the applicant is not eligible for no share of cost Medi-Cal using regular rules, the county Medi-Cal worker should apply institutional deeming rules and exclude all income and resources of the parents or spouse when determining eligibility.
- Report eligibility to the Medi-Cal Eligibility Data System (MEDS) using an aid code of 6V or 6W if a consumer is found eligible.

- Refer the case to the county IHSS staff who will:

    - Review the consumers' application.
    - Verify full-scope Medi-Cal eligibility. (The 6V or 6W aid code should be reflected on the MEDS screen. This code is specifically used for individuals who are qualified for the DDS Waiver and would not ordinarily qualify for Medi-Cal). **The Case Management, Information and Payrolling System (CMIPS) will issue instructions on the appropriate use of aid codes through a separate ACL. Until the 6V and 6W codes are available in CMIPS, an alternative method will be used. Counties are to set up these cases in aid code 60, then call the Electronic Data System (EDS) Help Desk at (916) 636-4280 to have it changed to aid code 64 (which is a closed MN aid code with no share of cost). The case will remain in aid code 64 until the 6V and 6W codes are effective in CMIPS. It is the responsibility of each county to keep track of these cases.**
    - Inform parent/guardian to get all the necessary information from the Regional Centers if additional information is needed.
    - Approve the client for PCSP if the client is deemed eligible,
    - Refer the client, if appropriate, to the Medi-Cal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) Program, which **may** provide supplemental services. (See Attachment IV)

Assessment

When the recipient is an institutionally deemed child, a non-parent provider may provide PCSP services even if the parent is present in the home. Therefore, counties should assess these children in a manner that will provide the services needed to allow them to remain in the home. The cap of 283 hours for allowable PCSP services remains unchanged.

DSS is working in collaboration with DDS and DHS to implement the changes to law and regulation needed to address the role of the parent in caring for the minor child who qualifies for personal care services.

Denied Cases

It is possible that some DDS Waiver consumers may have been denied PCSP coverage based on the income and resources of a parent or spouse. Other children may have been denied because the parent is the child's provider, creating ineligibility for PCSP. However, these parents shall be given the option of hiring another provider so the child may become eligible for PCSP.

Each county shall make an effort to identify these cases. These cases would have been in the DDS Waiver and known to the county's Medi-Cal staff. County social work staff shall complete another eligibility determination. If the client meets PCSP eligibility requirements, the social worker shall notify the applicant and/or parent of their eligibility.

If you have any questions regarding this letter, please contact Alan Stolmack, Chief, Adult Programs Branch at (916) 229-4582.

Sincerely,

Original Signed By
DONNA L. MANDELSTAM on 12/7/00

DONNA L. MANDELSTAM
Deputy Director
Disability and Adult Programs Division

Attachments

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY GRAY DAVIS, Governor
DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

June 13, 2002

ALL-COUNTY LETTER NO. 02-43

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order or Settlement Agreement
[X] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: COORDINATING SERVICES BETWEEN IN-HOME SUPPORTIVE SERVICES AND EARLY AND PERIODIC SCREENING, DIAGNOSIS AND TREATMENT SERVICES

This All-County Letter provides information on the Medi-Cal Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program, and provides guidance on the need for coordination between In-Home Supportive Services (IHSS) and EPSDT supplemental services.

EPSDT Background

Federal Medicaid law establishes a list of health care benefits and services that state Medicaid programs must furnish. The federal law also establishes a list of services and benefits that states may cover at their option under their Medicaid programs.

The EPSDT services are a federally mandated Medicaid (Medi-Cal) benefit for Medi-Cal beneficiaries who are under the age of 21. In California the EPSDT program is provided under the Child Health and Disability Prevention Program.

Under EPSDT, Federal law also mandates that any health care service or benefit that a state could opt to provide under its Medicaid program must be provided to an individual if the service or benefit is medically necessary to correct or ameliorate a defect or a physical or mental illness. This federal rule applies to all optional Medicaid services and benefits regardless of whether or not a state has opted to cover the service or benefit under its Medicaid program. These services are referred to as “EPSDT supplemental services.”

Under EPSDT, when a Medi-Cal beneficiary requires “diagnostic or treatment” services for a condition identified as the result of an EPSDT screening, these services are to be furnished through and funded by the Medi-Cal Program.

Is EPSDT an Alternative Resource?

Not always, for instance, one of the EPSDT supplemental services is private duty nursing care. In authorizing home nursing care, these services may include such services as bathing or range of motion exercises that have also been authorized by the In-Home Supportive Services/Personal Care Service Program (IHSS/PCSP) social worker. The Medi-Cal EPSDT supplemental services should not be automatically considered an alternative resource when assessing the need for IHSS/PCSP services. The EPSDT recipient may choose to receive an authorized IHSS service from either EPSDT or IHSS/PCSP, but not from both programs. It is important that there be no duplication of services.

Procedure

Counties must coordinate the needs assessment of EPSDT recipients through the following procedure:

1. The IHSS social worker must determine if the applicant or recipient is receiving Medi-Cal EPSDT Supplemental nursing or other services in the home. It is probable that the recipient is receiving EPSDT supplemental services if the recipient is a child under the age of 21 and receiving nursing services at home through the Medi-Cal program. If they are receiving EPSDT a licensed nurse or a Certified Home Health Aide may be providing home nursing services. As noted above, the services that are provided by these individuals could include personal care services such as bathing, range of motion, ambulation or paramedical care.

2. If the applicant or recipient is receiving EPSDT supplemental nursing services in their home, the IHSS social worker must contact Department of Health Services Medi-Cal In-Home Operations (IHO) to identify the nurse case manager assigned to the recipient. We are attaching a brief description of Medi-Cal IHO, and a copy of IHO list of contact numbers for their offices in Northern and Southern California.

3. In cases where duplicate service authorization occurs, the recipient must be provided the choice of receiving the service from either their IHSS/PCSP provider or from the EPSDT home nursing provider. This could mean that both a nurse and an IHSS/PCSP provider could be present in the child’s home at the same time to provide personal care services. The IHSS social worker and IHO nurse case manager should coordinate in developing or amending the recipient’s care plan.

4. Only if the recipient elects to receive care from their EPSDT supplemental services provider instead of their IHSS provider, should counties adjust the assessed IHSS accordingly. In some cases, this may mean that added IHSS/PCSP hours become available to meet the recipient’s unmet need for other IHSS/PCSP services.

If you have questions or concerns, you may contact your assigned Operations and Technical Assistance Unit staff member at (916) 229-4000.

Sincerely,

Original Signed by Donna L. Mandelstam
Date Signed June 13, 2002

DONNA L. MANDELSTAM
Deputy Director
Disability and Adult Programs Division

Attachment

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY GRAY DAVIS, *Governor*

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

ERRATA

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: CORRECTION TO ALL-COUNTY LETTER (ACL) 02-43

The purpose of this Errata is to clarify whether or not Early and Periodic Screening, Diagnosis and Treatment (EPSDT) is considered an alternative resource. On page two, ACL 02-43, under the heading **"Is EPSDT an Alternative Resource?"** should read as follows:

Is EPSDT an Alternative Resource?

No, EPSDT should not be considered an alternative resource, and IHSS/PCSP authorized recipient hours should not be reduced because they receive EPSDT services. EPSDT provides supplemental services that are prescribed by medical professionals who established the medical necessity of the services, which we consider distinct from IHSS/PCSP services.

We apologize for any inconvenience this may have caused. If you have questions or concerns, you may contact your assigned Operations and Technical Assistance Unit staff member at (916) 229-4000.

STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY PETE WILSON, *Governor*

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

October 5, 1998

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[X] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

ALL COUNTY LETTER NO: 98-79

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: INTERIM EMERGENCY REGIONAL CENTER FUNDED SERVICES ARE NOT ALTERNATIVE RESOURCES UNDER THE IN-HOME SUPPORTIVE SERVICES AND PERSONAL CARE SERVICES PROGRAMS

This All-County Letter informs counties of changes in the In-Home Supportive Services (IHSS) Program which resulted from the settlements of the following court cases: Gordilla v. Anderson; Christensen v. Anderson; and Stone, et al. v. Anderson. Judgments were served on all three of these cases on July 2, 1998. Under the terms of these judgments, the receipt of interim, emergency regional center funded services, which are available under Welfare and Institutions Code (WIC) sections 12300(b) and (c), 12300.1 and 14132.95(d)(copies attached) and are provided pending an award of IHSS/Personal Care Services Program (PCSP) services, is not a basis for denying eligibility or granting reduced hours of IHSS/PCSP services. These Regional Center services are not alternative resources pursuant to WIC section 12301(a)(copy attached) when the person with the developmental disabilities or the regional center reports that: (1) the services are being provided on an interim basis pending a determination of the person's eligibility for IHSS/PCSP; and (2) the interim Regional Center funded supported living or in-home services will cease upon initiation of those services by the County IHSS/PCSP program. Please note that the consent of the recipient or their legal representative is currently required before recipient information can be shared with Regional Centers.

Regional Center funded services which support a consumer in his/her own home, and are not available under WIC sections 12300(b) and (c), 12300.1 and 14132.95(d), shall not be used as a basis to deny eligibility for or reduce the number of hours of IHSS/PCSP services at any time. As previously determined in the Arp v. Anderson judgment, which was communicated in All County Letter Number 98-53, IHSS/PCSP services must be granted as though no services are being provided through a Regional Center. IHSS/PCSP determination of services must be based strictly on the County Welfare Department's assessment of the applicant.

Consumers of regional center services who receive interim services are entitled to IHSS/PCSP benefits if they are found to be eligible. Payments will be made from the date of the IHSS/PCSP application. Duplicate payments are not allowed to any provider, applicant or recipient when services have been provided at no cost to the claimant. Since IHSS/PCSP has been determined the payer of first resort, it is the responsibility of regional centers not to duplicate IHSS/PCSP services.

For new applicants, these changes are effective as of the date of this letter. Any changes in services or benefits for existing IHSS/PCSP recipients will be made during their annual reassessment.

Please contact Vickey Walker, Manager of Operations and Technical Assistance--North at (916) 229-4596 or Mike Ellison, Manager of Operations and Technical Assistance--South, at (916) 229-4036 of my staff, if you have any questions regarding this All-County Letter.

Sincerely,

Original Document Signed By Leonard Tozier For Donna L. Mandelstam On 10/5/98

DONNA L. MANDELSTAM
Deputy Director
Disability and Adult Programs Division

Attachments

12300. (a) The purpose of this article is to provide in every county in a manner consistent with this chapter and the annual Budget Act those supportive services identified in this section to aged, blind, or disabled persons, as defined under this chapter, who are unable to perform the services themselves and who cannot safely remain in their homes or abodes of their own choosing unless these services are provided.

(b) Supportive services shall include domestic services and services related to domestic services, heavy cleaning, and personal care services, accompaniment by a provider when needed during necessary travel to health-related appointments or to alternative resource sites, yard hazard abatement, protective supervision, teaching and demonstration directed at reducing the need for other supportive services, and paramedical services which make it possible for the recipient to establish and maintain an independent living arrangement.

(c) Personal care services shall mean all of the following:

(1) Assistance with ambulation.

(2) Bathing, oral hygiene, and grooming.

(3) Dressing.

(4) Care and assistance with prosthetic devices.

(5) Bowel, bladder, and menstrual care.

(6) Repositioning, skin care, range of motion exercises, and transfers.

(7) Feeding and assurance of adequate fluid intake.

(8) Respiration.

(9) Assistance with self-administration of medications.

12300.1. As used in Section 12300 and in this article, "supportive services" include those necessary paramedical services that are ordered by a licensed health care professional who is lawfully authorized to do so, which persons could provide for themselves but for their functional limitations. Paramedical services include the administration of medications, puncturing the skin or inserting a medical device into a body orifice, activities requiring sterile procedures, or other activities requiring judgment based on training given by a licensed health care professional. These necessary services shall be rendered by a provider under the direction of a licensed health care professional, subject to the informed consent of the recipient obtained as a part of the order for service. Any and all references to Section 12300 in any statute heretofore or hereafter enacted shall be deemed to be references to this section. All statutory references to the supportive services specified in Section 12300 shall be deemed to include paramedical services.

12301. (a) The intent of the Legislature in enacting this article is to provide supplemental or additional services to the social and rehabilitative services in Article 6 (commencing with Section 12250) of this chapter. The Legislature further intends that necessary in-home supportive services shall be provided in a uniform manner in every county based on individual need consistent with this chapter and, for the 1992-93 fiscal year the appropriation provided for those services in the Budget Act, in the absence of alternative in-home supportive services provided by an able and willing individual or local agency at no cost to the recipient, except as required under Section 12304.5. An able spouse who is available to assist the recipient shall be deemed willing to provide at no cost any services under this article except nonmedical personal services and paramedical services. When a spouse leaves full-time employment or is prevented from obtaining full-time employment because no other suitable provider is available and where the inability of the provider to provide supportive services may result in inappropriate placement or inadequate care, the spouse shall also be paid for accompaniment when needed during necessary travel to health-related appointments and protective supervision.

14132.95. (a) Personal care services, when provided to a categorically needy person as defined in Section 14050.1 and to any person for whom coverage would be mandatory under Title XIX of the Social Security Act (Subchapter 19 (commencing with Section 1396) of Chapter 7 of Title 42 of the United States Code), but for the provisions of Public Law 104-193 affecting eligibility under Title XVI of the Social Security Act (Subchapter 16 (commencing with Section 1381) of Chapter 7 of Title 42 of the United States Code), is a covered benefit to the extent federal financial participation is available if these services are:

(1) Provided in the beneficiary's home and other locations as may be authorized by the director subject to federal approval.

(2) Authorized by county social services staff in accordance with a plan of treatment.

(3) Provided by a qualified person.

(4) Provided to a beneficiary who has a chronic, disabling condition that causes functional impairment that is expected to last at least 12 consecutive months or that is expected to result in death within 12 months and who is unable to remain safely at home without the services described in this section.

(b) The department shall seek federal approval of a state plan amendment necessary to include personal care as a medicaid service pursuant to subdivision (f) of Section 440.170 of Title 42 of the Code of Federal Regulations. For any persons who meet the criteria specified in subdivision (a), but for whom federal financial participation is not available, eligibility shall be available pursuant to Section 12305.6. All persons who receive benefits pursuant to subdivision (a) shall meet all applicable deeming provisions pursuant to Title XVI of the Social Security Act (Subchapter 16 (commencing with Section 1381) of Chapter 7 of Title 42, United States Code).

(c) Subdivision (a) shall not be implemented unless the department has obtained federal approval of the state plan amendment described in subdivision (b), and the Department of Finance has determined, and has informed the department in writing, that the implementation of this section will not result in additional costs to the state relative to state appropriation for in-home supportive services under Article 7 (commencing with Section 12300) of Chapter 3, in the 1992-93 fiscal year.

(d) (1) For purposes of this section, personal care services shall mean all of the following:

(B) Bathing, oral hygiene and grooming.
(C) Dressing.
(D) Care and assistance with prosthetic devices.
(E) Bowel, bladder, and menstrual care.
(F) Skin care.
(G) Repositioning, range of motion exercises, and transfers.
(H) Feeding and assurance of adequate fluid intake.
(I) Respiration.
(J) Paramedical services.
(K) Assistance with self-administration of medications.

(2) Ancillary services including meal preparation and cleanup, routine laundry, shopping for food and other necessities, and domestic services may also be provided as long as these ancillary services are subordinate to personal care services. Ancillary services may not be provided separately from the basic personal care services.

STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY PETE WILSC

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

July 9, 1998

ALL COUNTY LETTER NO: 98-53

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[X] Court Order or Settlement Agreement
[ ] Clarification Requested by One or More Counties
[ ] Initiated by CDSS

TO: ALL COUNTY WELFARE DIRECTORS
ALL IHSS PROGRAM MANAGERS

SUBJECT: REGIONAL CENTER SERVICES ARE NOT ALTERNATIVE RESOURCES UNDER THE IN-HOME SUPPORTIVE SERVICES AND PERSONAL CARE SERVICES PROGRAMS

This All-County Letter informs counties of changes in the In-Home Supportive Services (IHSS) Program which resulted from the settlement of the Arp v. Anderson court case. These changes concern developmentally disabled people who are clients of Regional Centers and are also eligible for IHSS residual and Personal Care Services Program (PCSP) services.

Under the Lanterman Developmental Disabilities Services Act at Welfare & Institutions Code (W&IC) section 4500 et. seq., Regional Centers are prevented from purchasing services for their clients when these services can be provided by an agency which has a legal responsibility to serve members of the general public and receives public funds for providing such services. This is the so called “generic services rule”. The IHSS program provides such “generic services”. Therefore, IHSS and PCSP must be utilized first under this W&IC requirement.

Services provided by Regional Centers to their clients can no longer be considered an alternative resource under W&IC subsection 12301(a) and the Manual of Policies and Procedures subsection 30-763.61. PCSP/IHSS must be granted as though no services are being provided through a Regional Center. Determination of services to be provided by IHSS must be based strictly on the County Welfare Department’s assessment of the developmentally disabled applicant.

To the extent permitted by law, county welfare departments may inform Regional Centers of the PCSP/IHSS services authorized for clients of both programs. Consent from the recipient or their legal representative is currently required before informing Regional Centers about the PCSP/IHSS services which are authorized. Regional Centers can then determine what supplemental service(s) the client should receive that do not duplicate PCSP/IHSS services.

Please contact Cindy Munoz, Policy Analyst, at (916) 229-4587 or Phyllis Eversole, Manager, at (916) 229-4036 of my staff, if you have any questions regarding this All-County Letter.

Sincerely,

Original Document Signed By
Donna L. Mandelstam on 7/3/98

DONNA L. MANDELSTAM
Deputy Director
Disability and Adult Programs Division

STATE OF CALIFORNIA—HEALTH AND HUMAN SERVICES AGENCY
DEPARTMENT OF SOCIAL SERVICES
744 P Street • Sacramento, CA 95814 • *www.cdss.ca.gov*

CDSS
WILL LIGHTBOURNE
DIRECTOR

EDMUND G. BROWN JR
GOVERNOR

May 1, 2015

ALL-COUNTY LETTER NO: 15-45

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS

TO: ALL COUNTY WELFARE DIRECTORS
ALL COUNTY IN-HOME SUPPORTIVE SERVICES PROGRAM MANAGERS

SUBJECT: IMPLEMENTATION OF THE AMENDED MINOR RECIPIENTS LIVING WITH PARENT(S) REGULATIONS MANUAL OF POLICIES AND PROCEDURES SECTIONS 30-763.44 through 30.763.457

REFERENCE: WELFARE AND INSTITUTIONS CODE SECTION 12300(e);
MANUAL OF POLICY AND PROCEDURES SECTION 30-763

Purpose

The purpose of this All-County Letter (ACL) is to transmit the amended In-Home Supportive Services (IHSS) Minor Recipients Living with Parent(s) regulations, approved by the Office of Administrative Law on November 13, 2014, effective January 1, 2015. This ACL also provides answers to questions that arose during the regulation development process.

Background

In a California Department of Social Services (CDSS) Director's Alternate Decision (DAD), the Director invalidated the previous version of Manual of Policy and Procedures (MPP) Section 30-763.453(c), which prohibited payment for the provision of IHSS to a provider parent when a non-provider parent was present in the home. The DAD stated that the regulation went beyond the scope of Welfare and Institutions Code (WIC) Section 12300(e) by creating a limitation on compensation to parent providers where none was intended by the legislature. The purpose of this regulatory package was to resolve the discrepancy between MPP Section 30-763.453(c) and WIC Section 12300(e).

In addition to resolving this discrepancy, amendments were made to MPP Sections 30-763.44 through 30-763.457 to provide clarification to improve regulatory understanding and application.

Highlights of Changes

30-763.44

- Added reference to the parental duty under the Family Code to specify this regulation section is applicable only when the minor lives with the natural or adoptive parent(s).
- Amended to reflect that services must be provided during the parents' inability and unavailability.

30-763.444

- "Search for employment" was added as an additional reason to pay a provider, who is not the recipient's parent, for tasks that must be performed during the parental absence.
- Clarified that allowing a provider, who is not the recipient's parent, to be paid due to the unavailability of the parent(s), for the reasons outlined in this regulation section; and only for tasks that must be performed when the parent(s) is unavailable.

30-763.45

- Added reference to the parental duty under the Family Code to specify this regulation section is applicable only when the minor lives with his/her natural or adoptive parent(s).

30-763.451

- Revised to combine MPP Sections 30-763.451 (a) through (c) of the former regulations. This revision mirrors statutory language and permits a more consistent reading of this regulation.

30-763.451(a)

- Specified full-time parental employment for the purposes of IHSS as 40 hours a week, not including IHSS-funded care to his/her own child.

30-763.452

- A parent is only considered unavailable, if the unavailability occurs during a time when the recipient must receive a specific service, for the following reasons: employment, enrollment in an educational or vocational training program, or employment searches.

- Defined both a suitable provider who does not have a legal duty pursuant to the Family Code and a suitable provider who does have a legal duty pursuant to the Family Code.

30-763.455

- Clarified that if a parent provider meets the requirements in MPP Section 30-763.451, that parent shall be paid for performing authorized services regardless of the presence of another parent in the home, including non-work hours, weekends, and holidays.

30-76.457

- Added to clarify that a recipient's parent(s) are not eligible to be providers for the Personal Care Services Program (PCSP).

Questions and Answers

1. Q. If the non-provider parent in a two-parent household is not working, or going to school full-time, is the child still eligible for IHSS?

A. Yes, the child may be eligible for IHSS; however, the provider parent would not meet the qualifications to be a paid IHSS provider under MPP Section 30-763.451 because of the availability of the non-provider parent.

2. Q. When the parent(s) must be absent from the home to take the minor recipient's siblings to the doctor, how does a social worker assess and authorize IHSS hours (up to eight per week) allowed under MPP Section 30-763.444?

A. The IHSS time under MPP Section 30-763.444, is not authorized separately; it is already contained within the existing authorized hours based on the assessment. A provider, who is not the recipient's parent, shall only be paid for tasks that must be performed during the absence of the parent(s). No separate IHSS hour authorization is required. In a two-parent household, both parents must be absent to perform shopping and errands essential to the family in order for a provider, who is not the recipient's parent, to be paid in their absence under this regulation.

Also, during the initial assessment and reassessment process, the social worker should inform the recipient's parents of the provider enrollment process, so if needed, there is an enrolled provider available to perform the needed services during the parent's absence.

3. Q. Is a step-parent considered a parent for the purposes of MPP Sections 30-763.44 and 30.763.45?

A. No, a step-parent is not considered a parent for the purposes of MPP Sections 30-763.44 and 30.763.45, unless the step-parent has legally adopted the child. These regulation sections only apply to natural or adoptive parents. When a minor recipient is legally adopted by a step-parent, MPP Sections 30-763.44 and 30.763.45 would apply.

4. Q**.** A minor recipient is living in a household with his two full-time employed parents and three siblings, and a non-parent provider is currently hired to provide IHSS tasks when the parents are unavailable because of employment (MPP Section 30-763.441). Can the recipient have eight additional hours for respite on the weekends as the mother says the father is no help with the children?

A**.** No. On weekends, the father refusing, or being unwilling to assist with his child, is not a reason for a non-parent provider to complete IHSS tasks for the child. The non-parent provider can only be paid for reasons specified in MPP Sections 30-763.44 through 30-763.444, and only for the tasks that must be completed during the periods of parental unavailability (ADL care, Protective Supervision; not daycare). For example, if the parents had weekend errands such as shopping with their other children, the non-parent provider could be paid under MPP Section 30-763.444. However, if one parent takes the other kids out for weekend errands and the other parent is home watching TV, cleaning, or is unwilling to assist the recipient child, the regulation requirements of MPP Section 30-763.444 are not met; therefore, a non-parent provider could not be paid.

5. Q. Can a social worker authorize IHSS hours on a case for a minor recipient when the only available parent cannot be a paid IHSS provider due to a Tier 1 crime conviction?

A. No, if the parent with a Tier 1 conviction is able and available to provide the needed care they must meet their obligation to provide care under the Family Code, even if they are not eligible to be paid as an IHSS provider.

However, per MPP Sections 30-763.44 through 30-763.444, a non-parent provider may provide services only if the parent is unavailable because they are searching for employment or are enrolled in an educational or vocational training program; if the parent(s) is physically or mentally unable to provide the needed IHSS services; or if they are unavailable because of on-going medical, dental or other health-related treatment. Also, if the parent(s) must be unavailable to perform shopping and errands essential to the family, search for employment, or for essential purposes related to the care of the recipient's minor siblings, IHSS may be purchased from a provider other than the parent(s) for up to eight hours per week to perform IHSS tasks necessary during the unavailability of the parent(s).

6. Q. How does the social worker know if the parent is employed full-time?

A. During the assessment visit, the social worker should ask about the recipient's living arrangements and the parent(s) employment status and hours.

7. Q. Can a parent be employed full-time from home and be an IHSS provider to their child?

A. No, if a parent is working full-time (an average of 40 hours or more per week), even if they work from home, that parent is not prevented from full-time employment (Please note, a parent providing IHSS funded care to his/her own child is not full-time). The location of the parent's workplace does not make a difference. Since this parent is not prevented from full-time employment, the parent cannot be the IHSS provider (MPP Section 30-763.451).

However, a provider, who is not the recipient's parent, can be paid to provide the needed IHSS services, but only during periods of parental work-related unavailability (MPP Section 30-763.441).

For example, both parents are employed full-time, one works from home and one works outside the home. In this situation, neither parent is eligible to be the paid IHSS provider. A provider, who is not the recipient's parent, may be paid to provide the IHSS services that must be provided during periods when both parents are unavailable due to employment.

8. Q. In a two-parent household, one parent states he/she is prevented from full-time employment, and the other parent is not willing to assist with any of the IHSS care for their child. Can the parent, who states he/she is prevented from employment, be the IHSS provider?

A. No, pursuant to MPP Section 30-763.452, an individual who has a duty under the Family Code need only be able and available to provide the needed IHSS to be considered a suitable provider, they need not be willing. A parent being “unwilling” to provide assistance is not a valid reason to pay the other parent as an IHSS parent provider. Because the “unwilling” parent would still be a suitable provider, the other parent is not prevented from obtaining full-time employment because no other suitable provider is available.

However, if one of the parents is not mentally or physically “able” to perform the needed IHSS services, and the other parent is prevented from obtaining full-time employment because no other suitable provider is available, the parent who is prevented from obtaining full-time employment may be a paid provider.

9. Q. MPP Section 30-763.455 states "A parent provider.........shall be paid for performing authorized services regardless of the presence of the parent in the home, including non-work hours, weekends and holidays." In a two-parent home with one parent being the IHSS provider, is the other parent, who is employed outside the home, considered a suitable provider when they are available during non-work hours, weekends and holidays?

A. No, a parent, who is employed full-time, is not considered a “suitable provider” if he/she is only available during non-work hours, weekends, and holidays. “IHSS may be purchased from a parent under the condition that the parent has left full-time employment or is prevented from full-time employment because no other provider is available…” (MPP Section 30-763.451). This section refers to the presence of the other parent/non-provider parent in the home and should not affect payment to the parent provider.

10. Q. In a single parent home, when the parent is employed full-time (40 or more hours a week), can that parent be paid to be an IHSS provider when they are not at work?

A. No, a single parent, who is employed full-time, does not meet the criteria to be the parent provider under MPP Section 30-763.451 because they have not left full-time employment and are not prevented from full-time employment because of the care needs of the child. In this situation, a non-parent provider can be paid, but only for periods of parental inability or unavailability as detailed in MPP Section 30-763.44-.444.

11. Q. Can two parents, in the same household, who are not employed other than by IHSS, and who are otherwise both able and available to provide the needed IHSS at all times, be enrolled as the IHSS care providers for their one minor IHSS recipient child?

A. No, because both parents would not meet the qualifications to be a paid IHSS provider under MPP 30-763.451. In this situation, while one parent is providing IHSS, the other parent is able and available to provide IHSS. Therefore, the parents would not both be prevented from full-time employment because the other able and available parent is considered a suitable provider.

12. In a two-parent household, one parent operates a construction business full-time from home; the other parent is licensed to run a small family home for medically needy and fragile children. In the home, there are four adopted children and two children who are living in the home because they are medically needy, fragile, and receive care under the license. During the assessment process, the county should gather information to determine who is providing care and any additional case circumstances.

Q. Is the parent, who runs the licensed small family home and stays home to provide care for all the children, eligible to be an IHSS parent-provider for the adopted children under MPP Section 30-763.45?

A. No, the parents of the adopted children have a responsibility to provide care for their natural or adopted children under the Family Code. The parent who runs the licensed small family home is employed full-time to provide care to the medically needy and fragile children if he/she works an average of 40 or more hours per week. That parent is not prevented from full-time employment due to the care needs of their adopted children.

Q. Is this parent considered employed full-time because he/she runs a licensed small family home for medically needy and fragile children?

A. Yes, the parent who is licensed to run a licensed small family home, for medically needy children, is considered to be employed full-time if he/she works an average of 40 or more hours per week.

Q. Is the parent operating a construction business full-time, from their home, considered to be employed full-time?

A. Yes, the parent operating the construction business full-time, from home, is also considered to be employed full-time. Therefore, neither parent is eligible to be an IHSS parent-provider for their adopted children. In addition, the foster children are also ineligible for IHSS since they reside in a licensed facility.

13. Q. Does a notarized handwritten letter from a parent appointing a caregiver as a "guardian" for a child verify a Legal Guardianship of a child?

A. No, a Legal Guardianship is approved by a Superior Court Judge; therefore, a handwritten note, without supportive court documentation, does not meet the definition of "Legal Guardianship."

14. Q. How do MPP Sections 30-763.44 and 30-763.45 apply when a minor recipient lives with both his/her grandparent, who is also his/her Legal Guardian, and his/her biological parent?

A. When a Legal Guardianship is in place, the appointed Guardian assumes the care, custody, and control of the minor. Per Family Code Section 7505(a), when a Legal Guardianship is in place, it ceases the "parental authority" (ceasing parental authority is not the same as termination of parental rights, as termination of parental rights is permanent such as adoption or emancipation). Because the Legal Guardian (the grandparent) assumes the duty to care for the minor, the parent is absolved of his/her duty to provide care for the child. Because the parent is temporarily relieved of the duty of care, MPP Sections 30-763.44 and 30-763.45 do not apply to the parent, nor do they apply to the grandparent because the grandparent is not an adoptive parent. Therefore, either the grandparent and/or the biological parent could be the child's paid IHSS provider in this situation.

15. Q. If a minor does not live with his/her parent(s), would an informal caregiver be considered as a parent or non-parent for the purpose of IHSS?

A. A caregiver is considered a non-parent. In this case, MPP Sections 30-763.44 through 30-763.457 do not apply since the minor recipient is not the caregiver's natural or adoptive child. WIC Section 12300(e) states in pertinent part: "…a person having a legal duty pursuant to the Family Code to provide for the care of *his or her* child…" (Emphasis added.) Thus, because the recipient is not the child of the guardian, WIC Section 12300(e) and the related regulations do not apply.

County Responsibilities

Counties shall complete a review of impacted IHSS cases as soon as administratively feasible, but no later than the next regularly scheduled reassessment. As cases are reassessed and minors living with their parents are assessed according to the amended regulations, counties will be responsible for ensuring that time is authorized in compliance with the amended regulations.

Questions regarding the content of this ACL may be directed to the Policy and Operations Bureau within the Adult Programs Policy and Quality Assurance Branch at (916) 651-5350.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

c: CWDA

ADAPTED VINELAND SOCIAL MATURITY SCALE

This information is meant as a guide only and is not to replace individual assessments.

Task	Age**	Expected Behavior
*Domestic	8	Able to do simple household tasks
Laundry	14	Able to do laundry unassisted
Shopping & Errands	14	Makes minor purchases/runs errands
	17	Able to grocery shop unassisted
Meal Prep & Clean up	5	Uses table knife for spreading, etc
	6	Uses table knife for cutting
	8	Washes dishes and cleans up
	17	Able to cook simple meals and clean up
Ambulation	.5	Moves about on the floor, stands alone
	1	Walks about unassisted
	2	Walks upstairs unassisted
	3	Walks downstairs 1 step to tread
	5	Able to ambulate unassisted
Bathing, Oral Hygiene & Grooming	4	Washes hands and face unassisted
	6	Bathes self with some assistance
	8	Combs or brushes hair, able to bathe unassisted
Dressing	2	Removes coat or dress
	3	Puts on coat or dress unassisted
	4	Buttons coat or dress
	5	Dresses self except for tying
Bowel & Bladder	1	Asks to go to the bathroom
	4	Cares for self at toilet
Transfer	.5	Rolls over, balances head, pulls self upright, sits unsupported
	1.5	Able to transfer unassisted
Feeding	1	Eats with spoon, drinks unassisted from a glass, chews
	2	Eats with a fork
	8	Cares for self at the table
Respiration	17	Able to clean oxygen equipment
Respite	to 18	Restriction: Up to 8 hours per week maximum allowable only when a parent is providing services without compensation and must be out of the home to perform tasks essential to the recipient's minor siblings.
Accompaniment		Hours are not allowable for routine health care. Hours are allowable for health care specific to the child's disability, regardless of age.
Protective Supervision		Protective Supervision only as needed because of the functional limitations of the child.

Notes:

*May be authorized **ONLY** when the recipient child is living with his/her parent(s) and has a provider other than parent(s) **AS LONG AS** the parent(s) is unable to provide IHSS due to employment, educational or medical needs as stated in MPP 30-763.441-.444.

**This represents the age at which a child should be able to fully accomplish tasks as listed.

The Vineland Scale is a standardized test used to evaluate physically and mentally disabled children from birth to age 30.

DEVELOPMENTAL GUIDE

	Self Care			Gross Motor	Meal Prep & Consumption		Domestic Tasks		
Developmental Stage	**Bathing/Oral Hygiene/ Grooming**	**Bowel and Bladder**	**Dressing**	**Ambulation**	**Feeding**	**Meal Prep and Cleanup**	**Housework**	**Laundry**	**Shopping and Errands**
Infancy (0-2)	▨	▨	▨	Stands alone by 10-12 months; walks unassisted by 15 months; runs by 18 months	Eats with spoon by 12-14 months; drinks from cup by 10-12 months	▨	▨	▨	▨
Toddler (3-4)	Able to wash hands/face and brush teeth unassisted	Requires supervision and assistance with toileting; may ask to go to the bathroom	Removes shirt/dress/pant; puts on shirt/dress/pants with some assistance	Walks upstairs unassisted; requires super-vision/assistance walking downstairs	Uses fork correctly to eat	Able to wipe surface/table; able to pour from one container to another with supervision	Able to pick up and put away toys	▨	Can follow simple one-step directions *(e.g. Bring me the cup)*
Early Childhood (5-8)	Bathes self with some assistance and minor supervision	Cares for self at toilet unassisted; may experience bedwetting	Able to button shirt/dress/pant; dresses self; ties shoes	Able to skip and climb on and up structures	Able to use table knife to cut and spread	Able to help clear table and assist with cleanup	Cares for room/ makes bed	Able to put away clothes in drawers; fold clothes with assistance	Can follow three-step directions *(e.g. Go to your room, get your shoes on, and come to the car)*
Middle Childhood (9-11)	Combs or brushes hair; able to bathe unassisted and unsupervised	🟪	🟪	🟪	🟪	Washes dishes/cleans up with supervision	Able to sweep floors; take out the trash	Able to hang up clothes in closet; transfer and load clothes into washer/dryer	Able to follow more complex directions *(e.g. Get ready for school tomorrow);* able to handle money/change
Early Adolescence (12-14)	🟪	🟪	🟪	🟪	🟪	Able to cook simple meals and clean up unassisted and unsupervised	Able to vacuum	Able to use iron safely	Makes minor purchases/runs errands (short distances)
Late Adolescence (15-18)	🟪	🟪	🟪	🟪	🟪	Able to prepare meals and clean up	🟪	🟪	Able to shop for groceries unassisted

Key

Not Yet Age Appropriate	Fully Functional
▨	🟪

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NOTE: The information in this Guide represents developmental milestones. There are always variances from that norm.

This tool is currently under review by CDSS and will be changing.

FUNCTIONAL INDEX RANKING FOR MINOR CHILDREN IN IHSS
AGE APPROPRIATE GUIDELINE TOOL

Each child must be assessed individually.

Age	Housework	Laundry	Shopping and Errands	Meal Prep and Cleanup	Ambulation	Bathing/Oral Hygiene/ Grooming	Dressing	Bowel and Bladder	Feeding	Transfer	Respiration
0-1	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1	1, 5 or 6
2	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1-5	1, 5 or 6
3	1	1	1	1 or 6	1	1	1	1 or 6	1 or 6	1-5	1, 5 or 6
4	1	1	1	1 or 6	1	1	1	1-6	1 or 6	1-5	1, 5 or 6
5	1	1	1	1 or 6	1-5	1	1-5	1-6	1 or 6	1-5	1, 5 or 6
6	1	1	1	1 or 6	1-5	1	1-5	1-6	1 or 6	1-5	1, 5 or 6
7	1	1	1	1 or 6	1-5	1	1-5	1-6	1 or 6	1-5	1, 5 or 6
8	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
9	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
10	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
11	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
12	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
13	1	1	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
14	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
15	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
16	1	1, 4 or 5	1	1 or 6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6
17	1	1, 4 or 5	1, 3 or 5	1-6	1-5	1-5	1-5	1-6	1-6	1-5	1, 5 or 6

Notes:

- All minors should be assessed a functional rank of 1 when identified above unless extraordinary need is documented.
- Minors who live with their provider parents must be assessed a functional rank of 1 in Housework regardless of extraordinary need.
- For areas with ranges, the social worker should utilize the Annotated Assessment Criteria and Developmental Guide to determine the appropriate functional rank.
- Memory, Orientation and Judgment – FI ranks of 1, 2 or 5 should be assessed. The county staff must review a minor's mental functioning on an individualized basis and must not presume a minor of any age has a mental functioning score of 1. (ACL 98-87, MPP 30-756.372; WIC 12301(a), 12301.1.)
- The FI ranks listed above reflect the age at which a minor may be expected to complete <u>all</u> tasks within a service category independently and are based on the Vineland Social Maturity Scale. These rankings are provided as a guideline only. Each child must be assessed individually.

EXTRAORDINARY NEED ACTIVITY

No.	IHSS Category	Information from Assessment	Extraordinary Need/ IHSS Authorized?	
			Yes	No
1.	Domestic (Housework)	12-year-old with severe allergies to dust, pollen, and animals who lives with parents. Mother states that she is requesting IHSS payment for housework because she must vacuum and dust at last 3 times per day.		
2.	Laundry	8-year-old who is incontinent and wears diapers. Even with diapers and rubber sheeting, his bedding and clothing becomes soaked at night. His mother reports she often must get up at night and change his clothing and bedding. She requests IHSS for Laundry and other services.		
3.	Feeding	7-year-old with Autism. Will not eat what the rest of the family eats or when they eat. Information from mother and collaborating professionals indicates he requires constant presence of his mother when he eats. She must encourage him to take each bite. Mother states he eats at home 3 times per day and it takes 30 minutes for each meal.		
4.	Dressing	4-year-old with Cerebral Palsy who has severe contractures and constant spastic movements. Is unable to help with any dressing tasks. Mother states it takes approximately 20 minutes to dress child in morning and evening. She requests IHSS for Dressing and other services.		
5.	Bowel and Bladder	3-year-old who has diagnosis of ADHD. Mother states that she has tried to toilet train him, but he refuses to be trained. At the home visit, the child appeared functional and ran around the house with only underwear on. SW observed him taking clothes off when she entered the home. Mother requests IHSS for Bowel and Bladder and other services.		

EXTRAORDINARY NEED ACTIVITY

No.	IHSS Category	Information from Assessment	Extraordinary Need/ IHSS Authorized?	
			Yes	No
6.	Meal Preparation	10-year-old who has diagnosis of Down Syndrome. She has had successful cardiac surgery in the past and attends school 5 days per week. Observations show that the child is overweight for her age. Mother requests IHSS services to include Meal Preparation because she states that she should prepare special meals for her daughter who currently eats the same meals as the rest of the family.		
7.	Bathing/Grooming	7-year-old with multiple medical problems related to mother's drug abuse while pregnant. Currently resides with mother. Mother states that child has severe allergies to food. Mother states she tries to monitor and control what he eats, but he often sneaks food or eats food at school that he shouldn't eat. She states on a daily basis he gets severe welts all over his body and she often must bathe him two or three times per day in a solution prescribed by M.D. She requests IHSS for Bathing and other services.		

These examples have been created for training purposes only. They are provided to reinforce the use of existing regulations. Each consumer's needs should be individualized to ensure that their Functional Index rankings and hours authorized are correct.

HOW TO EFFECTIVELY IDENTIFY THE NEED FOR ASSISTANCE IN DAILY ACTIVITIES AMONG PEOPLE WITH MENTAL DISORDERS

How to Effectively Interact with People with Mental Disorders

Introduction

What is a mental disorder? It is defined by the American Psychiatric Association as a "clinically significant disturbance in an individual's cognition, emotional regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities" (APA, 2013, p. 20).

A mental disorder, like a physical impairment, can have a significant impact on an individual's ability to conduct activities of daily living. As an IHSS worker, you may have had difficulty determining functional impairment for IHSS of a person with a mental disorder and deciding which tasks to authorize. You know that assistance with shopping, cooking, bathing, and accompaniment to medical appointments is not only relevant to those who have physical handicaps. Those who experience severe symptoms of depressive disorder, schizophrenia or other mental disorders may exhibit impairments in Domestic, Related and Personal Care areas similar to those with limited mobility and dexterity caused by severe arthritis. And just like those with physical impairments, people with mental disorders have a range of symptoms. Two individuals diagnosed with Major Depressive Disorder may exhibit different deficits. One person with depressive disorder may not have enough energy to pay his/her bills while another person may not even have enough strength to eat regularly. In addition, a mental disorder such as depressive disorder can be related to a physical condition. For instance, someone who cannot go shopping because they are physically disabled may also be depressed because of the impairment. As a consequence, this person's depressive disorder may affect their ability to do simple tasks such as cooking and grooming.

There is great stigma attached to mental disorders. Much of society believes that mental disorders can be "overcome through 'will power' and is related to a person's 'character' or intelligence" (National Alliance for the Mentally Ill, n.d.). Though society doesn't blame a person for his/her cancer, many with a mental disorder are blamed for their condition that likewise holds them captive to their illness. More than 54 million Americans, in any given year, have a mental disorder. However, less than 8 million seek out help (National Mental Health Association, n.d.). Although some may not recognize that they have a problem, others may not want to deal with the reaction others may have towards them. They may feel that others will judge them and make them feel like they should have more control over their actions. People with mental disorders may be ashamed of their conditions, believing that they are weak if they seek out treatment. Therefore, you may get a medical report that does not mention a severe mental disorder the consumer is experiencing.

Substance Abuse and Mental Disorders It is also important to recognize that drug and alcohol use may be associated with mental health issues. It is estimated that around 15% of adults who have a mental disorder also have a substance abuse problem (National Mental Health Association, n.d.) A person who uses substances is in many ways self medicating. The psychological pain associated with a mental disorder can be tortuous. A drug or a drink may seem like the only solution to quell this pain. You may have preconceived notions about drug use or alcohol abuse. You may have a relative or friend whose substance use had a negative impact on others. Having a client who drinks heavily may bring up strong emotions, possibly from personal experience. It is important to realize that this is happening, and that it is normal to have these feelings. However, if you do not recognize them, your feelings about mental disorders and drug/alcohol use will hinder you from providing good service.

As IHSS workers, you are in the unique position of engaging people in a non-judgmental manner. While your consumer may have been turned away by families and friends because of their behaviors, you are a fresh face. It is crucial to accept people where they are. If the IHSS applicant or consumer believes that you are hold judgments against them, they will not want to work with you, affecting your ability to provide services. If you have difficulty working with a client because of certain personality or substance use issues, you should get support from your supervisor or a counselor through your work. These personal feelings can lead to burnout or apathy which neither helps you nor your client.

Schizophrenia

Schizophrenia affects more than 2.5 million Americans, or 1% of the population (National Mental Health Association, n.d.). Schizophrenia, like other disorders, affects many individuals differently. However, it is common for people with schizophrenia to exhibit what is known as positive and negative symptoms (American Psychological Association, 2000).

Positive symptoms are also referred to as psychotic or active symptoms. These include delusions, hallucinations, disorganized thinking, and disorganized behavior. Delusions are false personal beliefs that go against what other people believe. They may be persecutory, grandiose or religious beliefs. Someone may believe a neighbor is spying on them, looking through a crack in the wall. Someone else may believe that they are being sought after by the police or their landlord for some imagined action. A person may think that they have direct communication with the President or God. Delusions of any kind occur for 90% of people with the disorder (Schizophrenia Fellowship, n.d.).

Hallucinations can be associated with any of the five senses. However, auditory hallucinations are the most common. These auditory sensations usually come in the form of voices that are often criticizing a person or commanding them to do something. Hallucinations of any kind occur for 70% of people with schizophrenia. Disorganized thinking is usually manifested in how a person speaks. His/her speech is disjointed and lacks coherent structure, jumping from one subject to the next. Disorganized behavior can cause deficiencies in activities of daily living. This behavior may be demonstrated by aimless wandering, talking to oneself in public, or wearing many clothes on a hot day (Schizophrenia Fellowship, n.d.)

Negative symptoms relate to a loss of normal functioning. They include withdrawal or loss of motivation, inability to feel pleasure, lack of verbal speech, or a flat affect. Therefore, people with schizophrenia may lack energy to do daily activities such as grooming, household chores, or cooking. A person with schizophrenia may also be socially isolated, finding it difficult to have close friendships. They may also have a great reduction in an ability to respond to questioning, speaking very little. In addition, they have little eye contact or have flat facial features (Schizophrenia Fellowship, n.d.).

Medications meant to treat the symptoms of schizophrenia may also cause a person to feel a lack of physical or mental energy (Nathan, Gorman & Salkind, 1999, p. 170). Depressive symptoms can also be related to people with schizophrenia. They have greater rates of suicide than the general public (NetDoctor, n.d.). In the next section on depressive disorder, suicide risk will be discussed in greater detail

IHSS Functional Limitations

As a person's symptoms get worse, his/her ability to function normally in society deteriorates. Concentration or getting sleep is difficult. He/she may spend more time alone. Because of symptoms such as hallucinations or delusions, a person may find it difficult to carry out normal daily tasks. He/she may be so consumed by his/her delusion or hallucination that it would be difficult to clean, shop, or pay bills (Hales & Hales, 1995, p.416). If a person has a delusion that their landlord is trying to spy on them or evict them, he/she may not pay their rent, actually putting them at risk for eviction. Another person may have a delusion that turning on the stove may start a fire, causing them not to cook.

Having disorganized behaviors can lead to difficulties in activities such as bathing, grooming or cooking. People wearing multiple layers of clothes or having outbursts in public may not have the ability to understand how to turn on a stove or clean their apartment. Besides having disorganized behaviors, those with schizophrenia may be too apathetic to clean their rooms. They lack the energy to dress properly or to shower (Schizophrenia Fellowship, n.d.).

IHSS can assist in providing needed services such as domestic, laundry, shopping, and meal preparation. Although a person with schizophrenia may be unimpaired physically, their deficits in ADLs may be severe. Without assistance in these activities, a person may be at risk of eviction or health and safety hazards.

Techniques in Interacting with People with Schizophrenia

As an IHSS worker, you assess the person's home care needs, authorize services and implement a case plan so consumers can live safely in their home. Without the right approach to a client, those tasks may become difficult or impossible. When interviewing a person with schizophrenia, it is best to use short sentences, speaking calmly (Woolis, 1992). People with schizophrenia may have difficulties in processing a lot of information. It is important to speak calmly and slowly, so as not to cause alarm or tension in the client.

It is helpful with someone with schizophrenia to limit the amount of distractions in a room. Ask to turn off a TV, radio or some other appliance making noise (HealthyPlace, n.d.). Be mindful of your distance and position to client. Stand to a person's side rather than forward. Give a person a few feet distance, especially if they seem upset. Be mindful of your tone of voice. Never shout to get attention, and avoid close and direct eye contact if a person seems to be very upset (HealthyPlace, n.d.) And if the client's anger seems to be escalating, excuse yourself and leave.

When interviewing someone with schizophrenia, do not always expect rational discussion. Keep your discussions simple, repeating your questions or comments. It is also good to get a client to repeat or paraphrase what you are saying, possibly stating, "Just so I know that we are clear on what we are working on, can you tell me what you think I am asking?" Do not overburden a client with too much information. Focus on the necessary facts and questions. If you feel that the client is tired or anxious, you might ask if the client wants to take a break.

If a client talks about delusions or hallucinations, do not argue with them. You will not be able to convince them that these delusions are not real. However, you should not pretend that you see or experience the same delusions. You might say, "I see how terrible it must be to experience that". If a client asks if you see or hear the same thing he/she does, do not be afraid to say you do not. However, use empathy, concentrating on validating their experience and how painful or difficult it is for her/him. If someone does not believe that you care, they will not want to work with you.

It is important to remember that people with schizophrenia or severe depressive disorder may not be able to ask for help. In fact, they may have pushed a lot of people away from helping them. They can feel vulnerable and afraid, not wanting people involved in their lives. Do not take it personally if someone gets upset with you or is difficult to get along with. This defensiveness is because of the fear and mistrust they feel. After the client establishes a relationship with you and knows he/she can trust you, subsequent meetings will be easier.

Do not expect to get all the information you want in the first interview. Especially if a person is actively experiencing or relating to you hallucinations or delusions, they will be more preoccupied with that then what you have to offer. If a person is telling you in a haphazard way how a neighbor or landlord is spying on them, or how people come in his/her room in the middle of night, just listen. Be non-judgmental. Initially, do not interrupt. Just let the person talk through what he/she wants to. Non-verbal communication can be more powerful than interrupting and saying something that you feel would help.

Sometimes it can be difficult to get needed information from a client with schizophrenia. He/she may ramble on or have disjointed speech that is difficult to redirect. To bring forth your clear and concise information, you might need to interrupt. A good approach is to say, "That sounds really awful", or "that sounds really interesting", and then recap or reframe what they were saying, repeating it back to them. This gives him/her a chance to feel heard, but also give you a chance to move on. During some points of an interview, you may need to be directive, giving or getting needed information. However, never be confrontational or argumentative. When someone is in an acute psychotic state, rational discussion cannot exist.

Violence Most people with schizophrenia are not violent. For the most part, they are withdrawn from society, preferring to be alone (HealthyPlace, n.d.). However, it is important to keep in mind that people with schizophrenia, like non-psychotic people, may have outbursts that could put you in harm's way. One study notes that individuals with schizophrenia may have a difficulty in reading facial expressions. Therefore, if you are arguing with someone with schizophrenia, they may believe your intentions are more hostile than they actually are. While you may be just arguing a point, this person may believe you are trying to provoke a fight (Arehart-Treichel, 2005).

When you visit a client, you should be mindful of exit ways. If a client becomes loud or aggressive and you feel this situation could be dangerous, do not question leaving the interview. Your safety comes first.

Finally, if a person expresses a desire to harm himself/herself or another person, take these threats seriously. If he/she appears calm, try and get detailed information about how he/she may do this and who his/her intended victim is. Do not argue with the person, especially if he/she appears angry and upset. Politely excuse yourself from the interview, notifying your supervisor and possibly the police for evaluation.

Schizophrenia

Characteristics

- Schizophrenia affects around 1 percent of the American population.
- Schizophrenia consists of “positive” and “negative” symptoms.
- Positive symptoms refer to active symptoms, including delusions, hallucinations, disorganized thinking, and disorganized behavior.
- Negative symptoms refer to a loss in functioning, including withdrawal or lack of motivation, inability to feel pleasure, lack of verbal speech, or flat affect.

IHSS Functional Limitations

- Concentration or sleep can deteriorate, causing problems with simple tasks such as cooking, cleaning, or shopping.
- The delusions or hallucinations a person with schizophrenia experiences can consume all their energy, causing them to have problems with cleaning, shopping, or paying bills.
- The “negative” symptoms of schizophrenia can cause a total lack of motivation in doing cleaning or dress changes.
- Delusions like feeling a landlord is trying to evict him/her may trigger the client to not pay rent, actually putting him/her at risk for eviction.
- The client may have delusions about certain items in the home, believing that turning on the stove may cause a fire, causing them not to cook.

Techniques In Interacting With

- Use short simple phrases when asking questions or giving information.
- Use a calm and unhurried tone of voice.
- Never shout or try to argue with the client. Rational discussion will not be possible of the client is acutely psychotic.
- Give the client some physical space and try to avoid too much direct eye contact.
- If the client is tangential, politely interrupt by recapping what he/she said, and then move on to your questioning.
- Never be judgmental or put blame on the client for their condition. Do not try and convince the client their delusions or hallucinations are fake. However, do not go along with it, pretending you are experiencing them as well. Be empathetic by expressing your understanding of how the client feels because of these delusions/hallucinations.
- Turn down unnecessary noises in the apartment.
- If the client can not calm down and appears very angry, excuse yourself politely and leave.

Bipolar and Related Disorders

Bipolar Disorder, previously known as manic-depression, is a mental disorder that consists of depressive and manic episodes. The American Psychiatric Association (2013) now differentiates three of the types of bipolar disorders (Bipolar I Disorder, Bipolar II Disorder, and Cyclothymic Disorder) as follows: Bipolar I has the highs (manic episodes) and lows (major depressive episodes) associated with classic "manic-depression." In Bipolar II, the patient does not experience the extreme highs; rather he/she will have hypomanic episodes. In Cyclothymic Disorder, the patient experiences milder highs and lows. One author notes that these different types of bipolar disorders account for nearly a quarter of all depression disorders (Hales & Hales, 1995). Therefore, someone with depressive symptoms may not just have low moods. Nearly one out of every four people with these lows will also experience extreme highs.

A manic episode is described as having an abnormally and persistently elevated, expansive, or irritable mood and persistently increased goal-directed activity or energy, for at least a week. This mood may include a decreased need for sleep, an inflated self-esteem or grandiosity, and thoughts that appear to be racing. A person's speech is faster than normal, and he/she is easily distracted. The person may be involved in more activities that can also have painful consequences, such as unrestrained buying sprees, sexual indiscretions, or foolish business investments (American Psychiatric Association, 2013). When this manic episode bottoms out, the consumer will usually be depressed. This depressive episode can be worse than depression described earlier, with more risk for suicide and a longer duration of depressive symptoms.

One person may have manic episodes that require hospitalization, while another person may not have severe psychotic symptoms. In general, it is important to recognize that manic symptoms are different for each individual. Symptoms of mania can range from an elevated mood to aggressive and destructive behaviors that require an immediate psychiatric hospitalization.

One person describes the manic side of a bipolar episode as being pleasurable.

> As quickly as the door shut on my depression, so now does that same door spring open. I can see in color again. I can taste food. The depression lifts and I am headed for the other side of the mountain. The journey that takes me to the manic side of the illness is not unpleasant at all. I feel the energy rebounding in my veins again. I want to take on the world. My thoughts race with all the things I'm going to do now that I am free of that void (Shaw, 1996).

This description illustrates how a manic mood can be a relief to one's depression. Someone with such highs will not want to come down. Therefore, medicating someone with this disorder is difficult to do when he/she is in a manic state. He/she may not see the need to be stable, more likely to accept psychiatric treatment when his/her mood bottoms out, instead. Someone's manic state can also be dangerous. One real life example describes a 38-year-old male in a manic state. Confronted by his mother for not taking his medications, he became hostile and struck his mother (Quanbeck, Frye & Altshuler, 2003, p.1246).

Again, a person who experiences mania may feel optimistic, euphoric, or irritable. A person's thoughts will begin to race, one's self-confidence may be exaggerated, and in severe forms, a person may experience delusions or hallucinations. It is estimated that about a quarter of people with a bipolar disorder experience hallucinations (Maxmen & Ward, 1995). Someone with mania may believe that he/she is invincible, specially favored by God, or even hear commands to charge a special mission or crusade (Hales & Hales, 1995).

Besides having an elevated mood, someone in a manic state may feel a decreased need to sleep. He/she may be more talkative, making it difficult to interrupt him/her. If a person appears to be irritable, his/her speech may include hostile comments or angry or aggressive tirades (American Psychiatric Association, 2000). It is common for a person with mania to start unrealistic projects, spend large amounts of money indiscriminately, or engage in sexual behavior that is abnormal for him/her. As one's mania worsens, one's projects will become difficult to finish (Morrison, 1995). His/her racing thoughts and projects may keep him/her from being organized or from doing household tasks like cleaning.

It is important to recognize that due to a person's age, this disorder can affect someone differently. A 30-year-old may have a manic state that is much different than someone who is 80 years old. The younger person may have the physical ability to start projects or engage in risky activities that an elder may not be able to. A manic elder with physical impairments may be in physical danger by ambulating beyond their normal capabilities. In addition, an elder who is irritable or hostile in his/her manic state may alienate needed supportive care. One author also notes that the loss of a spouse or long-term caregiver for an elder can trigger a mood change, like mania (Healthy Place, n.d.). With all adults, drugs such as stimulants or hallucinogens can lead to a manic episode, or make mania worse (Hales & Hales, 1995).

Eventually, a manic episode ends. It may happen after a day, a week, or longer. However, as one author notes, a bipolar condition includes "higher highs" and "lower lows" (Hales & Hales, 1995). When a person with a bipolar disorder experiences depression depressive episode, it can be worse than for a person with general depression. This depressive episode can be more severe, be more prolonged, and require more hospitalizations. In addition, suicidal thoughts or actions may be more frequent for someone experiencing a bipolar depression (Maxmen & Ward, 1995). Therefore, all the symptoms discussed in the training on depression are relevant here. A consumer who has an elevated mood one week can feel suicidal the next week. Because of the unpredictability of one's change in mood with this disorder, it needs to be carefully monitored by involved staff, social workers, and other collaterals.

IHSS Functional Limitations

As with depression, people with a bipolar disorder may have different levels of ability in conducting activities of living. A person in a mild or hypomanic state may be motivated to keep his/her apartment and person clean. On the other hand, a person with more severe mania may not feel the need to keep themselves well groomed or his/her apartment clean (Sullivan, 2005). He/she may feel that taking medications for physical or mental problems is unnecessary. One author states that people with mania have fewer health complaints than usual (Hales & Hales, 1995). An elder with physical impairments may be at great risk in a manic state. He/she may not pay attention to his/her limitations in mobility or take necessary medications, potentially causing grave medical complications or serious falls.

As one's manic episode worsens, his/her thoughts and actions will have less focus, affecting his/her ability to conduct daily activities of living. One's need for sleep or for eating regularly may become less. This behavior can be especially trying on an elder's body. The lack of desire to keep nourished may cause more problems for an elder than a teenager in a manic state. For caregivers, a manic consumer's possible irritable behavior may be difficult to work with. An IHSS provider who tries to unsuccessfully reason with a consumer may find this job difficult or dangerous, especially if the consumer lashes out at him/her.

Again, a depressive episode for a person with a bipolar disorder can be worse than a general depression. Therefore, problems with toileting, dressing, grooming, preparing food, and taking medication may also be worse. Handling finances, shopping, or cleaning one's house can be extremely daunting tasks. It is also important to remember that suicidal behaviors may be more for those with a bipolar disorder than for consumers with general depression. In fact, those with a bipolar disorder commit more suicides than people with general depression (Maxmen & Ward, 1995). The American Psychiatric Association (2013) estimates that the lifetime risk of suicide among individuals with bipolar disorder is 15 times greater than the general population. An IHSS provider may be the best person to see the consumer's mood change. The rollercoaster ride of a bipolar condition may drive friends and family away, leaving a person more isolated. Therefore, it is important to recognize how important consistent contact from an IHSS provider can be.

It is important to remember that someone who is manic one week may be depressed the next. Therefore, your first assessment may not include all the information you need. A consumer who is manic may have the energy to do shopping and cleaning for themselves. However, this same person when depressed may have no energy to do any household tasks or even bathe himself/herself.

Techniques in Interacting with People with Bipolar Disorder

If a person is in a manic state, it can be tiring or even frightening. An IHSS provider or social worker can feel frustrated with an inability to focus or calm down a consumer. It is important to recognize that trying to calm someone down may not work. A person in a manic state is like a freight train running at full speed. It may be dangerous for you if you try and stop that freight train. As noted in an earlier example, a mother who tried to reason with her son became assaulted.

Therefore, avoid intense conversations with someone in a manic state. Do not debate or argue with her/him. Although his/her statements and beliefs may seem bizarre and incomprehensible, it is useless to argue with him/her. If he/she describes a new invention or plan to end world hunger, do not debate this. Try and gently steer the conversation to your interview goals. In addition, do not take a person's comments personally. Someone in a manic state who is acting irritably may say hurtful or mean things (Palo Alto Medical Foundation, n.d.). Do not become offended or act defensive. You may find that a person who says hurtful things in a manic state may feel very guilty for his/her behaviors when he/she eventually becomes depressed.

IHSS providers should prepare meals that are easy to eat such as peanut butter and jelly sandwiches or other finger foods. A person who is feeling manic may not want to sit down to eat a full meal. As with other people who are in anxious or excited states, keep the surrounding environment as quiet as possible. Speak calmly and at a low level, never raising your voice to compete with your consumer. If your consumer becomes agitated or argumentative, excuse yourself from the interview. Always have an exit strategy, creating a space where you can easily leave a consumer's apartment. Try not to have your agitated consumer situated between yourself and the exit. In addition, give your consumer some physical space. If he/she is feeling manic, he/she may want to move around a larger area. If a consumer appears to be agitated or angry to the point of threatening you, you should contact your supervisor or possibly the police, after you exit his/her room.

It is important to recognize that because someone in a manic state can be exhausting, others may not want to interact with him/her. Visits from an IHSS provider or social worker can help a consumer feel less isolated (Palo Alto Medical Foundation, n.d.). In conducting an assessment, getting needed information from someone who is manic can be difficult. His/her rants and excited dialogue can leave little room for an interruption. As with a schizophrenic consumer, you can use the reframing technique. You can recap what he/she is talking about, saying, "that sounds interesting," possibly repeating what he/she is talking about. This gives you a chance to move on, but also a chance for the consumer to feel heard.

As with any mental disorder, someone in a manic state is not feeling or acting normally. He/she should not be blamed for his/her behaviors. Keeping this in mind may make it easier for you to work with him/her, not taking his/her comments or actions personally. Also, the consumer you see as having an elevated and excited mood one week may be depressed and suicidal the next. The feelings of being on top of the world will change to feelings of being in a pit of despair. It is crucial to question a consumer in depth, if he/she expresses suicidal behaviors. If there is any concern about one's desire to hurt himself/herself, contact your supervisor and the police or a mental health specialist for an evaluation.

Bipolar and Related Disorders

Characteristics

- Consumer will have both manic and depressive episodes.
- Manic episodes include elevated or irritable mood, racing thoughts, and possible hallucinations or delusions.
- Someone who is having a manic episode may start unreasonable projects or engage in unsafe behavior. He/she may be charming or hostile.
- A person having a manic episode may not have the need to sleep for more than a couple of hours. As mania worsens, psychiatric hospitalization may be needed.
- Drugs may trigger the manic episode, or make it worse.
- Eventually, the manic episode turns into a depressive episode that can be more severe than just general depression.
- Bipolar depression may cause more suicidal thoughts or attempts than general depression will.
- All characteristics regarding depression, discussed in an earlier section, are relevant here.

IHSS Functional Limitations

- A consumer experiencing a severe manic episode may not have the ability or feel the need to keep their homes or their person clean.
- An elder consumer in a manic episode may ambulate beyond their normal abilities, causing a risk of falling.
- A consumer in a manic episode may not want to eat much, especially sit down meals.
- In a manic state, a person may feel that they have no medical problems, causing them to not take his/her medications.
- As the manic episode drops out and becomes depression depressive episode, consumers will have problems with more ADL/IADLS.
- A depressive episode will cause a person to be less interested in paying bills, shopping, cleaning, or cooking meals.

Techniques in Interacting with People with Bipolar Disorder

- Avoid arguing or engaging in intense conversation when a consumer is manic.
- Use a calm and unhurried tone of voice.
- Give the consumer a large space to move in, turning down unnecessary noises from a television or radio.
- To get your questions asked, try recapping what the consumer said and then move on to your assessment.
- If the consumer gets hostile or loud and will not calm down, excuse yourself politely and leave.
- Never judge or put blame on the consumer for his/her behaviors. You may find the same consumer a week later, depressed and feeling guilty for what he/she said or did in a manic state.

Depressive Disorder

Depressive disorder is one of the most common mental disorders. A person can be depressed because of a death in the family, a loss of income, or a divorce. Most people have gone through some time in their life where they have felt depressed or sad. However, it is important to distinguish between a time-limited depression and a major depressive disorder, which is ongoing. Contrary to society's general belief, a person with major depressive disorder can not will themselves out of that condition. Even with therapy, medication, and exercise, a person may still be depressed. Many intelligent and successful people suffer from major depression. For the population you work with, depression can be especially prevalent since people are being influenced by loss of functioning, environmental and financial factors. As with other mental disorders, drug or alcohol use may be used as self medication and as an escape from the socio-economic and psychological perils a person is experiencing.

A major depressive disorder is characterized by having a depressed mood for most of the day for nearly every day, as indicated by either subjective report or observation made by others. Other symptoms include a markedly diminished interest or pleasure in activities; significant weight loss when not dieting or gain weight or decrease or increase in appetite; insomnia or excessive sleep; agitation or lethargy; fatigue or loss of energy; feelings of worthlessness or inappropriate guilt; diminished ability to think or concentrate, or indecisiveness; or recurrent thoughts of death or suicidal thoughts (American Psychiatric Association, 2013).

Physically, a person who is depressed may have poor posture, walking with a slow gait. They may speak slowly and softly, not having eye contact. They may understate their need for help, not wanting to bother you, feeling ashamed about their depression. Particularly with elderly clients, it may be difficult to recognize if they are depressed. Some elders have slow or poor ambulation due to age. Unfortunately, an elder may be seen as being demented before they are seen as being depressed. An elder's memory can be affected by depression, which can mimic dementia symptoms. However, with most depressed elders, unlike elders with dementia, they will more often complain of memory problems (Kansas State University, n.d.).

Also because of the stigma with mental disorders, especially for an older generation, elders may not be forthcoming about being depressed. Depression can be expressed through physical complaints, either imagined or real. A client may describe problems with sleeping or lack of appetite, which can be signs of depression. Unlike most people with dementia, a depressed elder's engagement in the conversation may seem impaired (Kansas State University, n.d.). One important similarity to bear in mind is that demented and depressed elders can both have severe limitations in their ability to conduct activities of daily living.

Depression can also take unexpected forms. You may imagine a depressed person as being sullen and tearful. However, someone who is depressed may also be aggressive and angry. He/she may direct his/her anger at you, saying you are not helping enough or that you don't care. Or, they may express anger at their living situation or relationships with other people. It is important to understand that people who are depressed may have significant problems in relating to others. They may express their sadness or despair through anger.

In the section involving how to interact with depressed individuals, there will be a discussion about suicide risk. People experiencing depression should be asked about suicidal intent. Although this is beyond questioning and assessing for IHSS needs, it is crucial information to be gotten. You may be the only person this client has interacted with or has discussed depression with. Therefore, you are in a unique position to assess for suicidal risk and your actions may save this person's life.

IHSS Functional Limitations

As with schizophrenia, people with depressive disorder may exhibit different levels of functional ability in activities of daily living. A mildly or moderately depressed person may be able to function well in society, having a full time job. A person with severe depressive disorder however, will have marked impairment in their activities of daily living. Of course, this is a consequence of the disorder and not within his/her ability to control.

In one German study, researchers found that depressed elders were twice as likely to have problems with toileting, dressing, grooming, getting out of bed, cutting food, and taking medication as non-depressed elders. In addition, these depressed elders were twice as likely to have difficulties in handling their finances, shopping, cleaning house, or visit their doctor as non-depressed elders (Braune & Berger, 2005, p.178).

Because of a loss of energy and diminished ability to concentrate that is inherent in depressive disorder, daily tasks can become unbearable. A simple change of clothes can seem impossible. Preparing a meal or cleaning an apartment can be monumental. If your client spends most of his/her time lying in bed or pacing in his/her apartment, his/her ability to shop or cook for himself/herself is probably poor. Depression can be a never ending cycle. If a person is living in poor physical conditions, his/her inability to correct this can make him/her feel more depressed. A regular visit by an IHSS provider can not only provide needed human contact, it can also make a person feel better when his/her living space is cleaner.

Techniques in Interacting with People with Depressive Disorder

Though your job as an IHSS worker is not to provide therapy to a client with depressive disorder, you can provide real support and engage a person in a way that can better help you provide services. As in your work with any client, your first job is to establish rapport. Having rapport is gaining a mutual understanding or agreement between two people. Most importantly, this means that you and your client need to agree that you can both work together, and that he/she knows that you can serve him/her.

Establishing this rapport includes many steps. First, you should be friendly and non-judgmental. You should also not appear hurried, showing that you have time to spend with this person. You should define what confidentiality requirements you have with them, as well as what the limitations to confidentiality are. Interview the person alone, making sure that your meeting space gives the client a safe space to talk. Before talking about sensitive issues such as medical or psychological history, ask this person's permission (National Health and Medical Research Council, 2004). This will make him/her feel like you respect him/her more; consequently, it makes him/her want to reveal more. And most importantly, listen to the client. Listen without judging. If there are moments where you can offer praise or positive feedback, do this as well.

Listen without having to feel like you need to respond to a person's comments by saying something like, "Everything will be okay". For a client who is depressed, this reassurance will sound hollow and lacking in empathy. A simple non-verbal gesture of understanding or statement like "I hear what you are saying, that must be really hard to be going through that" can make a positive difference. Remember that with empathy, you are better able to understand how the environment, socio-economic factors, and loss that impacts his/her mood and his/her ability to adequately perform activities of daily living.

Suicide If you assess or are told by a client that he/she is depressed, you will want to question more. Although it may feel unnatural to do so, you should ask about any suicidal feelings. Some may feel that by asking about this, they are giving a client the idea to commit suicide. That is not true. Questions about suicidal intentions will not give a person any ideas that he/she did not already have (Preskorn, n.d.). In fact, it will probably be a relief to him/her that you care enough to ask about it.

Risk factors for suicide include being male, being older, having previous suicide attempts, using alcohol, having a lack of social support, having a medical sickness, lacking a significant other, and having a plan for committing suicide (Preskorn, n.d.). In questioning them about suicide you can say, "You sound as if you have been feeling pretty miserable. Has life ever seemed not worth living?" (Preskorn, n.d.) Or, you could simply ask your client if he/she has ever felt suicidal before.

After determining that this person has felt suicidal, you will want to ask if these feelings are recent. Then you will want to ask if he/she has thought about acting on these thoughts. A client may say, "I wouldn't actually do it" or "I would never do it, it's against my belief system". If a person states that they have thought about acting out suicidal thoughts, you should question if they have plan. If they do have a plan, ask what it is (Preskorn, n.d.). If a person describes the plan, ask if they have means to execute this plan. If a person plans on shooting himself/herself, this may be less risky than someone who plans to overdose on medications, if he/she does not have access to a gun.

If the person has a plan and has the means to carry it out, ask when he/she plans on doing this or if he/she has already started carrying out the plan, like overdosing. Even if the level of suicidal risk seems low to you, you should still consult with your supervisor. However, if the risk of suicide appears imminent, you may need to intervene by calling your supervisor and the police or a mental health specialist.

Depressive disorder

Characteristics

- Client appears sad or tearful.
- Client's posture, gait, and speech are slow. The client may also have a decreased tone when speaking.
- Alcohol/drug use may be present.
- The client may complain of restlessness or sleep deprivation.
- The client may show excessive weight loss or weight gain.
- The client may express feelings of excessive guilt or worthlessness.
- Although a depressed person will appear sad, they may also exhibit anxiousness or anger.
- The client has probably lost interest in activities that were once pleasurable.
- The client may complain of memory problems or difficulty concentrating, especially if they are older.
- The client may have a loss of energy or have fatigue.
- The client lives alone and/or was close to someone who recently passed away.
- The client may talk about death or express suicidal thoughts.

IHSS Functional Limitations

- Because of a lack of concentration, tasks such as bill paying, or shopping can be difficult.
- A client's sense of worthlessness or apathy can affect their ability to want to be clean or keep his/her dwelling clean.
- Depression can cause a lack of appetite and a desire to cook meals.
- Severe depression will make it difficult for a client to even get out of bed.

Techniques In Interacting With

- Develop rapport by showing that you are willing to spend the time to listen to your client. Show empathy and understanding by putting yourself in your client's shoes.
- Do not blame the client for his/her depression. Separate the disorder from your client. Do not expect a client to be able to do household tasks if they are depressed, even if they appear physically able to do so.
- Do not offer empty promises like "things will be okay". Listen to the client. It is okay not to have advice. The best thing you can do is show that you care enough to listen. This can be done without even talking.
- Give you and your client a private place to talk.
- Establish trust by explaining confidentiality rules.
- Assess for suicide risk by asking if the client has thought about harming himself/herself before. If so, ask if this is recent, does he/she have a plan and the means to carry it out.

Personality Disorders

Personality disorders are different than mood disorders because they describe long-term "ingrained, enduring patterns" in a person's personality (Maxmen & Ward, 1995). Therefore, someone with anxiety or depression may have cycles of mood disturbances. A personality disorder, on the other hand, looks at how one's personality may affect his/her ability to relate to others. Personality characteristics turn into a personality disorder when they are "inflexible and maladaptive" and "significantly impair social and occupational functioning" (Maxmen & Ward, 1995). In looking at personality traits, it is important to recognize that they are neither good nor bad in themselves. A person walking down a dark alley may feel paranoid of being attacked or robbed. In this situation, being paranoid is helpful since it helps to create a heightened sense of awareness. However, for someone with Paranoid Personality Disorder, he/she may feel paranoid or distrustful in most social situations (Hales & Hales, 1995).

Personality disorders are clustered into three different categories. These include individuals with "odd or eccentric behavior," "dramatic, overemotional, and erratic behavior," and "highly anxious and fearful affects" (Maxmen & Ward, 1995). In this training, we will look at two disorders which involve dramatic, overemotional and erratic behavior. Individuals with these disorders may be difficult to work with, alienating social workers and IHSS providers. Understanding one's traits will help decrease your negative feelings or reactions towards a consumer.

For this training, we will focus on Borderline and Histrionic Personality Disorders. In one study, it was found that among psychiatric patients with personality disorders, Borderline Personality Disorder was the most common. In the same study, it was found that 36% of patients were diagnosed with a personality disorder (Maxmen & Ward, 1995). Therefore, these people may have other psychological issues, like severe depression. Because these individuals may be difficult to work with, they may isolate themselves through their behavior. This can lead to periods of depression and suicidal attempts (American Psychiatric Association, 2000).

Borderline Personality Disorder

A person with Borderline Personality Disorder lives on a psychological border or edge. Relationships with others, moods, and one's sense of identity appear to be unstable. A person with this disorder will have instabilities in his/her relationships, self-image, and marked impulsivity in a variety of contexts that begins by early adulthood (American Psychiatric Association, 2013). As in other personality disorders, someone with this disorder will have difficulties in creating meaningful attachments with others. His/her behavior is characterized by intense reactions. Emotions are intense and raw. Sadness, worry, and anger are magnified. Relationships with others will be intense and turbulent.

At the core of someone with Borderline characteristics is an overwhelming sense of emptiness. He/she will always try to avoid being alone or abandoned (Hales & Hales, 1995). Sexual relationships can be intense but do not appear to be intimate. Because of a real or imagined feeling of abandonment, he/she may cling to others. However, because he/she may also fear being engulfed in a relationship, he/she will also push others away. This intense push and pull behavior will involve manipulative behaviors. He/she may idolize another person, and then completely devalue him/her. This devaluing may be accompanied by intense or inappropriate anger. These behaviors will cause others to abandon this individual. Therefore, the chronic feelings of emptiness worsen, leading to repeated suicidal threats or self-mutilating behaviors (Hales & Hales, 1995).

A consumer may also use suicidal threats or attempts as a way to draw in therapists and others in helping professions. Because this person has a difficulty with creating and maintaining stable relationships, this extreme call for help is characteristic of the disorder. This act, along with expressions of anger, is a manipulative technique to make you feel guilty for what the consumer perceives as abandonment. A consumer will act in extreme ways to try and keep others near, although it is done inappropriately and may actually drive others away (American Psychiatric Association, 2000).

An individual with Borderline Personality Disorder may also be impulsive in “potentially self-damaging” behaviors, such as, spending, sex, substance abuse, reckless driving, or binge eating (American Psychiatric Association, 2013). These behaviors are a way a person deals with his/her feelings of emptiness and unstable sense of self. Since he/she does not know how to get help in better ways, self-destructive activities are the alternative.

A person with this disorder simply lacks the ability to deal with situations and people in an appropriate way. His/her intense reactions are a result of his/her thinking in absolutes. Therefore, one can feel intense love or hate for others. This is referred to as “splitting” (Turner, 1992). For example, a person may be very fond of his/her caregiver one day, and then feel hostile to him/her the next. This feeling of hostility or disappointment can occur for no seemingly rational reason. A consumer may express one’s admiration for you during an interview, while talking negatively about another worker. This same consumer, conversely, may harshly criticize you when meeting with the other worker.

It is believed that this disorder may affect women more than men on a ratio of 3 to 1 (American Psychiatric Association, 2000). However, men may be diagnosed less, due to destructive or violent behaviors leading to imprisonment rather than therapy (Hales & Hales, 1995). One author notes that this disorder, along with other personality disorders, can be detrimental to elders. Because elders may be in need of help with daily activities of living, having a network of social support is crucial. However, this support may be absent due to a consumer’s inability to sustain friendships and relationships. Therefore, he/she will be an immense challenge for social workers as he/she ages (Rose, Soares, Joseph, 1992, p.153). In addition, even if a consumer accepts help, providers may continuously quit due to the consumer’s difficult behaviors.

<u>IHSS Functional Limitations</u>

Someone with Borderline Personality Disorder or another personality disorder can have severe functional impairments, especially among the elderly (Abrams, 1996). Someone with this disorder may alienate others, rejecting needed help. With the elderly, this isolated lifestyle may put him/her at great risk. Even if someone is receiving IHSS, he/she may be at risk of losing them if he/she becomes too difficult to work with.

One author characterizes a person's state of mind with this disorder as being a "run-away freight train". Because one's relationships and behaviors are usually unstable, a person can feel overwhelmed in dealing with them. Dealing with one's chronic feelings of emptiness and negativity become a priority. Unfortunately, dangerous drug-taking binges or suicidal gestures are ways a person may deal with these feelings. Because everything appears to be so overwhelming, meal preparations, shopping, or personal hygiene may not be a priority (Parkman, 2002).

In addition, this same author notes that many individuals with this disorder come from backgrounds of abuse and neglect. Therefore, basic skills in hygiene and housekeeping may not have been learned (Parkman, 2002). Because this disorder can coexist with depression, activities that suffer from feeling depressed, like bathing or doing housework, will also be deficient for those with this disorder. She also states that people with this disorder are easily distracted from having a routine, making it difficult to take medications regularly (Parkman, 2002).

A person with this disorder may have difficulty shopping or taking public transportation. During periods of depression and distress, one may find it difficult to leave the house or be around others. In addition, one may find it difficult to do anything alone, having the need to have company when shopping or in doing activities (Parkman, 2002).

Techniques in Interacting with People with Borderline Personality Disorder

Working with a consumer with Borderline Personality Disorder can be extremely challenging. Imagine working with a consumer whose cries for help involve blaming and manipulating others into paying attention. Suicide attempts may even occur. A person with this disorder may get a social worker to be inappropriately or overly involved by appearing to be in crisis. This can trigger feelings of guilt or a need to try and save this person. Conversely, this constant cry for help can be frustrating to a provider, leading to a premature withdrawing of his/her case (Rose, et al., 1992, p.164).

A benefit of being a social worker or provider of in-home support services is that you are able to offer tangible and concrete services. Stable in-home support can be just as nurturing and helpful as a psychotherapeutic relationship (Rose, et al., 1992, p. 162). It will be important to be clear with a consumer on what services you provide. Never offer more than you can do for a consumer. Reassurance can be a trap for manipulation or blame (Eddy, n.d.). A consumer in your first visit may describe how wonderful you are, blaming others for taking no interest in his/her case. This may cause you to feel more responsible for him/her, providing services that will get you over-involved.

It is important to remember that you as well as IHSS providers can be subject to manipulation or blame. An IHSS provider may be compelled to do more than they should be doing, due to feeling guilty. Manipulation by a consumer may be in the form of immense praise or extreme criticism, causing the provider to want to win the consumer's approval. On the other hand, a provider may quit quickly, not wanting to deal with such a consumer. As the social worker, you should provide information on this disorder to providers who serve people with Borderline Personality Disorder. You should also encourage him/her to work with the Public Authority or give referrals to other agencies that can teach him/her in sending boundaries with the consumer. Boundary setting should include only doing the tasks allotted for as well as not lending money to the consumer.

It is essential to have communication with the consumer's other social workers and therapists. Because a consumer may have the tendency to talk negatively about others, you will want to know what each person does. Therefore, you can set limits better with a consumer, explaining to them what person is most appropriate for his/her specific needs. For example, a consumer may ask you to take him/her to the bank, although you are only there as a social worker reassessing his/her in-home needs. The consumer complains that he/she needs money today, and that he/she does not want the normal IHSS provider to do it. He/she blames the worker for not being caring or patient.

A situation like this shows how a consumer can pit caregiving professionals against each other. It would be inappropriate to take this consumer to the bank, knowing that someone else is assigned to do the job. Therefore, it is essential to set limits from the start, letting the consumer know what you can and cannot do. Also, by having regular contact with other professionals, you can get support and feedback on how the consumer manipulates them.

Always be patient and do not take the consumer's statements personally. It is normal to feel angry and hurt when a consumer blames you for not helping them. However, you must recognize this, so that you do not retaliate in anger. Take a step back, knowing that a consumer's intense behavior is actually an expression of how lonely and miserable they feel. For example, a consumer may call you consistently, complaining of medical problems. He/she may blame you and others for not caring. It will be more helpful to simply acknowledge whatever pain the consumer is experiencing than acting defensive towards his/her comments (Rose, et al., 1992, 162).

If you feel yourself getting angry at a consumer because of his/her constant demands or manipulative behaviors, talk with your supervisor. Frustration and anger can lead to abandoning or ignoring a consumer. For instance, a consumer may be yelling at you, stating that he/she is going to slit his/her wrists because he/she feels that you are not helping. Since you are frustrated with him/her, you may ignore this threat as being another plea to get your attention. However, people with Borderline Personality Disorder have an elevated risk for suicide attempts, making the potential for self-injury or death very real. Therefore, consult with a supervisor, law enforcement, or a mental health specialist immediately if your consumer threatens suicide.

When meeting with a consumer, stay focused on your goals, possibly outlining with the consumer what you mean to accomplish in that meeting. This can help in directing the conversation, being very clear on your role. If a consumer becomes angry, listen respectfully and calmly. A consumer may talk badly about another social worker you know. Never take sides or reinforce what the consumer is saying. Just listen and try to move on with your interview as quickly as possible (Eddy, n.d.). However, when a consumer is angry, always be concerned for your safety. If a consumer appears to be threatening or does not calm down, you will want to exit the interview. Although you know that his/her anger is misdirected, the physical expression of anger can be very real.

Histrionic Personality Disorder

Someone with histrionic tendencies have a need to be the center of attention. His/her "speech, dress, and mannerisms are theatrical" (Hales & Hales, 1995). There is a need to be dramatic. Emotions seem exaggerated, and there is a constant seeking of reassurance and a concern for looking attractive (Rose, et al, p. 157). Situations that may not be stressful to another person may cause outbursts or temper tantrums in someone with this disorder. He/she may also use tantrums or emotional outbursts to get needed services or attention (Hales & Hales, 1995). Also, he/she may crave excitement and stimulation, feeling that normal routines are boring and dull (Maxmen & Ward, 1995).

In addition, a person may be perceived by others as being shallow, having a superficial charm. He/she may consider relationships to be more intimate than they actually are, being overly trusting. A person with histrionic characteristics may be sexually seductive or overly concerned with his/her appearance. Although this person may appear sexually provocative, his/her sexuality can be constricted and unfulfilling (Maxmen & Ward, 1995). Relationships and friendships may be strained due to dependent behavior, the consumer making continuous demands for reassurance. Consequently, a person can feel depressed when they are not the center of attention. Research suggests that consumers with this disorder may have an increased risk for suicidal behaviors (American Psychiatric Association, 2000). Therefore, like Borderline Personality Disorder, this disorder can co-exist with severe depression.

It can be difficult to interview someone with Histrionic Personality Disorder. His/her description of events may be vague. For example, in asking someone how long he/she has felt depressed, the consumer may answer, "Forever, a very long time" (Maxmen & Ward, 1995). Therefore, a consumer's speech and descriptions can appear impressionistic and lacking in detail. This can be frustrating for a social worker, attempting to discover what a consumer's needs are. One author notes that a consumer with Histrionic Personality Disorder may overburden providers, having complaints that are not real. For instance, he/she may complain of dying, but he/she is "actually shopping at the mall" (M. Parkman, personal interview, December 29, 2005).

As a person ages, this behavior can be harmful, because others may not take health concerns seriously. Descriptions of pain may be seen as normal attempts for attention. Therefore, needed treatment may not occur. Because of a need to be the center of attention, a drop in social activities can be a reason for concern. This may be indicative of real medical problems (M. Parkman, personal interview, December 29, 2005).

IHSS Functional Limitations

Because this disorder can co-exist with depression and Borderline Personality Disorder, you should be mindful of functional limitations noted in those sections. Like a consumer with borderline characteristics, a person with histrionic tendencies may unintentionally drive away assistance. He/she may have an emotional outburst that could drive away needed assistance, creating an isolated environment for him/her. It is also important to keep in mind that a consumer may exaggerate and be dramatic to get attention. Therefore, when asked about functional impairments, a consumer may exaggerate medical symptoms or functional limitations (PsychNet-UK, n.d.).

As a worker assessing for IHSS needs, you will want to look for tangible evidence of a person's deficiencies. Therefore, you will have to look for physical evidence of poor housekeeping or grooming. A consumer's description of needs may be vague. You may ask how often he or she cleans with the consumer replying, "I have to do everything myself, it is so difficult!" Because you may not get the information you need from conversation, getting physical evidence is crucial. Also, keep in mind that a consumer may have real difficulties with medical issues or in-home needs. However, because he/she may have "cried wolf" many times before, no one listens. If a consumer appears to be dropping out of social activities that he/she engaged in before, this is a good sign that the consumer may have medical problems or physical limitations.

Techniques in Working with People with Histrionic Personality Disorder

As with Borderline Personality Disorder, working with someone who has histrionic tendencies can be draining. A consumer with this disorder can be demanding, using dramatic flair to get his/her way. It is important to recognize how involved you are getting with a consumer. Do not over-extend yourself, or prematurely withdraw from working with a consumer because you are frustrated. As with consumers with Borderline Personality Disorder, set limits (Rose, et al., 1992, p. 158). Do not promise more than you can provide. Also, do not take a consumer's outbursts or temper tantrums personally. Again, this is a way the consumer has learned to express how lonely or miserable he/she feels.

Also recognize that someone with histrionic tendencies may over-exaggerate his/her needs or problems. The use of vague descriptions to explain his/her problems will make it difficult to get needed information. Carefully interview the consumer, getting concrete examples of help she/he needs. Also, this superficial behavior may make it difficult to establish rapport with a consumer. A consumer may try to win you over with his/her charm. This can be enjoyable but also frustrating if you are not able to get your job done. A male social worker working with a histrionic female may even find the consumer to be flirtatious and seductive (Sperry, 2003).

Because a consumer can be vague and dramatic, do not use open-ended questions or questions that do not elicit specific information. Instead of asking, "How are you doing with shopping?" you will want to ask how many times, specifically, this consumer shops a week or month. You may need to redirect a consumer's speech, the consumer being easily sidetracked (Sperry, 2003). Reframe and repeat back what a consumer is saying, letting him/her know that he/she is being listened to. Then move on to your questions, possibly explaining the need to get specific answers for assessment purposes.

Although it will be tempting to do so, do not ignore a consumer's complaints. His/her dramatic flair and cries for help may make you pay less attention to them. However, this can be dangerous, due to the consumer possibly needing real help. With regards to suicidal gestures, people with Histrionic Personality Disorder may have an increased risk for this behavior. Always take comments about suicide seriously, whether or not you believe your consumer is just seeking attention. Also, physical or medical complaints may be real, even though a consumer appears to be dramatic. When a consumer ages, it is especially important to recognize that he/she may have real medical problems. If a consumer is not engaging in social activities that he/she enjoys, this is a good indication of real disabilities or medical problems (M. Parkman, personal interview, December 29, 2005).

Borderline Personality Disorder

Characteristics

- The consumer may have unstable relationships and a poor self-image.
- Emotions are raw and magnified. Anger may be inappropriate or difficult for the consumer to control.
- The consumer will have chronic feelings of emptiness.
- The consumer may be very clingy and demanding, or push others away.
- Suicidal gestures or self-mutilating behaviors can be common. The consumer will do this to bring others in closer, having a fear of abandonment.
- The consumer may have impulsive behaviors in potentially harmful activities like gambling or drinking.
- The consumer thinks in absolutes, alternating between idealizing and devaluing a person, known as "splitting."
- This disorder is diagnosed in women 3 times more often than in men.

IHSS Functional Limitations

- The consumer, due to his/her behaviors, may isolate himself/herself. Therefore, as a person ages, his/her situation may become worse, due to pushing away needed help.
- Activities of daily living like bathing, shopping, or meal preparations may not be a priority. Managing negative internal states and feelings will be more important to a consumer.
- Because a consumer may have come from a neglectful or abusive environment, he/she may not have had proper training in activities of daily living.
- The consumer may have problems in doing things alone, making it difficult to shop or be on public transportation by himself/herself.
- The consumer may also feel overwhelmed in social situations, causing more isolation.

Techniques in Interacting with People with Borderline Personality Disorder

- Do not take the consumer's comments or behaviors personally.
- Remain calm and professional, never dealing with the consumer's anger by being angry yourself.
- Recognize your own difficulties in working with the consumer. Do not let frustration lead to withdrawing or ignoring the consumer.
- Do not over-extend yourself, recognizing when the consumer is trying to manipulate you into feeling guilty.
- Be clear about your role and be firm on what you can do for the consumer. Coordinate with others to see what they do for the consumer.
- Do not take sides when the consumer talks negatively about others.
- Be aware that the consumer's anger can be dangerous. Leave an interview if you feel unsafe.
- Remember that suicidal gestures can be common. Always take threats seriously.

Histrionic Personality Disorder

Characteristics

- The consumer may feel the need to be the center of attention, using dramatic flair. He/she may be vague when describing problems and needs.
- The consumer may have outbursts or temper tantrums if he/she does not feel others are paying attention.
- The consumer may be sexually provocative, overly concerned about appearances.
- Depression can occur, if a consumer is not attended to. The consumer may be demanding, appearing to exhibit dependent behaviors.
- The consumer may exaggerate his/her needs. When describing needs, the consumer may be vague and overly dramatic.
- The consumer may be overly trusting in others.
- There is an increased risk for suicidal gestures with this disorder.

IHSS Functional Limitations

- This disorder can co-exist with depression. Impairments are similar to those when a consumer is depressed.
- A consumer may drive away needed help due to his/her behaviors.
- As a person ages, he/she may have real needs. However, because the consumer may have kept others from taking him/her seriously, his/her needs are not being attended to.

Techniques in Working with People with Histrionic Personality Disorder

- Because the consumer may be demanding and overly dramatic, it is important to get tangible evidence for the consumer’s needs.
- As in working with someone with Borderline Personality Disorder, recognize your own reactions. Do not get overly involved or withdraw from working with a consumer because of your own feelings.
- Do not take the consumer’s outbursts and temper tantrums personally.
- When interviewing, avoid open-ended questions, trying to get concrete examples of the consumer’s needs.
- If the consumer is tangential, politely interrupt by recapping what he/she said, and then move on to your questioning.
- If a consumer expresses suicidal thoughts, take these threats seriously.

Obsessive-Compulsive Disorder

In the United States, Obsessive-Compulsive Disorder affects 1 in 50 adults (psychguides, n.d.). Another estimate shows that 2 to 3 percent of the U.S. population has this disorder, making it more common than having schizophrenia (Hales & Hales, 1995). A person with this disorder will more than likely have both obsessions and compulsions. However, it is possible to have just obsessions or compulsions. This disorder can affect people at any age, one study suggesting that obsessive-compulsive traits worsen with age (Engels, Duijsens, Haringsma, Putten, 456).

Obsessions are "intrusive, irrational ideas" that repeatedly spring up in one's mind (Hales & Hales, 1995). These thoughts can range from worrying that a car door is not locked to having obsessive fears of having harmed another person. An example of this is a person leaving for work, believing that he/she may have run over a dog or child, repeatedly imagining this scene. Having a concern that you have not locked a door or turned off your stove can be normal. However, a person with obsessive-compulsive traits will be consumed by the idea of having left the stove on, even after checking that the stove is off (American Psychiatric Association, 2000).

Common obsessions include having an irrational fear of germ contamination, intrusive sexual thoughts or urges, and a need to have things in a certain order (psychguides, n.d.). With regards to organization, if things are not placed in a particular order, severe distress or anxiety can occur. As discussed before, another common obsession is having repeated doubts, like believing one has run over a child. Also, a person may have intense recurring fantasies of physically harming someone else or a fear of shouting out obscenities in public. To the person experiencing these obsessions, he/she will probably recognize that these obsessive thoughts are irrational and senseless (helpguide, n.d.). However, the person is faced with intrusive thoughts that he/she cannot get rid of.

Compulsions, the companion to obsessions, are used as a way to prevent or keep intrusive thoughts away (helpguide, n.d.). As seen in the movie "The Aviator," the character of Howard Hughes had an obsession with germs, feeling that a handshake would contaminate him. Therefore, the compulsion of hand washing until his hands bled was a relief from his obsession. Compulsions can include counting, repeating a phrase, or walking without touching pavement cracks (Hales & Hales, 1995). They can also include checking things repeatedly, such as a stove that one thinks he/she left on, or retracing a road where one thought he/she hit someone. If someone has reoccurring thoughts that something bad may happen to him/her or others, repetitive rituals serve as a protection against this. Therefore, a ritual is performed with a person saying to himself/herself, "Something bad will happen unless I do this" (Maxmen & Ward, 1995).

These obsessive-compulsive behaviors consist of a disorder when they cause marked distress in a person's life. Therefore, these obsessions or compulsions must take up at least one hour a day. In addition, these thoughts or behaviors must cause impairment in one's normal routine or daily functioning (American Psychiatric Association, 2000). Someone with Obsessive-Compulsive Disorder is different than someone with schizophrenia since the latter individual cannot distinguish between reality and fantasy (psychguides, n.d.). Most often, a person with Obsessive-Compulsive Disorder will feel guilty or bad about their behaviors, knowing that they are irrational (Hales & Hales, 1995). Therefore, he/she may try to keep such rituals private and may be too ashamed to discuss them (Maxmen & Ward, 1995).

As with other mental disorders, it is important to recognize that a person with this disorder may self-medicate. He/she may drink heavily or use drugs to make obsessions and compulsions less intense (psychguides, n.d.). It is also important to keep in mind that this disorder afflicts people of all ages. One recent study showed that older consumers may have more obsessive-compulsive traits than younger age groups (Engels, et al, 456). One compulsion that some elders have, hoarding, may be related to obsessive-compulsive characteristics. Although there is current debate on whether this behavior is absolutely linked to this disorder, there still may be a connection between the two (Neziroglu, Bubrick, Yaryura-Tobias, 2004).

IHSS Functional Limitations

As noted before, a person's obsessions and compulsions can cause impairment in one's daily activities. He/she may be consumed by hand washing for an hour straight. Or, he/she may come back and forth to his/her apartment for the whole day, checking to make sure the stove is turned off. A consumer's planned trips to the market or to the bank may not occur because of this. He/she may repeat a phrase or count to a hundred by 2 incessantly, trying to manage and erase an obsession from the mind. As you can imagine, such behaviors can keep a person from having a job, meaningful relationships, or even do simple tasks. These obsessions and compulsions may be so all consuming that a person becomes a prisoner to them.

One German study notes that people with Obsessive-Compulsive Disorder had significantly lower scores in general life satisfaction, compared to average Germans. In addition, those with this disorder had higher levels of unemployment and were more likely not to ever have married (Grabe, Meyer, Hapke, Rumpf, Freyberger, Dilling, John, 267). One can infer from this data that someone with these traits may have difficulty in maintaining long-term relationships. The disorder may make it too difficult for others to be around him/her, or too consuming for a consumer to retain such relationships.

Another study echoes these findings. Researchers found that the quality of friendships for those with Obsessive-Compulsive Disorder were less than for consumers with major depression (Calvocoressi, Libman, Vegso, McDougle, Price, 380). Therefore, having this disorder can isolate a person from the rest of the world. With little social stimulation, a person could be further consumed by his/her obsessions and compulsions. And as stated before, a person may be very ashamed of his/her behaviors, causing him/her to be more inward and private.

IHSS Impact

People with obsessive-compulsive traits will have difficulty with their activities of daily living. Because of their poor concentration and the need to maintain repetitive behaviors, important daily tasks may not be completed. Personal hygiene, household chores, eating, and managing money are often compromised (Calvocoressi, et al, 381). As a person ages, he/she may have more difficulty with activities of daily living, due to physical impairments. However, if his/her obsessive-compulsive traits are difficult for others to endure, an elder may have completely isolated themselves. In addition, the need to have a certain organizational scheme may make providing care unbearable.

If a person has a compulsion to hoard items, it can make in-home tasks like cleaning and cooking impossible. A consumer may find it difficult to part with seemingly meaningless objects, causing it difficult to clean, cook or even ambulate around one's clutter. Although there is not a direct link between Obsessive-Compulsive Disorder and hoarding, some people with this disorder may have the compulsion to hoard.

Techniques in Interacting with People with Obsessive-Compulsive Disorder

When you assess someone with Obsessive-Compulsive Disorder, he/she may not appear to be physically disabled. A consumer may not appear depressed or psychotic. Yet, you may find his/her hygiene to be poor, his/her apartment to be mess, and no edible food around. It is important to recognize that although a consumer may appear physically capable of conducting activities of daily living, this disorder could disable him/her. In addition, a consumer may not be forthcoming about having obsessions and compulsions, since he/she is ashamed of the behavior.

It may be difficult in one visit to assess for obsessive-compulsive traits, especially when a consumer is not forthcoming. It will be most helpful to have a diagnosis from a psychiatrist or physician who diagnoses mental disorders. Therefore, you could make a better assumption about why a consumer's hygiene or other daily activities seem to suffer. During your interview, the consumer may have difficulty focusing or be mentally consumed by some thought. This may be a clue to how a person can have problems with daily chores, not being able to separate from his/her own thoughts. Also, the consumer may be performing some repetitive behavior like hand-washing or cleaning one area during the interview.

Because a consumer may want to keep his/her behaviors secret, he/she may over-estimate the ability to conduct activities of daily living. The consumer may state that he/she prepares meals. However, due to the lack of food in the apartment, you surmise that this consumer does not seem to cook much. The consumer may be saying this rather than stating that obsessions keep him/her from going out to shop.

It is important, as with other people with mental disorders, to not judge a consumer. Look at the consumer's ability to do things. It may be difficult to recognize disabilities in a person with obsessive-compulsive traits, causing you to be less empathetic. Remember though, that this disorder can be very painful and possibly more disabling for a person than depression can be. Avoid comments like, "You seem capable of doing some cleaning." Most likely, a person with Obsessive-Compulsive Disorder will be ashamed of his/her behaviors, consequently ashamed of the condition of his/her apartment or appearance.

As with any person you work with, be patient and empathetic. Try to see the person apart from the disorder, recognizing that a consumer may feel totally helpless to this disorder. If a person is engaging in compulsive behavior at the time of an interview, know that he/she may be too consumed by it to work with you. An excuse like, "I am too busy now," may really mean that he/she is engaged in some thought or behavior that cannot be stopped. If a person seems scattered or lacking in concentration, keep your questions and comments direct, clear and concise (Center for Addiction and Mental Health, n.d.). Also, keep in mind that if you are feeling uncomfortable during an interview, a consumer may feel the same way. It is okay to ask a consumer if he/she is feeling uncomfortable, asking if you can correct something. The consumer may be upset that you have inadvertently rearranged something, but may not tell you, not wanting you to judge him/her.

For tips on working with hoarders, see the Hoarding section in the IHSS Training Academy: Phase 1 participant binder. As noted, a consumer may be very sensitive to his/her items being called "trash" or "junk". Likewise a compulsion like counting repeatedly or incessant hand washing may be the only ways a consumer can deal with obsessions. Therefore, although these rituals seem irrational, you as a social worker should be non-judgmental if a consumer discusses them. Above all, be patient and empathetic (helpguides, n.d.). Empathy can include listening and providing positive feedback, such as acknowledging the difficulties a consumer must endure with this disorder.

Obsessive-Compulsive Disorder

Characteristics

- This disorder usually consists of both obsessions and compulsions.
- Obsessions are intrusive, irrational ideas like having a fear of germs or a fear of having hurt someone.
- Compulsions are used as a way to deal with these thoughts or keep them away. They can include incessant hand washing, counting numbers, or repeating phrases.
- This disorder can affect people of all ages, although it may worsen for people as they age.
- Obsessions and/or compulsions must last for at least an hour a day and cause distress in one's life to be considered part of a disorder.
- Friendships and relationships may suffer greatly due to this disorder.
- Hoarding behaviors may be related to this disorder.
- A consumer may self-medicate by using alcohol or other drugs.

IHSS Functional Limitations

- A person may be so consumed by obsessions and compulsions that they have impairment in activities of daily living.
- This can include problems with hygiene, eating, household chores, and paying bills.
- These deficiencies may be worse for someone with Obsessive-Compulsive Disorder than for a depressed consumer.

Techniques in Interacting with People with Obsessive-Compulsive Disorder

- Do not judge the consumer. Be patient and empathetic.
- Keep conversation and speech concise and clear.
- Understand that a consumer's obsession or compulsion may keep them from being interviewed.
- If you feel like you are uncomfortable during an interview, the consumer may also feel uncomfortable. You can ask them if you could do anything different.
- Ask before touching or moving items to make room for your interview.

Hoarding Disorder

Because of the nature of IHSS, you have probably encountered clients who have hoarding and cluttering behaviors. This kind of behavior can occur at any age, but it may be related to more than just obsessive-compulsive tendencies as a person ages. Although hoarding and clutter may not require emergency interventions, it can still pose a serious danger to a person's safety. It can also be a health hazard for others living around him/her.

Older adults have been found to hoard items that they perceive as being valuable or that provide a source of security. They may have a fear of losing items or have physical limitations which hamper their ability to organize. They may have experienced stressful events such as the Great Depression, when material goods were scarce (LA County Department of Mental Health, n.d.). An overarching theme is that these items replace intimate relationships or friendships. They provide a comfort zone from the outside world that may appear threatening. Throwing out a piece of clutter can seem to a person like a piece of him/her is being thrown out.

You may be tempted to call a client's clutter "junk" or "trash". Although it may appear like trash to you, it is precious goods to the client. However, a client may perceive that you may think their clutter is "junk", being skeptical of letting you in. Again, you must show that you are non-judgmental and that the condition of his/her apartment does not bother you. Use a very gentle approach, not expecting them to throw out clutter in one visit.

Safety evaluation You should evaluate for a client's ability to ambulate and open doors around the clutter. You should also see if the clutter is near ovens or electrical outlets, posing a fire risk. Clutter may also be obstructing a client's ability to take shower or go to the bathroom. An appeal to have things moved around because of safety reasons may have some success. Over time, a Provider may be able to work with the client in getting rid of small portions of clutter. A hasty intervention may cause the client to become anxious and very depressed. For elders, hoarding behavior like drug use, can serve as a coping mechanism for depression (Dunn, 1995).

Techniques in Interacting with People who Hoard

Success with hoarding behavior can be difficult. One author notes that the only successful interventions involve "social pressure and legal process" (Dunn, 1995). This means that some people will only change if forced to, by either the Health Department or by risk of eviction. This threat can be a motivating factor in decreasing the client's clutter. By focusing on the client's risk to health and safety or possible loss of housing, he/she may be more willing to accept services. It is important not be confrontational when raising these risks. However, if your assertiveness comes from an empathetic and caring position, a client will be more likely to work with you. Also, if you feel that the client's hoarding behaviors pose a serious health and safety risk to himself/herself or others, you should consult with your supervisor and/or make a referral to an appropriate mandated reporting agency, e.g. Adult Protective Services.

Hoarding Disorder

Characteristics

- Hoarding behavior can occur at any age, but may be related to more than just obsessive-compulsive traits as a person ages.
- Persistent difficulty discarding or parting with possessions and distress associated with the discarding of those possessions.
- The hoarding results in the accumulation of possessions that congest or clutter active living areas and substantially compromised their intended use.
- Elders have been found to hoard due to a fear of losing items, having physical limitations, having organizing problems, or using items as a psychological replacement for loved ones and friends who have passed.
- Elders may also hoard due to generational concerns, such as surviving the Great Depression.
- Throwing away a client's clutter can be psychologically damaging to the client, feeling like a part of himself/herself is being thrown away. Hoarding behaviors may serve as a coping mechanism against depression, like drugs or alcohol.

IHSS Functional Limitations

- Hoarding behaviors can limit a person's ability to ambulate, causing blockage to walkways and doorways.
- A client who hoards may store items in the bathroom, making it difficult or impossible to bathe or use the toilet properly.
- A client who hoards may also obstruct ovens and stoves, making it difficult to cook, the clutter also becoming a fire hazard if the client attempts to cook. The client may also have a refrigerator stacked with rotten food and liquids.
- As people age, they may have difficulties with ambulation. The fall risk for elders living in these environments can be very high.

Techniques In Interacting With

- Refrain from calling a client's clutter "junk" or "trash". These items are psychologically very valuable to the client.
- Approach the client with respect and non-judgment, showing that you do not mind the condition of the apartment. Use a gentle approach, especially when you first meet the client, not expecting them to immediately throw out their clutter.
- The in-home worker who is assigned may be able to convince the client to throw away small portions of clutter over time, or move it to help the client shower or cook. The client should be involved in this process.
- One author notes that only "social pressure and legal process" has been successful with hoarding behaviors. Therefore an appeal to the client's safety and/or risk of eviction may be helpful motivating factors.
- After establishing trust, using assertiveness can be helpful. A client will probably not throw clutter out on their own. Be assertive, yet caring, focusing on a risk for falls, safety hazards, threat of eviction, or threat of public health involvement with the client.

- Consult with your supervisor and/or make a referral to Adult Protective Services or appropriate mandated reporting agency if clutter becomes a great risk to the client.

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National Institutes of Health
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SCHIZOPHRENIA

What is schizophrenia?

Schizophrenia is a chronic, severe, and disabling brain disorder that has been recognized throughout recorded history. It affects about 1 percent of Americans. People with schizophrenia may hear voices other people don't hear or they may believe that others are reading their minds, controlling their thoughts, or plotting to harm them. These experiences are terrifying and can cause fearfulness, withdrawal, or extreme agitation. People with schizophrenia may not make sense when they talk, may sit for hours without moving or talking much, or may seem perfectly fine until they talk about what they are really thinking. Because many people with schizophrenia have difficulty holding a job or caring for themselves, the burden on their families and society is significant.

Available treatments can relieve many of the disorder's symptoms, but most people who have schizophrenia must cope with some residual symptoms as long as they live. Nevertheless, this is a time of hope for people with schizophrenia and their families. Many people with the disorder now lead rewarding and meaningful lives in their communities. Researchers are developing more effective medications and using new research tools to understand the causes of schizophrenia and to find ways to prevent and treat it.

What are the symptoms of schizophrenia?

The symptoms of schizophrenia fall into three broad categories:

- **Positive symptoms** are unusual thoughts or perceptions, including hallucinations, delusions, thought disorder, and disorders of movement.

- **Negative symptoms** represent a loss or a decrease in the ability to initiate plans, speak, express emotion, or find pleasure in everyday life. These symptoms are harder to recognize as part of the disorder and can be mistaken for laziness or depression.

- **Cognitive symptoms** (or cognitive deficits) are problems with attention, certain types of memory, and the executive functions that allow us to plan and organize. Cognitive deficits can also be difficult to recognize as part of the disorder but are the most disabling in terms of leading a normal life.

Positive Symptoms

Positive symptoms are easy-to-spot behaviors not seen in healthy people and usually involve a loss of contact with reality. They include hallucinations, delusions, thought disorder, and disorders of movement. Positive symptoms can come and go. Sometimes they are severe and at other times hardly noticeable, depending on whether the individual is receiving treatment.

Hallucinations

A hallucination is something a person sees, hears, smells, or feels that no one else can see, hear, smell, or feel. "Voices" are the most common type of hallucination in schizophrenia. Many people with the disorder hear voices that may comment on their behavior, order them to do things, warn them of impending danger, or talk to each other (usually about the patient). They may hear these voices for a long time before family and friends notice that something is wrong. Other types of hallucinations include seeing people or objects that are not there, smelling odors that no one else detects (although this can also be a symptom of certain brain tumors), and feeling things like invisible fingers touching their bodies when no one is near.

Delusions

Delusions are false personal beliefs that are not part of the person's culture and do not change, even when other people present proof that the beliefs are not true or logical. People with schizophrenia can have delusions that are quite bizarre, such as believing that neighbors can control their behavior with magnetic waves, people on television are directing special messages to them, or radio stations are broadcasting their thoughts aloud to others. They may also have delusions of grandeur and think they are famous historical figures. People with paranoid schizophrenia can believe that others are deliberately cheating, harassing, poisoning, spying upon, or plotting against them or the people they care about. These beliefs are called delusions of persecution.

Thought Disorder

People with schizophrenia often have unusual thought processes. One dramatic form is disorganized thinking, in which the person has difficulty organizing his or her thoughts or connecting them logically. Speech may be garbled or hard to understand. Another form is "thought blocking," in which the person stops abruptly in the middle of a thought. When asked why, the person may say that it felt as if the thought had been taken out of his or her head. Finally, the individual might make up unintelligible words, or "neologisms."

Disorders of Movement

People with schizophrenia can be clumsy and uncoordinated. They may also exhibit involuntary movements and may grimace or exhibit unusual mannerisms. They may repeat certain motions over and over or, in extreme cases, may become catatonic. Catatonia is a state of immobility and unresponsiveness. It was more common when treatment for schizophrenia was not available; fortunately, it is now rare.

Negative Symptoms

The term "negative symptoms" refers to reductions in normal emotional and behavioral states. These include the following:

- flat affect (immobile facial expression, monotonous voice),
- lack of pleasure in everyday life,
- diminished ability to initiate and sustain planned activity, and
- speaking infrequently, even when forced to interact.

People with schizophrenia often neglect basic hygiene and need help with everyday activities. Because it is not as obvious that negative symptoms are part of a psychiatric illness, people with schizophrenia are often perceived as lazy and unwilling to better their lives.

Cognitive Symptoms

Cognitive symptoms are subtle and are often detected only when neuropsychological tests are performed. They include the following:

- poor "executive functioning" (the ability to absorb and interpret information and make decisions based on that information),
- inability to sustain attention, and
- problems with "working memory" (the ability to keep recently learned information in mind and use it right away)

Cognitive impairments often interfere with the patient's ability to lead a normal life and earn a living. They can cause great emotional distress.

When does it start and who gets it?

Psychotic symptoms (such as hallucinations and delusions) usually emerge in men in their late teens and early 20s and in women in their mid-20s to early 30s. They seldom occur after age 45 and only rarely before puberty, although cases of schizophrenia in children as young as 5 have been reported. In adolescents, the first signs can include a change of friends, a drop in grades, sleep problems, and irritability. Because many normal adolescents exhibit these behaviors as well, a diagnosis can be difficult to make at this stage. In young people who go on to develop the disease, this is called the "prodromal" period. Research has shown that schizophrenia affects men and women equally and occurs at similar rates in all ethnic groups around the world.

Are people with schizophrenia violent?

People with schizophrenia are not especially prone to violence and often prefer to be left alone. Studies show that if people have no record of criminal violence before they develop schizophrenia and are not substance abusers, they are unlikely to commit crimes after they become ill. Most violent crimes are not committed by people with schizophrenia, and most people with schizophrenia do not commit violent crimes. Substance abuse always increases violent behavior, regardless of the presence of schizophrenia (see sidebar). If someone with paranoid schizophrenia becomes violent, the violence is most often directed at family members and takes place at home.

What about suicide?

People with schizophrenia attempt suicide much more often than people in the general population. About 10 percent (especially young adult males) succeed. It is hard to predict which people with schizophrenia are prone to suicide, so if someone talks about or tries to commit suicide, professional help should be sought right away.

What causes schizophrenia?

Substance abuse

Some people who abuse drugs show symptoms similar to those of schizophrenia, and people with schizophrenia may be mistaken for people who are high on drugs. While most researchers do not believe that substance abuse causes schizophrenia, people who have schizophrenia abuse alcohol and/or drugs more often than the general population.

Substance abuse can reduce the effectiveness of treatment for schizophrenia. Stimulants (such as amphetamines or cocaine), PCP, and marijuana may make the symptoms of schizophrenia worse, and substance abuse also makes it more likely that patients will not follow their treatment plan.

Schizophrenia and Nicotine

The most common form of substance abuse in people with schizophrenia is an addiction to nicotine. People with schizophrenia are addicted to nicotine at three times the rate of the general population (75–90 percent vs. 25–30 percent).

Research has revealed that the relationship between smoking and schizophrenia is complex. People with schizophrenia seem to be driven to smoke, and researchers are exploring whether there is a biological basis for this need. In addition to its known health hazards, several studies have found that smoking interferes with the action of antipsychotic drugs. People with schizophrenia who smoke may need higher doses of their medication.

Quitting smoking may be especially difficult for people with schizophrenia since nicotine withdrawal may cause their psychotic symptoms to temporarily get worse. Smoking cessation strategies that include nicotine replacement methods may be better tolerated. Doctors who treat people with schizophrenia should carefully monitor their patient's response to antipsychotic medication if the patient decides to either start or stop smoking.

Like many other illnesses, schizophrenia is believed to result from a combination of environmental and genetic factors. All the tools of modern science are being used to search for the causes of this disorder.

Can schizophrenia be inherited?

Scientists have long known that schizophrenia runs in families. It occurs in 1 percent of the general population but is seen in 10 percent of people with a first-degree relative (a parent, brother, or sister) with the disorder. People who have second-degree relatives (aunts, uncles, grandparents, or cousins) with the disease also develop schizophrenia more often than the general population. The identical twin of a person with schizophrenia is most at risk, with a 40 to 65 percent chance of developing the disorder.

Although there is a genetic risk for schizophrenia, it is not likely that genes alone are sufficient to cause the disorder. Interactions between genes and the environment are thought to be necessary for schizophrenia to develop. Many environmental factors have been suggested as risk factors, such as exposure to viruses or malnutrition in the womb, problems during birth, and psychosocial factors, like stressful environmental conditions.

Do people with schizophrenia have faulty brain chemistry?

It is likely that an imbalance in the complex, interrelated chemical reactions of the brain involving the neurotransmitters dopamine and glutamate (and possibly others) plays a role in schizophrenia. Neurotransmitters are substances that allow brain cells to communicate with one another. Basic knowledge about brain chemistry and its link to schizophrenia is expanding rapidly and is a promising area of research.

Do the brains of people with schizophrenia look different?

The brains of people with schizophrenia look a little different than the brains of healthy people, but the differences are small. Sometimes the fluid-filled cavities at the center of the brain, called ventricles, are larger in people with schizophrenia; overall gray matter volume is lower; and some areas of the brain have less or more metabolic activity. Microscopic studies of brain tissue after death have also revealed small changes in the distribution or characteristics of brain cells in people with schizophrenia. It appears that many of these changes were prenatal because they are not accompanied by glial cells, which are always present when a brain injury occurs after birth. One theory suggests that problems during brain development lead to faulty connections that lie dormant until puberty. The brain undergoes major changes during puberty, and these changes could trigger psychotic symptoms.

The only way to answer these questions is to conduct more research. Scientists in the United States and around the world are studying schizophrenia and trying to develop new ways to prevent and treat the disorder.

How is schizophrenia treated?

Because the causes of schizophrenia are still unknown, current treatments focus on eliminating the symptoms of the disease.

Antipsychotic medications

Antipsychotic medications have been available since the mid-1950s. They effectively alleviate the positive symptoms of schizophrenia. While these drugs have greatly improved the lives of many patients, they do not cure schizophrenia.

Everyone responds differently to antipsychotic medication. Sometimes several different drugs must be tried before the right one is found. People with schizophrenia should work in partnership with their doctors to find the medications that control their symptoms best with the fewest side effects.

The **older antipsychotic medications** include chlorpromazine (Thorazine®), haloperidol (Haldol®), perphenazine (Etrafon®, Trilafon®), and fluphenzine (Prolixin®). The older medications can cause extrapyramidal side effects, such as rigidity, persistent muscle spasms, tremors, and restlessness.

In the 1990s, new drugs, called **atypical antipsychotics**, were developed that rarely produced these side effects. The first of these new drugs was clozapine (Clozaril®). It treats psychotic symptoms effectively even in people who do not respond to other medications, but it can produce a serious problem called agranulocytosis, a loss of the white blood cells that fight infection. Therefore, patients who take clozapine must have their white blood cell counts monitored every week or two. The inconvenience and cost of both the blood tests and the medication itself has made treatment with clozapine difficult for many people, but it is the drug of choice for those whose symptoms do not respond to the other antipsychotic medications, old or new.

Some of the drugs that were developed after clozapine was introduced—such as risperidone (Risperdal®), olanzapine (Zyprexa®), quietiapine (Seroquel®), sertindole (Serdolect®), and ziprasidone (Geodon®)—are effective and rarely produce extrapyramidal symptoms and do not cause agranulocytosis; but they can cause weight gain and metabolic changes associated with an increased risk of diabetes and high cholesterol.

Aripiprazole (Abilify) is another atypical antipsychotic medication used to treat the symptoms of schizophrenia and manic or mixed (manic and depressive) episodes of bipolar I disorder. Aripiprazole is in tablet and liquid form. An injectable form is used in the treatment of symptoms of agitation in schizophrenia and manic or mixed episodes of bipolar I disorder.

People respond individually to antipsychotic medications, although agitation and hallucinations usually improve within days and delusions usually improve within a few weeks. Many people see substantial improvement in both types of symptoms by the sixth week of treatment. No one can tell beforehand exactly how a medication will affect a particular individual, and sometimes several medications must be tried before the right one is found.

When people first start to take atypical antipsychotics, they may become drowsy; experience dizziness when they change positions; have blurred vision; or develop a rapid heartbeat, menstrual problems, a sensitivity to the sun, or skin rashes. Many of these symptoms will go away after the first days of treatment, but people who are taking atypical antipsychotics should not drive until they adjust to their new medication.

If people with schizophrenia become depressed, it may be necessary to add an antidepressant to their drug regimen.

Length of Treatment

Like diabetes or high blood pressure, schizophrenia is a chronic disorder that needs constant management. At the moment, it cannot be cured, but the rate of recurrence of psychotic episodes can be decreased significantly by staying on medication. Although responses vary from person to person, most people with schizophrenia need to take some type of medication for the rest of their lives as well as use other approaches, such as supportive therapy or rehabilitation.

Relapses occur most often when people with schizophrenia stop taking their antipsychotic medication because they feel better, or only take it occasionally because they forget or don't think taking it regularly is important. It is very important for people with schizophrenia to take their medication on a regular basis and for as long as their doctors recommend. If they do so, they will experience fewer psychotic symptoms.

No antipsychotic medication should be discontinued without talking to the doctor who prescribed it, and it should always be tapered off under a doctor's supervision rather than being stopped all at once.

There are a variety of reasons why people with schizophrenia do not adhere to treatment. If they don't believe they are ill, they may not think they need medication at all. If their thinking is too disorganized, they may not remember to take their medication every day. If they don't like the side effects of one medication, they may stop taking it without trying a different medication. Substance abuse can also interfere with treatment effectiveness. Doctors should ask patients how often they take their medication and be sensitive to a patient's request to change dosages or to try new medications to eliminate unwelcome side effects.
There are many strategies to help people with schizophrenia take their drugs regularly:

- Long-acting, injectable forms, which eliminate the need to take a pill every day
- Medication calendars or pillboxes labeled with the days of the week can both help patients remember to take their medications and let caregivers know whether medication has been taken.
- Electronic timers on clocks or watches can be programmed to beep when people need to take their pills.
- Pairing medication with routine daily events, like meals, can help patients adhere to dosing schedules.

Medication Interactions
Antipsychotic medications can produce unpleasant or dangerous side effects when taken with certain other drugs. **For this reason, the doctor who prescribes the antipsychotics should be told about all medications (over-the-counter and prescription) and all vitamins, minerals, and herbal supplements the patient takes. Alcohol or other drug use should also be discussed.**

Psychosocial Treatment
Numerous studies have found that psychosocial treatments can help patients who are already stabilized on antipsychotic medications **deal with certain aspects of schizophrenia, such as difficulty with communication, motivation, self-care, work, and establishing and maintaining relationships with others.**

Illness Management Skills

People with schizophrenia can take an active role in managing their own illness. Once they learn basic facts about schizophrenia and the principles of schizophrenia treatment, they can make informed decisions about their care. If they are taught how to monitor the early warning signs of relapse and make a plan to respond to these signs, they can learn to prevent relapses. Patients can also be taught more effective coping skills to deal with persistent symptoms.

Integrated Treatment for Co-occurring Substance Abuse

Substance abuse is the most common co-occurring disorder in people with schizophrenia, but ordinary substance abuse treatment programs usually do not address this population's special needs. Integrating schizophrenia treatment programs and drug treatment programs produces better outcomes.

Rehabilitation

Rehabilitation emphasizes social and vocational training to help people with schizophrenia function more effectively in their communities. Because people with schizophrenia frequently become ill during the critical career-forming years of life (ages 18 to 35) and because the disease often interferes with normal cognitive functioning, most patients do not receive the training required for skilled work. Rehabilitation programs can include vocational counseling, job training, money management counseling, assistance in learning to use public transportation, and opportunities to practice social and workplace communication skills.

Family Education.

Patients with schizophrenia are often discharged from the hospital into the care of their families, so it is important that family members know as much as possible about the disease to prevent relapses. Family members should be able to use different kinds of treatment adherence programs and have an arsenal of coping strategies and problem-solving skills to manage their ill relative effectively. Knowing where to find outpatient and family services that support people with schizophrenia and their caregivers is also valuable.

Cognitive Behavioral Therapy

Cognitive behavioral therapy is useful for patients with symptoms that persist even when they take medication. The cognitive therapist teaches people with schizophrenia how to test the reality of their thoughts and perceptions, how to "not listen" to their voices, and how to shake off the apathy that often immobilizes them. This treatment appears to be effective in reducing the severity of symptoms and decreasing the risk of relapse.

Self-Help Groups

Self-help groups for people with schizophrenia and their families are becoming increasingly common. Although professional therapists are not involved, the group members are a continuing source of mutual support and comfort for each other, which is also therapeutic. People in self-help groups know that others are facing the same problems they face and no longer feel isolated by their illness or the illness of their loved one. The networking that takes place in self-help groups can also generate social action. Families working together can advocate for research and more hospital and community treatment programs, and patients acting as a group may be able to draw public attention to the discriminations many people with mental illnesses still face in today's world.

What is the role of the patient’s support system?

There are many situations in which people with schizophrenia will need help from other people.

Getting Treatment

People with schizophrenia often resist treatment, believing that their delusions or hallucinations are real and psychiatric help is not required. If a crisis occurs, family and friends may need to take action to keep their loved one safe.

The issue of civil rights enters into any attempt to provide treatment. Laws protecting patients from involuntary commitment have become very strict, and trying to get help for someone who is mentally ill can be frustrating. These laws vary from state to state, but, generally, when people are dangerous to themselves or others because of mental illness and refuse to seek treatment, family members or friends may have to call the police to transport them to the hospital. In the emergency room, a mental health professional will assess the patient and determine whether a voluntary or involuntary admission is needed.

A person with mental illness who does not want treatment may hide strange behavior or ideas from a professional; therefore, family members and friends should ask to speak privately with the person conducting the patient's examination and explain what has been happening at home. The professional will then be able to question the patient and hear the patient's distorted thinking for themselves. Professionals must personally witness bizarre behavior and hear delusional thoughts before they can legally recommend commitment, and family and friends can give them the information they need to do so.

Caregiving

Ensuring that people with schizophrenia continue to get treatment and take their medication after they leave the hospital is also important. If patients stop taking their medication or stop going for follow-up appointments, their psychotic symptoms will return. If these symptoms become severe, they may become unable to care for their own basic needs for food, clothing, and shelter; they may neglect personal hygiene; and they may end up on the street or in jail, where they rarely receive the kind of help they need.

Family and friends can also help patients set realistic goals and regain their ability to function in the world. Each step toward these goals should be small enough to be attainable, and the patient should pursue them in an atmosphere of support. People with a mental illness who are pressured and criticized usually regress and their symptoms worsen. Telling them what they are doing right is the best way to help them move forward.

How should you respond when someone with schizophrenia makes statements that are strange or clearly false? Because these bizarre beliefs or hallucinations are real to the patient, it will not be useful to say they are wrong or imaginary. Going along with the delusions will not be helpful, either. It is best to calmly say that you see things differently than the patient does but that you acknowledge that everyone has the right to see things in his or her own way. Being respectful, supportive, and kind without tolerating dangerous or inappropriate behavior is the most helpful way to approach people with this disorder.

For more information

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National Institutes of Health
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BIPOLAR DISORDER

Introduction

Bipolar disorder, also known as manic-depressive illness, is a brain disorder that causes unusual shifts in a person's mood, energy, and ability to function. Different from the normal ups and downs that everyone goes through, the symptoms of bipolar disorder are severe. They can result in damaged relationships, poor job or school performance, and even suicide. But there is good news: bipolar disorder can be treated, and people with this illness can lead full and productive lives.

About 5.7 million American adults or about 2.6 percent of the population age 18 and older in any given year, have bipolar disorder. Bipolar disorder typically develops in late adolescence or early adulthood. However, some people have their first symptoms during childhood, and some develop them late in life. It is often not recognized as an illness, and people may suffer for years before it is properly diagnosed and treated. Like diabetes or heart disease, bipolar disorder is a long-term illness that must be carefully managed throughout a person's life.

> ***"Manic-depression distorts moods and thoughts, incites dreadful behaviors, destroys the basis of rational thought, and too often erodes the desire and will to live. It is an illness that is biological in its origins, yet one that feels psychological in the experience of it; an illness that is unique in conferring advantage and pleasure, yet one that brings in its wake almost unendurable suffering and, not infrequently, suicide."***
>
> ***"I am fortunate that I have not died from my illness, fortunate in having received the best medical care available, and fortunate in having the friends, colleagues, and family that I do."***
>
> Kay Redfield Jamison, Ph.D., An Unquiet Mind, 1995, p. 6.
> (Reprinted with permission from Alfred A. Knopf, a division of Random House, Inc.)

What Are the Symptoms of Bipolar Disorder?

Bipolar disorder causes dramatic mood swings—from overly "high" and/or irritable to sad and hopeless, and then back again, often with periods of normal mood in between. Severe changes in energy and behavior go along with these changes in mood. The periods of highs and lows are called **episodes** of mania and depression.

Signs and symptoms of *mania* (or a *manic episode*) include:

- Increased energy, activity, and restlessness
- Excessively "high," overly good, euphoric mood
- Extreme irritability
- Racing thoughts and talking very fast, jumping from one idea to another
- Distractibility, can't concentrate well

- Little sleep needed
- Unrealistic beliefs in one's abilities and powers
- Poor judgment
- Spending sprees
- A lasting period of behavior that is different from usual
- Increased sexual drive
- Abuse of drugs, particularly cocaine, alcohol, and sleeping medications
- Provocative, intrusive, or aggressive behavior
- Denial that anything is wrong

A manic episode is diagnosed if elevated mood occurs with three or more of the other symptoms most of the day, nearly every day, for 1 week or longer. If the mood is irritable, four additional symptoms must be present.

Signs and symptoms of *depression* (or a *depressive episode*) include:

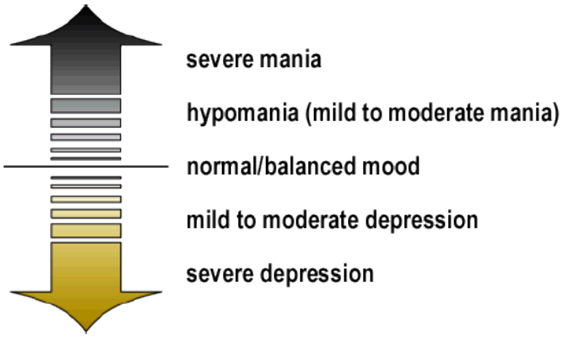
- Lasting sad, anxious, or empty mood
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Loss of interest or pleasure in activities once enjoyed, including sex
- Decreased energy, a feeling of fatigue or of being "slowed down"
- Difficulty concentrating, remembering, making decisions
- Restlessness or irritability
- Sleeping too much, or can't sleep
- Change in appetite and/or unintended weight loss or gain
- Chronic pain or other persistent bodily symptoms that are not caused by physical illness or injury
- Thoughts of death or suicide, or suicide attempts

A depressive episode is diagnosed if five or more of these symptoms last most of the day, nearly every day, for a period of 2 weeks or longer.

A mild to moderate level of mania is called **hypomania**. Hypomania may feel good to the person who experiences it and may even be associated with good functioning and enhanced productivity. Thus even when family and friends learn to recognize the mood swings as possible bipolar disorder, the person may deny that anything is wrong. Without proper treatment, however, hypomania can become severe mania in some people or can switch into depression.

Sometimes, severe episodes of mania or depression include symptoms of **psychosis** (or psychotic symptoms). Common psychotic symptoms are hallucinations (hearing, seeing, or otherwise sensing the presence of things not actually there) and delusions (false, strongly held beliefs not influenced by logical reasoning or explained by a person's usual cultural concepts). Psychotic symptoms in bipolar disorder tend to reflect the extreme mood state at the time. For example, delusions of grandiosity, such as believing one is the President or has special powers or wealth, may occur during mania; delusions of guilt or worthlessness, such as believing that one is ruined and penniless or has committed some terrible crime, may appear during depression. People with bipolar disorder who have these symptoms are sometimes incorrectly diagnosed as having schizophrenia, another severe mental illness.

It may be helpful to think of the various mood states in bipolar disorder as a spectrum or continuous range. At one end is severe depression, above which is moderate depression and then mild low mood, which many people call "the blues" when it is short-lived but is termed "dysthymia" when it is chronic. Then there is normal or balanced mood, above which comes hypomania (mild to moderate mania), and then severe mania.



In some people, however, symptoms of mania and depression may occur together in what is called a **mixed** bipolar state. Symptoms of a mixed state often include agitation, trouble sleeping, significant change in appetite, psychosis, and suicidal thinking. A person may have a very sad, hopeless mood while at the same time feeling extremely energized.

Bipolar disorder may appear to be a problem other than mental illness—for instance, alcohol or drug abuse, poor school or work performance, or strained interpersonal relationships. Such problems in fact may be signs of an underlying mood disorder.

Suicide

Some people with bipolar disorder become suicidal. **Anyone who is thinking about committing suicide needs immediate attention, preferably from a mental health professional or a physician. Anyone who talks about suicide should be taken seriously.** Risk for suicide appears to be higher earlier in the course of the illness. Therefore, recognizing bipolar disorder early and learning how best to manage it may decrease the risk of death by suicide.

Signs and symptoms that may accompany suicidal feelings include:

- talking about feeling suicidal or wanting to die
- feeling hopeless, that nothing will ever change or get better
- feeling helpless, that nothing one does makes any difference
- feeling like a burden to family and friends
- abusing alcohol or drugs
- putting affairs in order (e.g., organizing finances or giving away possessions to prepare for one's death)
- writing a suicide note
- putting oneself in harm's way, or in situations where there is a danger of being killed

If you are feeling suicidal or know someone who is:

- call a doctor, emergency room, or 911 right away to get immediate help
- make sure you, or the suicidal person, are not left alone
- make sure that access is prevented to large amounts of medication, weapons, or other items that could be used for self-harm

While some suicide attempts are carefully planned over time, others are impulsive acts that have not been well thought out; thus, the final point in the box above may be a valuable *long-term* strategy for people with bipolar disorder. Either way, it is important to understand that suicidal feelings and actions are symptoms of an illness that can be treated. With proper treatment, suicidal feelings can be overcome.

What Is the Course of Bipolar Disorder?

Episodes of mania and depression typically recur across the life span. Between episodes, most people with bipolar disorder are free of symptoms, but as many as one-third of people have some residual symptoms. A small percentage of people experience chronic unremitting symptoms despite treatment.

The classic form of the illness, which involves recurrent episodes of mania and depression, is called **bipolar I disorder**. Some people, however, never develop severe mania but instead experience milder episodes of hypomania that alternate with depression; this form of the illness is called **bipolar II disorder**. When four or more episodes of illness occur within a 12-month period, a person is said to have **rapid-cycling** bipolar disorder. Some people experience multiple episodes within a single week, or even within a single day. Rapid cycling tends to develop later in the course of illness and is more common among women than among men.

People with bipolar disorder can lead healthy and productive lives when the illness is effectively treated (see “How Is Bipolar Disorder Treated?”). Without treatment, however, the natural course of bipolar disorder tends to worsen. Over time a person may suffer more frequent (more rapid-cycling) and more severe manic and depressive episodes than those experienced when the illness first appeared. But in most cases, proper treatment can help reduce the frequency and severity of episodes and can help people with bipolar disorder maintain good quality of life.

Can Children and Adolescents Have Bipolar Disorder?

Both children and adolescents can develop bipolar disorder. It is more likely to affect the children of parents who have the illness.

Unlike many adults with bipolar disorder, whose episodes tend to be more clearly defined, children and young adolescents with the illness often experience very fast mood swings between depression and mania many times within a day. Children with mania are more likely to be irritable and prone to destructive tantrums than to be overly happy and elated. Mixed symptoms also are common in youths with bipolar disorder. Older adolescents who develop the illness may have more classic, adult-type episodes and symptoms.

Bipolar disorder in children and adolescents can be hard to tell apart from other problems that may occur in these age groups. For example, while irritability and aggressiveness can indicate bipolar disorder, they also can be symptoms of attention deficit hyperactivity disorder, conduct disorder, oppositional defiant disorder, or other types of mental disorders more common among adults such as major depression or schizophrenia. Drug abuse also may lead to such symptoms.

For any illness, however, effective treatment depends on appropriate diagnosis. Children or adolescents with emotional and behavioral symptoms should be carefully evaluated by a mental health professional. **Any child or adolescent who has suicidal feelings, talks about suicide, or attempts suicide should be taken seriously and should receive immediate help from a mental health specialist.**

What Causes Bipolar Disorder?

Scientists are learning about the possible causes of bipolar disorder through several kinds of studies. Most scientists now agree that there is no single cause for bipolar disorder—rather, many factors act together to produce the illness.

Because bipolar disorder tends to run in families, researchers have been searching for specific genes—the microscopic “building blocks” of DNA inside all cells that influence how the body and mind work and grow—passed down through generations that may increase a person’s chance of developing the illness. But genes are not the whole story. Studies of identical twins, who share all the same genes, indicate that both genes and other factors play a role in bipolar disorder. If bipolar disorder were caused entirely by genes, then the identical twin of someone with the illness would *always* develop the illness, and research has shown that this is not the case. But if one twin has bipolar disorder, the other twin is more likely to develop the illness than is another sibling.

In addition, findings from gene research suggest that bipolar disorder, like other mental illnesses, does not occur because of a single gene. It appears likely that many different genes act together, and in combination with other factors of the person or the person's environment, to cause bipolar disorder. Finding these genes, each of which contributes only a small amount toward the vulnerability to bipolar disorder, has been extremely difficult. But scientists expect that the advanced research tools now being used will lead to these discoveries and to new and better treatments for bipolar disorder.

How Is Bipolar Disorder Treated?

Most people with bipolar disorder—even those with the most severe forms—can achieve substantial stabilization of their mood swings and related symptoms with proper treatment. Because bipolar disorder is a recurrent illness, long-term preventive treatment is strongly recommended and almost always indicated. A strategy that combines medication and psychosocial treatment is optimal for managing the disorder over time.

In most cases, bipolar disorder is much better controlled if treatment is continuous than if it is on and off. But even when there are no breaks in treatment, mood changes can occur and should be reported immediately to your doctor. The doctor may be able to prevent a full-blown episode by making adjustments to the treatment plan. Working closely with the doctor and communicating openly about treatment concerns and options can make a difference in treatment effectiveness.

In addition, keeping a chart of daily mood symptoms, treatments, sleep patterns, and life events may help people with bipolar disorder and their families to better understand the illness. This chart also can help the doctor track and treat the illness most effectively.

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Medications

Medications for bipolar disorder are prescribed by psychiatrists—medical doctors (M.D.) with expertise in the diagnosis and treatment of mental disorders. While primary care physicians who do not specialize in psychiatry also may prescribe these medications, it is recommended that people with bipolar disorder see a psychiatrist for treatment.

Medications known as "mood stabilizers" usually are prescribed to help control bipolar disorder.[10] Several different types of mood stabilizers are available. In general, people with bipolar disorder continue treatment with mood stabilizers for extended periods of time (years). Other medications are added when necessary, typically for shorter periods, to treat episodes of mania or depression that break through despite the mood stabilizer.

- **Lithium**, the first mood-stabilizing medication approved by the U.S. Food and Drug Administration (FDA) for treatment of mania, is often very effective in controlling mania and preventing the recurrence of both manic and depressive episodes.
- Anticonvulsant medications, such as valproate (**Depakote**®) or carbamazepine (**Tegretol**®), also can have mood-stabilizing effects and may be especially useful for difficult-to-treat bipolar episodes. Valproate was FDA-approved in 1995 for treatment of mania.
- Newer anticonvulsant medications, including lamotrigine (**Lamictal**®), gabapentin (**Neurontin**®), and topiramate (**Topamax**®), are being studied to determine how well they work in stabilizing mood cycles.
- Anticonvulsant medications may be combined with lithium, or with each other, for maximum effect.
- Children and adolescents with bipolar disorder generally are treated with lithium, but valproate and carbamazepine also are used. Researchers are evaluating the safety and efficacy of these and other psychotropic medications in children and adolescents. *There is some evidence that valproate may lead to adverse hormone changes in teenage girls and polycystic ovary syndrome in women who began taking the medication before age 20.*[13] *Therefore, young female patients taking valproate should be monitored carefully by a physician.*
- Women with bipolar disorder who wish to conceive, or who become pregnant, face special challenges due to the possible harmful effects of existing mood stabilizing medications on the developing fetus and the nursing infant. Therefore, the benefits and risks of all available treatment options should be discussed with a clinician skilled in this area. New treatments with reduced risks during pregnancy and lactation are under study.

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Treatment of Bipolar Depression

Research has shown that people with bipolar disorder are at risk of switching into mania or hypomania, or of developing rapid cycling, during treatment with antidepressant medication. Therefore, *"mood-stabilizing" medications generally are required, alone or in combination with antidepressants, to protect people with bipolar disorder from this switch*. Lithium and valproate are the most commonly used mood-stabilizing drugs today. However, research studies continue to evaluate the potential mood-stabilizing effects of newer medications.

- Atypical antipsychotic medications, including clozapine (**Clozaril**®), olanzapine (**Zyprexa**®), risperidone (**Risperdal**®), quetiapine (**Seroquel**®), and ziprasidone (**Geodon**®), are being studied as possible treatments for bipolar disorder. Evidence suggests clozapine may be helpful as a mood stabilizer for people who do not respond to lithium or anticonvulsants. Other research has supported the efficacy of olanzapine for acute mania, an indication that has recently received FDA approval. Olanzapine may also help relieve psychotic depression.
- If insomnia is a problem, a high-potency benzodiazepine medication such as clonazepam (**Klonopin**®) or lorazepam (**Ativan**®) may be helpful to promote better sleep. However, since these medications may be habit-forming, they are best prescribed on a short-term basis. Other types of sedative medications, such as zolpidem (**Ambien**®), are sometimes used instead.
- Changes to the treatment plan may be needed at various times during the course of bipolar disorder to manage the illness most effectively. A psychiatrist should guide any changes in type or dose of medication.
- Be sure to tell the psychiatrist about all other prescription drugs, over-the-counter medications, or natural supplements you may be taking. This is important because certain medications and supplements taken together may cause adverse reactions.
- To reduce the chance of relapse or of developing a new episode, it is important to stick to the treatment plan. Talk to your doctor if you have any concerns about the medications.

Thyroid Function

People with bipolar disorder often have abnormal thyroid gland function. Because too much or too little thyroid hormone alone can lead to mood and energy changes, it is important that thyroid levels are carefully monitored by a physician.

People with rapid cycling tend to have co-occurring thyroid problems and may need to take thyroid pills in addition to their medications for bipolar disorder. Also, lithium treatment may cause low thyroid levels in some people, resulting in the need for thyroid supplementation.

Medication Side Effects

Before starting a new medication for bipolar disorder, always talk with your psychiatrist and/or pharmacist about possible side effects. Depending on the medication, side effects may include weight gain, nausea, tremor, reduced sexual drive or performance, anxiety, hair loss, movement problems, or dry mouth. Be sure to tell the doctor about all side effects you notice during treatment. He or she may be able to change the dose or offer a different medication to relieve them. Your medication should not be changed or stopped without the psychiatrist's guidance.

Psychosocial Treatments

As an addition to medication, psychosocial treatments—including certain forms of psychotherapy (or "talk" therapy)—are helpful in providing support, education, and guidance to people with bipolar disorder and their families. Studies have shown that psychosocial interventions can lead to increased mood stability, fewer hospitalizations, and improved functioning in several areas. A licensed psychologist, social worker, or counselor typically provides these therapies and often works together with the psychiatrist to monitor a patient's progress. The number, frequency, and type of sessions should be based on the treatment needs of each person.

Psychosocial interventions commonly used for bipolar disorder are:

- **Cognitive behavioral therapy** helps people with bipolar disorder learn to change inappropriate or negative thought patterns and behaviors associated with the illness.
- **Psychoeducation** involves teaching people with bipolar disorder about the illness and its treatment, and how to recognize signs of relapse so that early intervention can be sought before a full-blown illness episode occurs. Psychoeducation also may be helpful for family members.
- **Family therapy** uses strategies to reduce the level of distress within the family that may either contribute to or result from the ill person's symptoms.
- **Interpersonal and social rhythm therapy** helps people with bipolar disorder both to improve interpersonal relationships and to regularize their daily routines. Regular daily routines and sleep schedules may help protect against manic episodes.
- As with medication, it is important to follow the treatment plan for any psychosocial intervention to achieve the greatest benefit.

Other Treatments

- In situations where medication, psychosocial treatment, and the combination of these interventions prove ineffective, or work too slowly to relieve severe symptoms such as psychosis or suicidality, **electroconvulsive therapy (ECT)** may be considered. ECT may also be considered to treat acute episodes when medical conditions, including pregnancy, make the use of medications too risky. ECT is a highly effective treatment for severe depressive, manic, and/or mixed episodes. The possibility of long-lasting memory problems, although a concern in the past, has been significantly reduced with modern ECT techniques. However, the potential benefits and risks of ECT, and of available alternative interventions, should be carefully reviewed and discussed with individuals considering this treatment and, where appropriate, with family or friends.
- Herbal or natural supplements, such as St. John's wort *(Hypericum perforatum)*, have not been well studied, and little is known about their effects on bipolar disorder. Because the FDA does not regulate their production, different brands of these supplements can contain different amounts of active ingredient. **Before trying herbal or natural supplements, it is important to discuss them with your doctor. There is evidence that St. John's wort can reduce the effectiveness of certain medications. In addition, like prescription antidepressants, St. John's wort may cause a switch into mania in some individuals with bipolar disorder, especially if no mood stabilizer is being taken.**
- Omega-3 fatty acids found in fish oil are being studied to determine their usefulness, alone and when added to conventional medications, for long-term treatment of bipolar disorder.

A Long-Term Illness That Can Be Effectively Treated

Even though episodes of mania and depression naturally come and go, it is important to understand that bipolar disorder is a long-term illness that currently has no cure. Staying on treatment, even during well times, can help keep the disease under control and reduce the chance of having recurrent, worsening episodes.

Do Other Illnesses Co-occur with Bipolar Disorder?

Alcohol and drug abuse are very common among people with bipolar disorder. Research findings suggest that many factors may contribute to these substance abuse problems, including self-medication of symptoms, mood symptoms either brought on or perpetuated by substance abuse, and risk factors that may influence the occurrence of both bipolar disorder and substance use disorders. Treatment for co-occurring substance abuse, when present, is an important part of the overall treatment plan.

Anxiety disorders, such as post-traumatic stress disorder and obsessive-compulsive disorder, also may be common in people with bipolar disorder. Co-occurring anxiety disorders may respond to the treatments used for bipolar disorder, or they may require separate treatment.

How Can Individuals and Families Get Help for Bipolar Disorder

Anyone with bipolar disorder should be under the care of a psychiatrist skilled in the diagnosis and treatment of this disease. Other mental health professionals, such as psychologists, psychiatric social workers, and psychiatric nurses, can assist in providing the person and family with additional approaches to treatment.

People with bipolar disorder may need help to get help.

- Often people with bipolar disorder do not realize how impaired they are, or they blame their problems on some cause other than mental illness.
- A person with bipolar disorder may need strong encouragement from family and friends to seek treatment. Family physicians can play an important role in providing referral to a mental health professional.
- Sometimes a family member or friend may need to take the person with bipolar disorder for proper mental health evaluation and treatment.
- A person who is in the midst of a severe episode may need to be hospitalized for his or her own protection and for much-needed treatment. There may be times when the person must be hospitalized against his or her wishes.
- Ongoing encouragement and support are needed after a person obtains treatment, because it may take a while to find the best treatment plan for each individual.
- In some cases, individuals with bipolar disorder may agree, when the disorder is under good control, to a preferred course of action in the event of a future manic or depressive relapse.
- Like other serious illnesses, bipolar disorder is also hard on spouses, family members, friends, and employers.

- Family members of someone with bipolar disorder often have to cope with the person's serious behavioral problems, such as wild spending sprees during mania or extreme withdrawal from others during depression, and the lasting consequences of these behaviors.
- Many people with bipolar disorder benefit from joining support groups such as those sponsored by the National Depressive and Manic Depressive Association (NDMDA), the National Alliance for the Mentally Ill (NAMI), and the National Mental Health Association (NMHA). Families and friends can also benefit from support groups offered by these organizations.

For More Information

Bipolar Disorder Information and Organizations from NLM's MedlinePlus
http://www.nlm.nih.gov/medlineplus/bipolardisorder.html (also in Spanish) .

PERSONALITY DISORDER TYPES

The personality disorders defined by *DSM-5* (APA, 2013) are as follows:

Paranoid

The essential feature of paranoid personality disorder is a pattern of pervasive distrust and suspiciousness of others. People with this disorder assume that other people will exploit, harm, or deceive them, even if no evidence exists to support this expectation. They tend to scrutinize friends and associates and have unjustified doubts about the loyalty and trustworthiness of those people. They are reluctant to confide in or become close to others. Estimates on the prevalence of paranoid personality disorder range from 2.3% to 4.4% (APA, 2013).

Schizoid

The essential feature of schizoid personality disorder is a pervasive pattern of detachment from social relationships and a restricted range of expression of emotions in interpersonal settings. People with this disorder appear to lack a desire for intimacy and opportunities for close relationships. Often appearing to others as socially isolated or “loners,” they do not get satisfaction from being part of a family or social group, choosing solitary activities instead. Estimates of the prevalence of schizoid personality disorder range from 3.1% to 4.9% (APA, 2013).

Schizotypal

The essential feature of schizotypal personality disorder is a pervasive pattern of social and interpersonal deficits, marked by discomfort with close personal relationships and perceptual distortions and behavioral eccentricities. People with this disorder often make incorrect interpretations of casual incidents or external events. They can be superstitious and/or preoccupied with paranormal phenomena, along with an idiosyncratic or digressive speech pattern. Estimates of the prevalence of schizotypal personality disorder range from 3.9% to 4.6% (APA, 2013).

Antisocial

The essential feature of antisocial personality disorder is a pervasive pattern of disregard for, and violation of, the rights of others. Common names used to describe antisocial personality disorder are psychopathy and sociopathy. Diagnosis is only given when the patient has reached the age of majority (18 years old), and has a history of some symptoms of conduct disorder before the age of 15. People with this disorder are frequently deceitful or manipulative for personal profit or pleasure. Impulsiveness is another common feature. Estimates of the prevalence of antisocial personality disorder range from 2% to 3.3%, with the great majority (more than 70%) being male (APA, 2013)

Borderline

The essential feature of borderline personality disorder is a pervasive pattern of instability of interpersonal relationships, self-image, and emotions or feelings. People with this disorder make frantic efforts to avoid real or imagined abandonment. They often display patterns of unstable and intense relationships, and identity disturbances marked by unstable self-image or sense of self. Impulsivity is common, especially in self-damaging ways, along with recurrent suicidal behavior and gestures and self-mutilating behaviors. Estimates of the prevalence of borderline personality disorder range from 1.6% to 5.9%, but can be as high as 20% among patients in an inpatient psychiatric setting. The great majority of all those diagnosed with this disorder are female (75%) (APA, 2013).

Histrionic

The essential feature of histrionic personality disorder is a pervasive and excessive emotionality and attention-seeking behavior. People with this disorder are uncomfortable or feel unappreciated when they are not the center of attention. They may display inappropriately sexually provocative or seductive behavior. Their emotional expression may be shallow and rapidly shifting. The estimate of prevalence of histrionic personality disorder is 1.84%.

Narcissistic

The essential features of narcissistic personality disorder are a pervasive pattern of grandiosity, the need for attention, and a lack of empathy. People with this disorder have a sense of self-importance. They routinely overestimate their abilities and inflate their accomplishments, often appearing boastful and pretentious. They are often preoccupied with fantasies of unlimited success, power, brilliance, beauty, or ideal love. They tend to believe they are superior, special, or unique, and expect others to recognize them as such. Estimates of the prevalence of narcissistic personality disorder range up to 6.2%, with males making up 50% to 75% of those diagnosed with this disorder (APA, 2013).

Avoidant

The essential feature of avoidant personality disorder is a pervasive pattern of social inhibition, feelings of inadequacy, and hypersensitivity to negative evaluation. People with this disorder avoid work activities that involve significant interpersonal contact. They avoid making new friends unless they are certain that they will be liked and accepted without criticism. They may have difficulty talking about themselves or may withhold intimate feelings, fearing being exposed, ridiculed, or shamed. The estimate of prevalence of avoidant personality disorder is about 2.4% (APA, 2013).

Dependent

The essential feature of dependent personality disorder is an excessive need to be taken care of, leading to fear of separation and clinging or submissive behavior. People with this disorder have difficulty making everyday decisions and tend to be passive, allowing others to take initiative and to assume responsibility for most areas in their lives. They have difficulty expressing disagreement, especially with those on whom they are dependent. Estimates of the prevalence of dependent personality disorder range from 0.5% to 0.6%. It is notable that the

DSM-5 advises to consider this diagnosis only when the types of behaviors seen in dependent personality disorder are outside social and cultural norms (APA, 2013).

Obsessive-compulsive

The essential feature of obsessive-compulsive personality disorder is a preoccupation with orderliness, perfection, and mental and interpersonal control, at the expense of flexibility, openness, and efficiency. People with this disorder pay painstaking attention to rules, details, procedures, lists, and schedules--to the point that the major point of the endeavor is lost. They may become so involved in making every detail of a project absolutely perfect, that the project is never finished. They often devote excessive energy to work and productivity, to the exclusion of leisure activities and friendships. Estimates of the prevalence of obsessive-compulsive personality disorder range from 2.1% to 7.9%, with males twice as likely to be diagnosed as females (APA, 2013).

NOTE: Obsessive-compulsive *personality* disorder should not be confused with Obsessive-Compulsive Disorder, even though some of the features are similar.

Reference:

American Psychiatric Association. (2013). *Diagnostic and statistical manual of psychiatric disorders* (5th ed.) Washington, DC: American Psychiatric Association.

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DEPRESSION

What Is Depression?

Everyone occasionally feels blue or sad, but these feelings are usually fleeting and pass within a couple of days. When a person has a depressive disorder, it interferes with daily life, normal functioning, and causes pain for both the person with the disorder and those who care about him or her. Depression is a common but serious illness, and most who experience it need treatment to get better.

Many people with a depressive illness never seek treatment. But the vast majority, even those with the most severe depression, can get better with treatment. Intensive research into the illness has resulted in the development of medications, psychotherapies, and other methods to treat people with this disabling disorder.

What are the different forms of depression?

There are several forms of depressive disorders. The most common are major depressive disorder and dysthymic disorder.

Major depressive disorder, also called major depression, is characterized by a combination of symptoms that interfere with a person's ability to work, sleep, study, eat, and enjoy once–pleasurable activities. Major depression is disabling and prevents a person from functioning normally. An episode of major depression may occur only once in a person's lifetime, but more often, it recurs throughout a person's life.

Dysthymic disorder, also called dysthymia, is characterized by long–term (two years or longer) but less severe symptoms that may not disable a person but can prevent one from functioning normally or feeling well. People with dysthymia may also experience one or more episodes of major depression during their lifetimes.

Some forms of depressive disorder exhibit slightly different characteristics than those described above, or they may develop under unique circumstances. However, not all scientists agree on how to characterize and define these forms of depression. They include:

Psychotic depression, which occurs when a severe depressive illness is accompanied by some form of psychosis, such as a break with reality, hallucinations, and delusions.

Postpartum depression, which is diagnosed if a new mother develops a major depressive episode within one month after delivery. It is estimated that 10 to 15 percent of women experience postpartum depression after giving birth.

Seasonal affective disorder (SAD), which is characterized by the onset of a depressive illness during the winter months, when there is less natural sunlight. The depression generally lifts during spring and summer. SAD may be effectively treated with light therapy, but nearly half of those with SAD do not respond to light therapy alone. Antidepressant medication and psychotherapy can reduce SAD symptoms, either alone or in combination with light therapy.

Bipolar disorder, also called manic-depressive illness, is not as common as major depression or dysthymia. Bipolar disorder is characterized by cycling mood changes-from extreme highs (e.g., mania) to extreme lows (e.g., depression).

What are the symptoms of depression?

People with depressive illnesses do not all experience the same symptoms. The severity, frequency and duration of symptoms will vary depending on the individual and his or her particular illness.

Symptoms include:

- Persistent sad, anxious or "empty" feelings
- Feelings of hopelessness and/or pessimism
- Feelings of guilt, worthlessness and/or helplessness
- Irritability, restlessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Difficulty concentrating, remembering details and making decisions
- Insomnia, early–morning wakefulness, or excessive sleeping
- Overeating, or appetite loss
- Thoughts of suicide, suicide attempts
- Persistent aches or pains, headaches, cramps or digestive problems that do not ease even with treatment

What illnesses often co-exist with depression?

Depression often co-exists with other illnesses. Such illnesses may precede the depression, cause it, and/or be a consequence of it. It is likely that the mechanics behind the intersection of depression and other illnesses differ for every person and situation. Regardless, these other co-occurring illnesses need to be diagnosed and treated.

Anxiety disorders, such as post-traumatic stress disorder (PTSD), **obsessive–compulsive disorder**, **panic disorder**, **social phobia** and **generalized anxiety disorder**, often accompany depression. People experiencing PTSD are especially prone to having co-occurring depression.

Alcohol and other substance abuse or dependence may also co-occur with depression. In fact, research has indicated that the co-existence of mood disorders and substance abuse is pervasive among the U.S. population.

Depression also often co-exists **with other serious medical illnesses** such as heart disease, stroke, cancer, hiv/aids, diabetes, and Parkinson's disease. Studies have shown that people who have depression in addition to another serious medical illness tend to have more severe symptoms of both depression and the medical illness, more difficulty adapting to their medical condition, and more medical costs than those who do not have co-existing depression. Research has yielded increasing evidence that treating the depression can also help improve the outcome of treating the co-occurring illness.

What causes depression?

There is no single known cause of depression. Rather, it likely results from a combination of genetic, biochemical, environmental, and psychological factors.

Research indicates that depressive illnesses are disorders of the brain. Brain-imaging technologies, such as magnetic resonance imaging (MRI), have shown that the brains of people who have depression look different than those of people without depression. The parts of the brain responsible for regulating mood, thinking, sleep, appetite and behavior appear to function abnormally. In addition, important neurotransmitters–chemicals that brain cells use to communicate–appear to be out of balance. But these images do not reveal why the depression has occurred.

Some types of depression tend to run in families, suggesting a genetic link. However, depression can occur in people without family histories of depression as well. Genetics research indicates that risk for depression results from the influence of multiple genes acting together with environmental or other factors.

In addition, trauma, loss of a loved one, a difficult relationship, or any stressful situation may trigger a depressive episode. Subsequent depressive episodes may occur with or without an obvious trigger.

How do women experience depression?

Depression is more common among women than among men. Biological, life cycle, hormonal and psychosocial factors unique to women may be linked to women's higher depression rate. Researchers have shown that hormones directly affect brain chemistry that controls emotions and mood. For example, women are particularly vulnerable to depression after giving birth, when hormonal and physical changes, along with the new responsibility of caring for a newborn, can be overwhelming. Many new mothers experience a brief episode of the "baby blues," but some will develop postpartum depression, a much more serious condition that requires active treatment and emotional support for the new mother. Some studies suggest that women who experience postpartum depression often have had prior depressive episodes.

Some women may also be susceptible to a severe form of premenstrual syndrome (PMS), sometimes called premenstrual dysphoric disorder (PMDD), a condition resulting from the hormonal changes that typically occur around ovulation and before menstruation begins. During the transition into menopause, some women experience an increased risk for depression. Scientists are exploring how the cyclical rise and fall of estrogen and other hormones may affect the brain chemistry that is associated with depressive illness.

Finally, many women face the additional stresses of work and home responsibilities, caring for children and aging parents, abuse, poverty, and relationship strains. It remains unclear why some women faced with enormous challenges develop depression, while others with similar challenges do not.

How do men experience depression?

Men often experience depression differently than women and may have different ways of coping with the symptoms. Men are more likely to acknowledge having fatigue, irritability, loss of interest in once–pleasurable activities, and sleep disturbances, whereas women are more likely to admit to feelings of sadness, worthlessness and/or excessive guilt.

Men are more likely than women to turn to alcohol or drugs when they are depressed, or become frustrated, discouraged, irritable, angry and sometimes abusive. Some men throw themselves into their work to avoid talking about their depression with family or friends, or engage in reckless, risky behavior. And even though more women attempt suicide, many more men die by suicide in the United States.

How do children and adolescents experience depression?

Scientists and doctors have begun to take seriously the risk of depression in children. Research has shown that childhood depression often persists, recurs and continues into adulthood, especially if it goes untreated. The presence of childhood depression also tends to be a predictor of more severe illnesses in adulthood.

A child with depression may pretend to be sick, refuse to go to school, cling to a parent, or worry that a parent may die. Older children may sulk, get into trouble at school, be negative and irritable, and feel misunderstood. Because these signs may be viewed as normal mood swings typical of children as they move through developmental stages, it may be difficult to accurately diagnose a young person with depression.

Before puberty, boys and girls are equally likely to develop depressive disorders. By age 15, however, girls are twice as likely as boys to have experienced a major depressive episode.

Depression in adolescence comes at a time of great personal change–when boys and girls are forming an identity distinct from their parents, grappling with gender issues and emerging sexuality, and making decisions for the first time in their lives. Depression in adolescence frequently co–occurs with other disorders such as anxiety, disruptive behavior, eating disorders or substance abuse. It can also lead to increased risk for suicide.

How is depression detected and treated?

Depression, even the most severe cases, is a highly treatable disorder. As with many illnesses, the earlier that treatment can begin, the more effective it is and the greater the likelihood that recurrence can be prevented.

Once diagnosed, a person with depression can be treated with a number of methods. The most common treatments are medication and psychotherapy.

Medication

Antidepressants work to normalize naturally occurring brain chemicals called neurotransmitters, notably serotonin and norepinephrine. Other antidepressants work on the neurotransmitter dopamine. Scientists studying depression have found that these particular chemicals are involved in regulating mood, but they are unsure of the exact ways in which they work.

The newest and most popular types of antidepressant medications are called selective **serotonin reuptake inhibitors (SSRIs)**. SSRIs include fluoxetine (Prozac), citalopram (Celexa), sertraline (Zoloft) and several others. **Serotonin and norepinephrine reuptake inhibitors (SNRIs)** are similar to SSRIs and include venlafaxine (Effexor) and duloxetine (Cymbalta). SSRIs and SNRIs are more popular than the older classes of antidepressants, such as tricyclics–named for their chemical structure–and (MAOIs) because they tend to have fewer side effects. However, medications affect everyone differently–no one–size–fits–all approach to medication exists. Therefore, for some people, tricyclics or MAOIs may be the best choice.

People taking **MAOIs** (monoamine oxidase inhibitors) must adhere to significant food and medicinal restrictions to avoid potentially serious interactions. They must avoid certain foods that contain high levels of the chemical tyramine, which is found in many cheeses, wines and pickles, and some medications including decongestants. MAOIs interact with tyramine in such a way that may cause a sharp increase in blood pressure, which could lead to a stroke. A doctor should give a patient taking an MAOI a complete list of prohibited foods, medicines and substances.

For all classes of antidepressants, patients must take regular doses for at least three to four weeks before they are likely to experience a full therapeutic effect. They should continue taking the medication for the time specified by their doctor, even if they are feeling better, in order to prevent a relapse of the depression. Medication should be stopped only under a doctor's supervision. Some medications need to be gradually stopped to give the body time to adjust. Although antidepressants are not habit–forming or addictive, abruptly ending an antidepressant can cause withdrawal symptoms or lead to a relapse. Some individuals, such as those with chronic or recurrent depression, may need to stay on the medication indefinitely.

In addition, if one medication does not work, patients should be open to trying another. NIMH–funded research has shown that patients who did not get well after taking a first medication increased their chances of becoming symptom–free after they switched to a different medication or added another medication to their existing one.

What are the side effects of antidepressants?

Antidepressants may cause mild and often temporary side effects in some people, but they are usually not long–term. However, any unusual reactions or side effects that interfere with normal functioning should be reported to a doctor immediately.

The **most common side effects associated with SSRIs and SNRIs include**:

- Headache–usually temporary and will subside.
- Nausea–temporary and usually short–lived.
- Insomnia and nervousness (trouble falling asleep or waking often during the night)–may occur during the first few weeks but often subside over time or if the dose is reduced.
- Agitation (feeling jittery).

- Sexual problems–both men and women can experience sexual problems including reduced sex drive, erectile dysfunction, delayed ejaculation, or inability to have an orgasm.

Tricyclic antidepressants also can cause side effects including:

- Dry mouth-it is helpful to drink plenty of water, chew gum, and clean teeth daily.
- Constipation-it is helpful to eat more bran cereals, prunes, fruits, and vegetables.
- Bladder problems–emptying the bladder may be difficult, and the urine stream may not be as strong as usual. Older men with enlarged prostate conditions may be more affected. The doctor should be notified if it is painful to urinate.
- Sexual problems–sexual functioning may change, and side effects are similar to those from SSRIs.
- Blurred vision–often passes soon and usually will not require a new corrective lenses prescription.
- Drowsiness during the day–usually passes soon, but driving or operating heavy machinery should be avoided while drowsiness occurs. The more sedating antidepressants are generally taken at bedtime to help sleep and minimize daytime drowsiness.

FDA Warning on antidepressants

Despite the relative safety and popularity of SSRIs and other antidepressants, some studies have suggested that they may have unintentional effects on some people, especially adolescents and young adults. In 2004, the Food and Drug Administration (FDA) conducted a thorough review of published and unpublished controlled clinical trials of antidepressants that involved nearly 4,400 children and adolescents. The review revealed that 4% of those taking antidepressants thought about or attempted suicide (although no suicides occurred), compared to 2% of those receiving placebos.

This information prompted the FDA, in 2005, to adopt a "black box" warning label on all antidepressant medications to alert the public about the potential increased risk of suicidal thinking or attempts in children and adolescents taking antidepressants. In 2007, the FDA proposed that makers of all antidepressant medications extend the warning to include young adults up through age 24. A "black box" warning is the most serious type of warning on prescription drug labeling.

The warning emphasizes that children, adolescents and young adults taking antidepressants should be closely monitored, especially during the initial weeks of treatment. Possible side effects to look for are worsening depression, suicidal thinking or behavior, or any unusual changes in behavior such as sleeplessness, agitation, or withdrawal from normal social situations.

Results of a comprehensive review of pediatric trials conducted between 1988 and 2006 suggested that the benefits of antidepressant medications likely outweigh their risks to children and adolescents with major depression and anxiety disorders. The study was funded in part by the National Institute of Mental Health.

What about St. John's wort?

The extract from St. John's wort (Hypericum perforatum), a bushy, wild-growing plant with yellow flowers, has been used for centuries in many folk and herbal remedies. Today in Europe, it is used extensively to treat mild to moderate depression. In the United States, it is one of the top–selling botanical products.

To address increasing American interests in St. John's wort, the National Institutes of Health conducted a clinical trial to determine the effectiveness of the herb in treating adults who have major depression. Involving 340 patients diagnosed with major depression, the eight–week trial randomly assigned one-third of them to a uniform dose of St. John's wort, one–third to a commonly prescribed SSRI, and one–third to a placebo. The trial found that St. John's wort was no more effective than the placebo in treating major depression. Another study is looking at the effectiveness of St. John's wort for treating mild or minor depression.

Other research has shown that St. John's wort can interact unfavorably with other medications, including those used to control HIV infection. On February 10, 2000, the FDA issued a Public Health Advisory letter stating that the herb appears to interfere with certain medications used to treat heart disease, depression, seizures, certain cancers, and organ transplant rejection. The herb also may interfere with the effectiveness of oral contraceptives. Because of these potential interactions, patients should always consult with their doctors before taking any herbal supplement.

Psychotherapy

Several types of psychotherapy–or "talk therapy"–can help people with depression.

Some regimens are short–term (10 to 20 weeks) and other regimens are longer–term, depending on the needs of the individual.

Two main types of psychotherapies–**cognitive–behavioral therapy (CBT)** and **interpersonal therapy (IPT)-**have been shown to be effective in treating depression. By teaching new ways of thinking and behaving, CBT helps people change negative styles of thinking and behaving that may contribute to their depression. IPT helps people understand and work through troubled personal relationships that may cause their depression or make it worse.

For mild to moderate depression, psychotherapy may be the best treatment option. However, for major depression or for certain people, psychotherapy may not be enough. Studies have indicated that for adolescents, a combination of medication and psychotherapy may be the most effective approach to treating major depression and reducing the likelihood for recurrence. Similarly, a study examining depression treatment among older adults found that patients who responded to initial treatment of medication and IPT were less likely to have recurring depression if they continued their combination treatment for at least two years.

Electroconvulsive Therapy

For cases in which medication and/or psychotherapy does not help alleviate a person's treatment–resistant depression, electroconvulsive therapy (ECT) may be useful. ECT, formerly known as "shock therapy," once had a bad reputation. But in recent years, it has greatly improved and can provide relief for people with severe depression who have not been able to feel better with other treatments.

Before ECT is administered, a patient takes a muscle relaxant and is put under brief anesthesia. He or she does not consciously feel the electrical impulse administered in ECT. A patient typically will undergo ECT several times a week, and often will need to take an antidepressant or mood stabilizing medication to supplement the ECT treatments and prevent relapse. Although some patients will need only a few courses of ECT, others may need maintenance ECT, usually once a week at first, then gradually decreasing to monthly treatments for up to one year.

ECT may cause some short-term side effects, including confusion, disorientation and memory loss. But these side effects typically clear soon after treatment. Research has indicated that after one year of ECT treatments, patients showed no adverse cognitive effects.

How can I help a friend or relative who is depressed?

If you know someone who is depressed, it affects you too. The first and most important thing you can do to help a friend or relative who has depression is to help him or her get an appropriate diagnosis and treatment. You may need to make an appointment on behalf of your friend or relative and go with him or her to see the doctor. Encourage him or her to stay in treatment, or to seek different treatment if no improvement occurs after six to eight weeks.

To help a friend or relative:

- Offer emotional support, understanding, patience and encouragement.
- Engage your friend or relative in conversation, and listen carefully.
- Never disparage feelings your friend or relative expresses, but point out realities and offer hope.
- Never ignore comments about suicide, and report them to your friend's or relative's therapist or doctor.
- Invite your friend or relative out for walks, outings and other activities. Keep trying if he or she declines, but don't push him or her to take on too much too soon. Although diversions and company are needed, too many demands may increase feelings of failure.
- Remind your friend or relative that with time and treatment, the depression will lift.

How can I help myself if I am depressed?

If you have depression, you may feel exhausted, helpless and hopeless. It may be extremely difficult to take any action to help yourself. But it is important to realize that these feelings are part of the depression and do not accurately reflect actual circumstances. As you begin to recognize your depression and begin treatment, negative thinking will fade.

To help yourself:

- Engage in mild activity or exercise. Go to a movie, a ballgame, or another event or activity that you once enjoyed. Participate in religious, social or other activities.
- Set realistic goals for yourself.
- Break up large tasks into small ones, set some priorities and do what you can as you can.
- Try to spend time with other people and confide in a trusted friend or relative. Try not to isolate yourself, and let others help you.
- Expect your mood to improve gradually, not immediately. Do not expect to suddenly "snap out of" your depression. Often during treatment for depression, sleep and appetite will begin to improve before your depressed mood lifts.
- Postpone important decisions, such as getting married or divorced or changing jobs, until you feel better. Discuss decisions with others who know you well and have a more objective view of your situation.
- Remember that positive thinking will replace negative thoughts as your depression responds to treatment.

National Institutes of Health
The Nation's Medical Research Agency

For More Information

Visit the National Library of Medicine's MedlinePlus http://www.nlm.nih.gov/medlineplus/
(also in Spanish)

National Institute of Mental Health
E-mail: nimhinfo@nih.gov
Web site: http://www.nimh.nih.gov

National Institutes of Health
The Nation's Medical Research Agency

OLDER ADULTS: DEPRESSION AND SUICIDE FACTS

How common is suicide among older adults?

Older Americans are disproportionately likely to die by suicide.

- Although they comprise only 12 percent of the U.S. population, people age 65 and older accounted for 16 percent of suicide deaths in 2004.
- 14.3 of every 100,000 people age 65 and older died by suicide in 2004, higher than the rate of about 11 per 100,000 in the general population.
- Non-Hispanic white men age 85 and older were most likely to die by suicide. They had a rate of 49.8 suicide deaths per 100,000 persons in that age group.

What role does depression play?

Depression, one of the conditions most commonly associated with suicide in older adults, is a widely under-recognized and undertreated medical illness. Studies show that many older adults who die by suicide — up to 75 percent — visited a physician within a month before death. These findings point to the urgency of improving detection and treatment of depression to reduce suicide risk among older adults.

- The risk of depression in the elderly increases with other illnesses and when ability to function becomes limited. Estimates of major depression in older people living in the community range from less than 1 percent to about 5 percent, but rises to 13.5 percent in those who require home healthcare and to 11.5 percent in elderly hospital patients.
- An estimated 5 million have **subsyndromal depression**, symptoms that fall short of meeting the full diagnostic criteria for a disorder.
- Subsyndromal depression is especially common among older persons and is associated with an increased risk of developing major depression.

Isn't depression just part of aging?

Depressive disorder is not a normal part of aging. Emotional experiences of sadness, grief, response to loss, and temporary "blue" moods are normal. Persistent depression that interferes significantly with ability to function is not.

Health professionals may mistakenly think that persistent depression is an acceptable response to other serious illnesses and the social and financial hardships that often accompany aging - an attitude often shared by older people themselves. This contributes to low rates of diagnosis and treatment in older adults.

Depression can and should be treated when it occurs at the same time as other medical illnesses. Untreated depression can delay recovery or worsen the outcome of these other illnesses.

What are the treatments for depression in older adults?

Antidepressant medications or psychotherapy, or a combination of the two, can be effective treatments for late-life depression.

Medications

Antidepressant medications affect brain chemicals called neurotransmitters. For example, medications called **SSRIs (selective serotonin reuptake inhibitors)** affect the neurotransmitter serotonin. Different medications may affect different neurotransmitters.

Some older adults may find that newer antidepressant medications, including SSRIs, have fewer side effects than older medications, which include **tricyclic antidepressants** and **monoamine oxidase inhibitors (MAOIs)**. However, others may find that these older medications work well for them.

It's important to be aware that there are several medications for depression, that different medications work for different people, and that it takes four to eight weeks for the medications to work. If one medication doesn't help, research shows that a different antidepressant might.

Also, older adults experiencing depression for the first time should talk to their doctors about continuing medication even if their symptoms have disappeared with treatment. Studies showed that patients age 70 and older who became symptom-free and continued to take their medication for two more years were 60 percent less likely to relapse than those who discontinued their medications.

Psychotherapy

In psychotherapy, people interact with a specially trained health professional to deal with depression, thoughts of suicide, and other problems. Research shows that certain types of psychotherapy are effective treatments for late-life depression.

For many older adults, especially those who are in good physical health, combining psychotherapy with antidepressant medication appears to provide the most benefit. A study showed that about 80 percent of older adults with depression recovered with this kind of combined treatment and had lower recurrence rates than with psychotherapy or medication alone.

Another study of depressed older adults with physical illnesses and problems with memory and thinking showed that combined treatment was no more effective than medication alone.

Are some ethnic/racial groups at higher risk of suicide?

For every 100,000 people age 65 and older in each of the ethnic/racial groups below, the following number died by suicide in 2004:

- Non-Hispanic Whites — 15.8 per 100,000
- Asian and Pacific Islanders — 10.6 per 100,000
- Hispanics — 7.9 per 100,000
- Non-Hispanic Blacks — 5.0 per 100,000

Assessment

Ask the person if they feel:

- nervous
- empty
- worthless
- that they don't enjoy things they used to
- restless
- irritable
- unloved
- that life isn't worth living

…or if they are:

- sleeping more or less than usual
- eating more or less than usual

These may be symptoms of depression, a treatable illness. A referral to a physician would be warranted.

Other symptoms that may signal depression, but may also be signs of other serious illnesses, should be checked by a doctor, whatever the cause. They include:

- being very tired and sluggish
- frequent headaches
- frequent stomachaches
- chronic pain

For More Information

Depression Information and Organizations from NLM's MedlinePlus
http://www.nlm.nih.gov/medlineplus/depression.html (also in Spanish)

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WHEN UNWANTED THOUGHTS TAKE OVER: OBSESSIVE-COMPULSIVE DISORDER

Obsessive-Compulsive Disorder

Everyone double-checks things sometimes. For example, checking the stove before leaving the house, to make sure it's turned off. But people with OCD feel the need to check things over and over, or have certain thoughts or perform routines and rituals over and over. The thoughts and rituals of OCD cause distress and get in the way of daily life.

The repeated, upsetting thoughts of OCD are called **obsessions.**

To try to control them, people with OCD repeat rituals or behaviors, which are called **compulsions**. People with OCD can't control these thoughts and rituals.

Examples of obsessions are fear of germs, of being hurt or of hurting others, and troubling religious or sexual thoughts. Examples of compulsions are repeatedly counting things, cleaning things, washing the body or parts of it, or putting things in a certain order, when these actions are not needed, and checking things over and over.

People with OCD have these thoughts and do these rituals for at least an hour on most days, often longer. The reason OCD gets in the way of their lives is that they can't stop the thoughts or rituals, so they sometimes miss school, work, or meetings with friends, for example.

What are the symptoms of OCD?

People with OCD:

- **have repeated thoughts or images** about many different things, such as fear of germs, dirt, or intruders; violence; hurting loved ones; sexual acts; conflicts with religious beliefs; or being overly neat.
- **do the same rituals over and over** such as washing hands, locking and unlocking doors, counting, keeping unneeded items, or repeating the same steps again and again.
- **have unwanted thoughts and behaviors** they can't control.
- **don't get pleasure from the behaviors or rituals**, but get brief relief from the anxiety the thoughts cause.
- **spend at least an hour a day** on the thoughts and rituals, which cause distress and get in the way of daily life.

When does OCD start?

For many people, OCD starts during childhood or the teen years. Most people are diagnosed at about age 19. Symptoms of OCD may come and go and be better or worse at different times.

Is there help?

There is help for people with OCD. The first step is to go to a physician or health clinic to talk about symptoms. The physician will do an exam to make sure that another physical problem isn't causing the symptoms. The physician may make a referral to a mental health specialist.

Physicians may prescribe medication to help relieve OCD. It's important to know that some of these medicines may take a few weeks to start working. Only a physician (a family physician or psychiatrist) can prescribe medications.

The kinds of medicines used to treat OCD are listed below. Some of these medicines are used to treat other problems, such as depression, but also are helpful for OCD.

- antidepressants,
- antianxiety medicines, and
- beta-blockers.

Physicians also may ask people with OCD to go to therapy with a licensed social worker, psychologist, or psychiatrist. This treatment can help people with OCD feel less anxious and fearful.

There is no cure for OCD yet, but treatments can give relief to people who have it and help them live a more normal life. If you know someone with signs of OCD, talk to him or her about seeing a physician. Offer to go along for support. **To find out more about OCD, call 1-866-615-NIMH (1-866-615-6464)** to have free information mailed to you.

Who pays for treatment?

Most insurance plans cover treatment for anxiety disorders. People who are going to have treatment should check with their own insurance companies to find out about coverage. For people who don't have insurance, local city or county governments may offer treatment at a clinic or health center, where the cost is based on income. Medicaid plans also may pay for OCD treatment.

Why do people get OCD?

OCD sometimes runs in families, but no one knows for sure why some people have it while others don't. When chemicals in the brain are not at a certain level it may result in OCD. Medications can often help the brain chemicals stay at the correct levels.

To improve treatment, scientists are studying how well different medicines and therapies work. In one kind of research, people with OCD choose to take part in a clinical trial to help physicians find out what treatments work best for most people, or what works best for different symptoms. Usually, the treatment is free. Scientists are learning more about how the brain works, so that they can discover new treatments.

Personal story

"I couldn't touch any doors or countertops in public areas. I knew it didn't make any sense, but I was terrified of getting germs that could kill me. I almost couldn't go out in public, I was so afraid. If I thought I had touched anything, I would have to wash myself for hours. Sometimes I washed so much that my skin would get red and raw and bleed.

"At first I was too embarrassed to get help, but a friend told me to call the doctor. I'm so glad I did. I took the medicine my doctor gave me. I also talked with a counselor, in therapy. I learned to cope with my fear of germs and to stop washing so much."

For More Information

Obsessive-Compulsive Disorder Information and Organizations are available from NLM's MedlinePlus http://www.nlm.nih.gov/medlineplus/obsessivecompulsivedisorder.html (also in Spanish)

For information about how to take part in a clinical trial, call 1-866-615-6464 (toll-free) or 1-866-415-8051 (TTY toll-free)

HOARDING

Frost & Hartl's (1996) definition of clinical hoarding:
(1) the acquisition of, and failure to discard, a large number of possessions that appear to be of useless or of limited value; (2) living spaces sufficiently cluttered so as to preclude activities for which those spaces were designed; and (3) significant distress or impairment in functioning caused by the hoarding.

Hoarding is often a specific symptom of OCD that results in the collection of large amounts of items that to the outside world may appear excessive or worthless. The disorder is surrounded with secrecy and shame and the causes are still unknown. Importantly, hoarding isn't only associated with OCD and can be found independently. Many elderly people deal with hoarding and may have a lifetime accumulation of things that gradually gets worse as they age.

- Hoarding & Saving Symptoms are found in 18% to 42% of OCD patients and most people who hoard will also exhibit OCD symptoms. Less than 1% of the population hoards (non- clinical populations are also known to hoard).
- There are other mental disorders in which hoarding Behavior is seen. These include: Anorexia Nervosa, Dementia, and sometimes Psychotic Disorders. The difference between the hoarding behaviors in these disorders is unknown.
- Four key words that are common when talking about hoarding: Indecisiveness, Perfectionism, Procrastination, and Avoidance. These are symptoms that are known to be difficult to treat, especially if there is little willingness to change.
- The usual medications that can help with many other OCD symptoms seem to be less effective in the treatment of hoarding.
- Behavior Therapy (BT) does prove to show some benefits. However, as mentioned above, hoarders do not benefit greatly from the traditional treatments for OCD.

Hoarding creates a vicious circle in which the hoarder almost literally becomes trapped. The mess can become so dominant that self-esteem and social life suffers. People may start to feel that they can no longer invite people over and with that, an important motivation to clean their house will disappear.

Hoarding, like any other aspects of OCD, exists in different degrees. The severe cases of hoarding may truly devastate a person's life if no help is sought.

The Difference Between a Hoarder and a Clutterer
While both terms are used to denote someone who detrimentally accumulates many things, there is a medical difference:

Hoarder:

- Someone who hoards has psychiatric condition that affects less than 1% of the population.
- The person obsesses over his/her stuff and will most likely not find a solution unless professional help is sought.
- The collected stuff will cause serious distress and discomfort and will limit the person's ability to make good use of his house or rooms. He/she will not take out trash and will often keep close to everything.

Clutterer:

- Cluttering affects millions of people.
- Someone that lives amongst clutter accumulates without much thought and would probably be able to make the changes themselves if motivated enough to do so.
- Often this will never get to such an extreme point as to debilitate the persons freedom and comfort. He/she will be able to take out trash and throw things away if given enough reason.

The Possible Causes of OCHD:

Many people may jump to the conclusion that people who hoard must have a background in which they have been deprived of material things, providing an explanation for their behavior that can be more easily accepted or understood. Studies have looked into the link between the Material Deprivation in Childhood and Hoarding Behavior. While this showed no positive co-relation, researchers did find that there seems to be a tendency for Hoarders to report some material deprivation.

Why People Hoard

Sentimental Value:

- For the person that hoards, **the usefulness and/or value may lay in the most unexpected things. Sentimental value** is only one of the criteria used by hoarders to keep just about anything. This value is also about feeling the item is part of a person, not just an independent object.
  <u>**MISCONCEPTION:**</u> **"The moment I discard of this item I discard a part of myself.**"

Decision Making:

- Those with Hoarding Behavior find it **extremely difficult to make decisions** and end up avoiding having to make any by keeping everything. "What if I may need this one day? Where is the harm in keeping just this one extra thing?"

- Not having to make the decision to discard something means that mistakes can't be made while doing so.

MISCONCEPTION: **“The moment I decide to throw something away I may be making the wrong choice.** “

Organizing:

- A hoarder may experience difficulty with organization of objects or how things can be stored in a logical fashion. While this chaos may be painfully apparent for outsiders, the hoarder himself often finds some logic in this. To him/her a pile of junk may be the only way to feel some control and order. Piles are usually created by stacking the most important items on top.
  MISCONCEPTION: **“The moment I am unable to know how to categorize an item, I will place it in sight so I will know where it is.**”

Responsibility:

- As in OCD, hoarders may have a tendency to feel hyper-responsible for what is happening around them and the people they care for. With hoarding this can result in the accumulation of "just in case" objects that are carried around with them at all times. For example: carrying a large and unwieldy purse
- In addition there is the obligation of having to use a certain item. Discarding items seems wasteful and thus many things will be categorized as "recycling," or "giving away,” etc.
  MISCONCEPTION: **“The moment my object has a use, I have to keep/use it so it doesn't get wasted.**”

Control/Perfection:

- Hoarders struggle with the reality that when you throw something away, it's gone and once the trash will be picked up you will never be able to find an item again.
  MISCONCEPTION: **“The moment I decide to throw something away, I am no longer the person in control and what happens to this item will be in the hands of others.**”

Fear of Forgetting:

- The fear of forgetting causes items to be kept. This is especially true with written/printed material which is kept so it can be re-read at all times. The inability to remember everything becomes the behavior of keeping everything.
  MISCONCEPTION: **“The moment I throw something away, I may forget its content or the way it looked and it will be gone forever.**”

Letting go of Things:

- A motivation to hoard can be the fear of letting go or moving on. Personal example: “I used to hoard when I was younger. I would keep candy wrappers, elastic bands and small pieces of about...anything. The idea of losing things that had even a remotely sentimental value to me scared me. Because there would be no turning back and no control. But to me it also had something to do with things being ephemeral; keeping things or parts of them meant that I would literally prevent them from ceasing to exist, scared that parts of my life may be forever forgotten. So I picked up small stones, leaves, and kept notes and bills. I didn't want to let go of my life and forgot there was still much more to come."

- Items became part of who the person is. Letting go would be letting go of part of themself.
  <u>MISCONCEPTION:</u> "The moment I throw something away, I let go of that specific part of your life, however insignificant it may be."

Adapted from "Hoarding," http://understanding_ocd.tripod.com/hoarding.html

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757
(Continued)

.15 Assistance by the provider is available for transportation when the recipient's presence is required at the destination and such assistance is necessary to accomplish the travel, limited to:

.151 Transportation to and from appointments with physicians, dentists and other health practitioners.

.152 Transportation necessary for fitting health related appliances/devices and special clothing.

.153 Transportation under .151 and .152 above shall be authorized only after social service staff have determined that Medi-Cal will not provide transportation in the specific case.

.154 Transportation to the site where alternative resources provide in-home supportive services to the recipient in lieu of IHSS.

.16 Yard hazard abatement is light work in the yard which may be authorized for:

.161 Removal of high grass or weeds, and rubbish when this constitutes a fire hazard.

.162 Removal of ice, snow or other hazardous substances from entrances and essential walkways when access to the home is hazardous.

.163 Such services are limited by Sections 30.763.235(b) and .24.

.17 Protective Supervision consists of observing recipient behavior and intervening as appropriate in order to safeguard the recipient against injury, hazard, or accident.

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757
(Continued)

.171 Protective Supervision is available for observing the behavior of nonself-directing, confused, mentally impaired, or mentally ill persons only.

(a) Protective Supervision may be provided through the following, or combination of the following arrangements.

(1) In-Home Supportive Services program;

(2) Alternative resources such as adult or child day care centers, community resource centers, Senior Centers; respite centers;

(3) Voluntary resources;

(4) Repealed by Manual Letter No. SS-07-01

.172 Protective Supervision shall not be authorized:

(a) For friendly visiting or other social activities;

(b) When the need is caused by a medical condition and the form of the supervision required is medical.

(c) In anticipation of a medical emergency;

(d) To prevent or control anti-social or aggressive recipient behavior.

(e) To guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.

.173 Protective Supervision is only available under the following conditions as determined by social service staff:

(a) At the time of the initial assessment or reassessment, a need exists for twenty-four-hours-a-day of supervision in order for the recipient to remain at home safely.

(1) For a person identified by county staff to potentially need Protective Supervision, the county social services staff shall request that the form SOC 821 (3/06), “Assessment of Need for Protective Supervision for In-Home Supportive Services Program," which is incorporated by reference, be completed by a physician or or other appropriate medical professional to certify the need for Protective Supervision and returned to the county.

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757

(Continued)

(A) For purposes of this regulation, appropriate medical professional shall be limited to those with a medical specialty or scope of practice in the areas of memory, orientation, and/or judgment.

(2) The form SOC 821 (3/06) shall be used in conjunction with other pertinent information, such as an interview or report by the social service staff or a Public Health Nurse, to assess the person's need for Protective Supervision.

(3) The completed form SOC 821 (3/06) shall not be determinative, but considered as one indicator of the need for Protective Supervision.

(4) In the event that the form SOC 821 (3/06) is not returned to the county, or is returned incomplete, the county social services staff shall make its determination of need based upon other available information.

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HANDBOOK BEGINS HERE

(5) Other available information can include, but is not limited to, the following:

(A) A Public Health Nurse interview;

(B) A licensed health care professional reports;

(C) Police reports;

(D) Collaboration with Adult Protective Services, Linkages, and/or other social service agencies;

(E) The social service staff's own observations.

HANDBOOK ENDS HERE

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(b) At the time of reassessment of a person receiving authorized Protective Supervision, the county social service staff shall determine the need to renew the form SOC 821 (3/06).

(1) A newly completed form SOC 821 (3/06) shall be requested if determined necessary, and the basis for the determination shall be documented in the recipient's case file by the county social service staff.

30-757 PROGRAM SERVICE CATEGORIES AND TIME GUIDELINES 30-757

(Continued)

(c) Recipients may request protective supervision. Recipients may obtain documentation (such as the SOC 821) from their physicians or other appropriate medical professionals for submission to the county social service staff to substantiate the need for protective supervision.

.174 Social Services staff shall explain the availability of protective supervision and discuss the need for twenty-four-hours-a-day supervision with the recipient, or the recipient's parent(s), or the recipient's guardian or conservator, the appropriateness of out-of-home care as an alternative to Protective Supervision.

.175 (Reserved.)

.176 County Social Services staff shall obtain a signed statement from the provider(s) of record or any other person(s) who agrees to provide any In-Home Supportive Services (IHSS) or PCSP compensable service voluntarily. The statement [Form SOC 450 (10/98)] shall indicate that the provider knows of the right to compensated services, but voluntarily chooses not to accept any payment, or reduced payment, for the provision of services.

(a) The voluntary services certification for IHSS shall contain the following information:

(1) Services to be performed;

(2) Recipient(s) name;

(3) Case number;

(4) Day(s) and/or hours per month service(s) will be performed;

(5) Provider of services;

(6) Provider's address and telephone number;

(7) Provider's signature and date signed;

(8) Name and signature of Social Service Worker;

(9) County; and

(10) Social Security Number (Optional, for identification purposes only [Authority: Welfare and Institutions Code Section 12302.2]).

PROTECTIVE SUPERVISION
ENVIRONMENTAL MODIFICATIONS

1. The county may not require a consumer or the consumer's family to make any environmental modifications, even if those modifications would alleviate the need for Protective Supervision (PS).

2. If environmental modifications have been made that safeguard the consumer and the consumer is no longer at risk of injury, hazard, or accident as a result of his/her mental impairment and there is no longer a need for PS, then PS should not be authorized.

3. Environmental modifications that might safeguard a consumer who is at risk because of his/her mental impairments may include such things as:
   a. Removing knobs from the stove if the consumer is likely to light the stove and burn things.
   b. Locking the drawer(s) where knives are stored.
   c. Having a consumer wear a helmet to prevent head injury if the consumer bangs his/her head.

4. In some cases, environmental modifications may aid in making the consumer safe in the home, but will not totally eliminate the need for PS. Examples:
   a. Using a baby monitor may aid in reducing the risk of injury, hazard, or accident, but in most cases serves only to alert the provider of the need for intervention.
   b. Installing an audible alarm that rings when an external door is opened may aid in providing PS, but will not entirely eliminate the need for PS.

5. Sometimes, providers might restrain the consumer or seclude him/her as a means of preventing unwanted behavior. There is a strong possibility that such action is considered abuse. If the IHSS worker sees such efforts, the worker should advise the provider or family member of the problem with taking these actions and file an APS/CPS report. These types of environmental barriers that may not be allowed include:
   a. Tying or otherwise restraining a consumer in a chair, wheelchair, or bed.
   b. Locking a consumer in a room.

6. If PS is authorized and the provider(s) is still having difficulty safeguarding the consumer, the worker should refer the provider to other agencies, such as the Regional Center and the Family Caregiver Alliance that may provide services to the consumer and advice on alternate strategies.

7. At some point, the consumer may be too difficult to manage and safeguard at home. MPP §30-757.174 requires the worker to discuss out-of-home placement as an alternative to PS with the consumer, his/her parent(s), guardian, or conservator.

LAWSUITS THAT AFFECT PROTECTIVE SUPERVISION

Marshall et al., v. Linda McMahon – Superior Court of San Diego County No. 610664

(No. DO15184, Fourth District, Div 1, 17 Cal. App. 4th 1841)

Summary – The court ruled in favor of CDSS and agreed that Protective Supervision is available only for those persons who are non-self-directing and is not available in anticipation of a medical emergency.

The Plaintiff in this case was a 94-year-old person who applied for IHSS in 1987. The county authorized 104.10 hours of services per month based on the plaintiff's "general weakness due to old age, urinary incontinence and deafness." A request for Protective Supervision was not authorized on the basis she was alert and not mentally impaired. The primary issue dealt with in this lawsuit was the plaintiff's contention that persons with certain physical impairments, such as breathing problems or frequent strokes, also require continuous care and should be given protective supervision to live safely in the home. The plaintiff's attorneys argued that persons unable to anticipate a life-threatening event such as a stroke seizure or heart attack should be eligible for Protective Supervision.

The conclusion of the court in this case was that it is permissible to limit Protective Supervision to only those disabled people who are so unaware of their being and conduct as to require non-medical oversight, akin to baby-sitting, and that even though similar constant watchfulness of alert but otherwise endangered disabled people might be beneficial, the state is not constitutionally required to provide it.

Calderon v. Anderson – Superior Court of Los Angeles County No. BC081253

(No. B084320, Second District, Div 45, Cal. App. 4th 607)

Summary – The court ruled in favor of CDSS and agreed that in order to qualify for Protective Supervision, the recipient must have the physical ability to engage in any activities that would require observation or preventive intervention.

The plaintiff was a 35-year-old who suffered from severe mental retardation, physical deformities, and Cerebral Palsy, which rendered him completely bedridden. He functioned at the cognitive level of a one-year-old child. He had no use of his extremities, which remained in a fixed position, could not move his head, was nonverbal, and was unable to care for himself. The county authorized 169.6 hours of services which did not include Protective Supervision.

The plaintiff's attorneys argued that he was non-self-directing and mentally impaired, and in need of total care, and, therefore, eligible for such services. They further argued that he would be unable to summon assistance in the event of fire, environmental hazards, a need for water, or interference with his breathing.

It was agreed that Calderon is non-self directing; however, it was noted that his physical condition makes it impossible for him to engage in any activities that would require observation or preventive intervention. The court acknowledged that his medical condition is severe and situation unfortunate, but also indicated that Protective Supervision is not available merely to provide constant oversight in anticipation of environmental or medical emergencies.

Garrett v. Anderson – Superior Court of San Diego County No. 712208
Lam v. Anderson – Superior Court of Sacramento County No. 98CS00002

Summary – These lawsuits relate to the assessment of Protective Supervision for minors. The court ruled that in assessing the need for Protective Supervision for a minor, the county social worker must comply with the following:

- The social worker must review a minor's mental functioning on an individualized basis and must not presume a minor of any age has a mental functioning score of "1."
- The social worker must request the parent or guardian to obtain available information and documentation about the existence of a mental impairment.
- The social worker must determine whether a minor needs more supervision because of his/her mental impairment than a minor of the same age without such impairment.
- A minor cannot be refused Protective Supervision authorization based solely on age or the fact that the minor has had no injuries at home due to the mental impairment so long as the minor has the potential for injury by having the physical ability to move around the house.
- Protective Supervision authorization cannot be refused solely because a parent leaves the child alone for a fixed period of time, like five minutes.
- The social worker must consider factors such as age, lack of injuries and parental absence, together with all other facts, in determining whether or not a minor needs Protective Supervision.

PROTECTIVE SUPERVISION (PS) ASSESSMENT AND ELIGIBILITY TIPS

Hot Spot	Requirements	Things to Consider
Mental Status (MPP 30-757.171; ACL 15-25)	• Carefully assess mental impairment/illness **and** nonself -directing behavior. • In addition to all other relevant eligibility criteria, a person must be both mentally impaired or mentally ill ***and*** nonself-directing to be eligible for PS. • It is not sufficient for someone to be exclusively mentally impaired/mentally ill; there must also be evidence that he/she is nonself-directing.	• Be diligent not to confuse trained or instinctive behaviors with the ability to self-direct.
Nonself-directed Behavior (ACL 15-25)	• For the purpose of PS eligibility, nonself-direction is an inability, due to a mental impairment/mental illness, for individuals to assess danger and the risk of harm, and therefore, the individuals would most likely engage in potentially dangerous activities that may cause self-harm. • If the consumer engages in dangerous behavior and the behavior is beyond the consumer's control, PS could be authorized.	• Carefully assess if the consumer is willfully engaging in harmful behavior. • Determine whether the consumer understands what he/she is doing the behavior and if they understand the associated risks.
Physical ability to Engage in Potentially Dangerous Activities (ACL 15-25;Calderon v. Anderson)	• The consumer must be physically capable to engage in behavior that puts his/her safety at risk.	• Consider the specific circumstances of the individual when determining whether s/he has the physical ability to engage in potentially dangerous activities. • For example, a mentally impaired or mentally ill individual who is bedridden or in a wheelchair may be but is not necessarily incapable of engaging in activities that would require observation or

Hot Spot	Requirements	Things to Consider
In Anticipation of a Medical Emergency (MPP §30-757.172 (b, c); ACL 15-25)	• PS cannot be authorized when the supervision required is caused by a medical condition or in anticipation of a medical emergency. • It is not appropriate to authorize PS because a consumer has a medical condition that might get worse or become a medical emergency (e.g. the consumer might have a heart attack or a seizure).	• PS should not be authorized because the consumer's behavior might result in a medical emergency (e.g. the consumer has no concern for traffic and is likely to run into traffic and get hit). • Is the risk is based on a medical condition or nonself-directed, self-injurious behavior?
Anti-social, Aggressive, or Deliberate Self-Destructive Behavior (MPP §30-757.172 (d, e); ACL 15-25)	• PS cannot be authorized to prevent or control antisocial or aggressive behavior or to guard against self-destructive behavior. • PS cannot be authorized to prevent the consumer from injuring others. • PS cannot be used to guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.	• Evaluate whether the consumer's actions are deliberate and self-directed. • Determine if the consumer has the ability to make a decision. Can they take pieces of information, put them together, and come out with a decision. • Ask questions that are specific about their day to day actions that will help you to assess ability to make decisions.
Variations in Behaviors (MPP § 30-757.172; ACL 15-25)	• If a person displays both excluded behaviors and non-excluded behaviors, they can still qualify for PS. • Distinguish between behaviors that are excluded from PS and those that would qualify a consumer for PS.	• During the assessment, keep an open mind and ask thorough questions to understand all behaviors exhibited by the consumer. • For example, a person who exhibits antisocial and aggressive behaviors towards others and also exhibits self-harming behaviors may qualify for PS.

PROTECTIVE SUPERVISION (PS) ASSESSMENT AND ELIGIBILITY TIPS

Hot Spot	Requirements	Things to Consider
Environmental Modifications (ACL 15-25)	• If environmental modifications are made which eliminate the hazard, there is no longer a need for PS and PS should not be authorized. • Modifications can be used to eliminate the need for PS; however, they cannot be required.	• If an environmental modification is used, explore whether there are other behaviors that also require PS and monitoring. • Suggest available environment modifications but these cannot be required.
Fluctuating / Episodic Behavior (MPP § 30-757.173; ACL 15-25)	• PS requires a 24/7 need. • If the behavior in question is considered predictable, and the need for supervision is at certain times of the day, there is no PS eligibility because there is not a 24 hour-a-day need. • Alternatively, unpredictable episodic behavior does meet the 24/7 requirement as the need for supervision is constant. • The unpredictable episodic behavior must be frequent and long enough that constant supervision is necessary.	• Examine the behaviors that might require PS and when/how they occur. • Assess if the consumer might engage in the behavior that requires PS during sleeping hours. The consumer should not be considered ineligible just because s/he sleeps. • If there is a report that the consumer does not engage in behaviors that put him/her at risk while in a program/school/ADHC, etc., confirm whether that is because of staff interventions at the program. • PS can be authorized to safeguard the consumer even if the behavior involved going outside, such as wandering and getting lost or bolting into traffic.
Actual Injury vs. Propensity to Harm Self (ACL 15-25)	• The person does not have to suffer actual injury to be eligible for PS but only have a history of a propensity for placing him/herself in danger.	• Determine if the lack of injuries is due to preventive interventions previously applied.
Routine Childcare (ACL 14-105)	• Protective Supervision cannot be authorized for routine child care or supervision. • Like all other tasks, PS must be related to the functional limitations of the child and this criteria applies to all providers, not just parent providers.	• Assess what needs are due to the child's disability versus which are routine childcare. • Utilize the Age Appropriate Guideline Tool.

PROTECTIVE SUPERVISION (PS) ASSESSMENT AND ELIGIBILITY TIPS

Hot Spot	Requirements	Things to Consider
Assessing Children (ACL 15-25; MPP 757.17; ACL and Errata 98-87**)**	• All Protective Supervision rules apply to children cases. • Children PS is further mandated based on the settlements of the *Garrett v. Anderson* and the *Lam v. Anderson* superior court cases. • Assess all IHSS eligible minors for a mental impairment/mental illness and request the parent or guardian obtain available information and documentation about the existence of a minor's mental impairment/mental illness. • Evaluate a mentally ill/mentally impaired minor in the functions of memory, orientation, and judgment, on an individualized basis. • Review any relevant information provided by the parent. • The fact that there are no injuries is not a sole reason for not authorizing PS. • Age is not a sole reason for not authorizing PS. • Assess whether the minor needs more supervision because of his/her mental impairment than a minor of the same age without such impairment. • The fact that the minor is left home alone for a fixed period of time, like 5 minutes, is not a sole reason for not authorizing PS. • Advise parents or guardians of the availability of, and the conditions for receiving Protective Supervision. • Do not presume that services, which are otherwise compensable, will be provided voluntarily by a parent or guardian or anyone else.	• Be cognizant of all the specific requirements that apply to children's cases based on regulations and court case rulings. • During assessment be sure to interact and observe the minor carefully. Think of ways to get them perform activities that will give you some insight into their ability to be self-directing. • Ask questions that require the minor to use thought process or problem solving vs. questions that are frequently asked and can answers can be memorized (i.e. address, phone number, name) • Gather information from all sources once you have a release of information signed. Look at school program, Regional Center, healthcare practitioners for information that can bring clarity to your assessment.

PROTECTIVE SUPERVISION (PS) ASSESSMENT AND ELIGIBILITY TIPS

Hot Spot	Requirements	Things to Consider
24-hour Plan (MPP 30-757.174; ACL 15-25)	• A 24-hour care plan is needed to explain how the recipient will be protectively supervised for any hours above those that are provided by IHSS or Alternative Resources. • A discussion regarding 24 hour care plan must be held and documented. The SOC 864 is required for all cases. • It is mandated to discuss the appropriateness of out-of-home care as an alternative to PS. • If the need is not being met, the consumer is at risk and referrals to appropriate agencies should be made.	• Explain the availability of Protective Supervision and discuss the need for 24-hours-a-day supervision. • Look for other service providers to help with the care as IHSS can only pay for 9 hours a day. • Always ask pertinent questions to determine how the need is met. • Discuss the need of provider respite and pay careful attention to signs of provider burnout. • Contingency plans should be discussed in the event that the provider becomes ill. • Though **the** SOC 825 form is not required it is a very useful form to have in the case file, for the safety of the recipient.
Removing Protective Supervision (MPP §30-757.173)	• PS is only available if, at the time of assessment or reassessment, a need exists for 24 hours a day of supervision in order for the recipient to remain at home safely. • Authorization of PS must be reassessed at every annual assessment and if the consumer's condition changes. • The SW's documentation should justify and substantiate all decisions.	• When removing PS consider the reason must be substantiated by evidence to one of the following: o regulations were misapplied, o if the consumer's mental condition improved so s/he is no longer at risk, or o if consumer's condition deteriorated to the point that s/he is no longer capable of putting self at risk. • When documenting the removal of PS it is import to include regulatory language as support to your decision.

Hot Spot	Requirements	Things to Consider
State Hearings	• You must notify the consumer that they have the right to a fair hearing.	• PS cases are more likely than others to be challenged in State Hearings because there are many factors to consider when assessing for this service. Have a regulation/ACL justification for all actions. • The basis of the decision of approval or not should be documented thoroughly so the county Appeals Specialist can represent the position well. • At the hearing, stay open to new information that may or may not change the PS determination. • Take the appropriate action without trying to second-guess the outcome of a hearing. • Hearing decisions are not precedent setting. • Always be objective during the assessment process, communicate openly with family member/provider during assessment, and refrain from waiting to communicate bad news in the NOA.
Assessment of Need for PS for In-Home Supportive Services Program (SOC 821) (MPP 303-757.173(a)(1-4)	• The SOC 821 must be requested by the SW for any potential PS case. • The SOC 821 must be completed by a physician or other appropriate medical professional to certify the need for PS. • Completed SOC 821 is not determinative but should be used in conjunction with other assessed information. • If the SOC 821 is not returned or is incomplete, the determination of need can be based upon other available information.	• If the SW receives a SOC 821 certifying that the consumer needs PS but there is substantial evidence to the contrary, SW should contact and discuss the need for PS with the medical professional that signed the SOC 821. • Utilized other county staff such as PHN and/or your supervisor to help assess the need for PS. • The doctor may not know IHSS policies so s/he may need to be educated in the completion of the form. • Clear and thorough documentation of substantiating or corroborating information should accompany any decision. When documenting, cite and use regulation language to support your decision.

PROTECTIVE SUPERVISION (PS) ASSESSMENT AND ELIGIBILITY TIPS

Hot Spot	Requirements	Things to Consider
Consumers who Live Alone (MPP 30-757.171 (a)(1-4)	• Consumers who live alone must meet all requirements for PS. Living alone does not mean the person is eligible or not eligible for PS. • A plan for 24/hour a day support must be met. • Document all providers (IHSS and others) and the times they are providing PS services to ensure 24 hour need is met.	• Find out if someone else who is familiar with the consumer can participate in the assessment. • Identify as correctly as possible collateral individuals who can help gather information to correctly assess the consumer's need for PS and other IHSS services. • Obtain a signed release for information to speak with family and other resources. • Additional resources for information may include police and medical personnel. • Information from outside resources won't be as complete a picture of the consumer's behavior as someone who lives with the consumer. • A need for PS may be suspected because of assessment in the areas of M/O/J, but it may be difficult to find out about behaviors. • It may be beneficial to refer the consumer to APS for a resource that could help build a plan of care and be involved in seeking conservatorship if the consumer is alone.
Pressure from Providers	• Policies stated in the regulations and ACLs should always be followed. • SW should communicate PS rules to the provider so that they understand the service rules and limitations.	• Communication with the provider should be open, calm, professional. • The provider usually knows the consumer better than anyone else and this can be useful in assessment. • It is important for the SW to recognize the burden on the provider for the level of care they provide and that they may have little personal space because of this role. • Additionally, SWs should recognize the emotional toll on a relative-provider in losing the relationship they once had.

Hot Spot	Requirements	Things to Consider
Pressure from others – Community Based Organizations, Regional Centers, advocates	• Communicate with possible alternative resources in relation to the consumer, especially during the creation of the 24-hour plan.	• Remember that all agencies are required to explore all alternative resources available to meet the needs of the consumer. • Agency staff may not fully understand the program and its limitations but may have a unique view of the consumer to help in the assessment and creation of a case plan.

CDSS
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GOVERNOR

REASON FOR THIS TRANSMITTAL

[ ] State Law Change
[ ] Federal Law or Regulation Change
[ ] Court Order
[ ] Clarification Requested by One or More Counties
[X] Initiated by CDSS

March 19, 2015

ALL-COUNTY LETTER (ACL) NO.: 15-25

TO: ALL COUNTY WELFARE DIRECTORS
ALL IN-HOME SUPPORTIVE SERVICES (IHSS) PROGRAM MANAGERS

SUBJECT: PROTECTIVE SUPERVISION CLARIFICATIONS

REFERENCES: ACL 98-87 (October 30, 1998), ERRATA – ACL 98-87 (October 30, 1998)

This ACL provides clarifications regarding existing Protective Supervision policies.

Protective Supervision Regulations

Protective Supervision regulations are based on Welfare and Institutions Code (WIC) §12300(b). The Manual of Policies and Procedures (MPP) § 30-700 contains the following sections that are specifically applicable to the assessment, and authorization of Protective Supervision:

- MPP §§ 30-757.17 through .172
  .17 Protective Supervision consists of observing recipient behavior and intervening as appropriate in order to safeguard the recipient against injury, hazard, or accident.
    .171 Protective Supervision is available for observing the behavior of nonself-directing, confused, mentally impaired, or mentally ill persons only.
      (a) Protective Supervision may be provided through the following, or combination of the following arrangements.
        (1) In-Home Supportive Services program;
        (2) Alternative resources such as [1]adult or child day care centers, community resource centers, Senior Centers; respite centers;
        (3) Voluntary resources;
        (4) Repealed by Manual Letter No. SS-07-01

    .172 Protective Supervision shall not be authorized:

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[1] Please note: Effective April 1, 2012, Adult Day Health Care (ADHC) is now referred to as Community-Based Adult Services (CBAS).

(a) For friendly visiting or other social activities;
(b) When the need is caused by a medical condition and the form of the supervision required is medical.
(c) In anticipation of a medical emergency;
(d) To prevent or control anti-social or aggressive recipient behavior.
(e) To guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.

- MPP §§ 30-757.173 and .174 pertain to the 24 hour-a-day need requirement and the Assessment of Need for Protective Supervision for In-Home Supportive Services Program, SOC 821, form.

- MPP § 30-756.37 Mental functioning shall be evaluated as follows:
  .371 The extent to which the recipient's cognitive and emotional impairment (if any) impacts his/her functioning in the 11 physical functions listed in Sections 30-756.2(a) through (k) is ranked in each of those functions. The level and type of human intervention needed shall be reflected in the rank for each function.
  .372 The recipient's mental function shall be evaluated on a three-point scale (Ranks 1, 2, and 5) in the functions of memory, orientation and judgment. This scale is used to determine the need for protective supervision.

- MPP § 30-763.33
  .33 The need for protective supervision shall be assessed based on the recipient's individual need provided that:
  .331 When two (or more) IHSS recipients are living together and both require protective supervision, the need shall be treated as a common need and prorated accordingly. In the event that proration results in one recipient's assessed need exceeding the payment and hourly maximums provided in Section 30-765, the apportionment of need shall be adjusted between the recipients so that all, or as much as possible of the total common need for protective supervision may be met within the payment and hourly maximums.

  .332 For service authorization purposes, no need for protective supervision exists during periods when a provider is in the home to provide other services.

Specific Policies
To provide ongoing guidance to counties, the following information sets forth specific existing Protective Supervision policies based on CDSS interpretations of regulations and relevant court cases:

Mentally Impaired/Mentally Ill and Nonself-Directing
In addition to all other relevant eligibility criteria, a person must be both mentally impaired or mentally ill *and* nonself-directing to be eligible for Protective Supervision. It

is not sufficient for someone to just be mentally impaired/mentally ill, there must also be evidence that he/she is nonself-directing. This policy is based on the court rulings in the *Marshall v. McMahon,* (1993) 17 Cal. App. 4th 1841, and *Calderon v. Anderson,* (1996) 45 Cal. App. 4th 607, cases, and will also be reflected in forthcoming amendments to the Protective Supervision regulations found at MPP § 30-757.17.

For the purpose of Protective Supervision eligibility, nonself-direction is an inability, due to a mental impairment/mental illness, for individuals to assess danger and the risk of harm, and therefore, the individuals would most likely engage in potentially dangerous activities that may cause self-harm.

Physical Ability to Engage in Potentially Dangerous Activities

Protective Supervision recipients must be physically capable of harming themselves. In *Calderon v. Anderson* (1996)*,* the court held that the plaintiff was not entitled to Protective Supervision under the IHSS Program because his physical condition made it impossible for him to engage in any activities that would require observation or preventative intervention, and Protective Supervision was not available merely to provide constant oversight in anticipation of environmental or medical emergencies.

However, a mentally impaired or mentally ill individual who is bedridden, or in a wheelchair, is not necessarily incapable of engaging in activities that would require observation or preventative intervention under Protective Supervision. The specific factual circumstances of the individual must be considered when determining whether s/he has the physical ability to engage in potentially dangerous activities.

For example:

- A mentally impaired/mentally ill bedridden individual may still have the physical ability to pull at his or her G-tube that requires observation or intervention under Protective Supervision.

This risk of harm is different than the types of medical emergencies/medical conditions for which Protective Supervision is not available under MPP § 30-757.172, such as the potential to fall because the mentally impaired/mentally ill person experiences poor balance.

Excluded Needs and Behaviors under MPP § 30-757.172

The exclusions listed under MPP § 30-757.172 are applicable if a recipient is otherwise eligible for Protective Supervision in that s/he has the requisite mental impairment/ mental illness, is nonself-directing, and would likely engage in potentially dangerous activities. MPP § 30-757.172 states Protective Supervision shall not be authorized:

(a) For friendly visiting or other social activities;
(b) When the need is caused by a medical condition and the form of the supervision required is medical.
(c) In anticipation of a medical emergency;
(d) To prevent or control anti-social or aggressive recipient behavior.

(e) To guard against deliberate self-destructive behavior, such as suicide, or when an individual knowingly intends to harm himself/herself.

An example of an excluded need/behavior for “(b) When the need is caused by a medical condition and the form of the supervision required is medical,” is:

- A recipient who has diabetes and the need for Protective Supervision is to help if/when the recipient has an episode of hypoglycemia.

Additionally, an example of an excluded need/behavior for “(c) In anticipation of a medical emergency” is:

- A recipient who has Congestive Heart Failure and the need for Protective Supervision is in anticipation of a heart attack.

If a recipient only displays needs or behaviors excluded under MPP § 30-757.172, they are not eligible for Protective Supervision. If a recipient displays self-injurious behavior that would qualify for Protective Supervision, but also displays excluded behavior(s) based on MPP § 30-757.172, they may still be eligible for Protective Supervision for the non-excluded behaviors.

For example:

- A recipient who displays multiple self-injurious behaviors such as attempting suicide and wandering would be eligible for Protective Supervision to intervene to prevent wandering, but not to prevent suicide attempts.

The IHSS program is not intended to prevent or control dangerous behaviors, and IHSS providers are not trained to intervene when recipients are displaying such behaviors. *The non-IHSS program remedy for suicide attempts and other dangerous behavior is still to call 911.*

Additional Excluded Needs and Behaviors

The *Calderon v. Anderson* decision states that “protective supervision is not available merely to provide constant oversight in anticipation of environmental or medical emergency or exigent circumstances.”

For example:

- A mentally ill/mentally impaired recipient who would not know how to exit his/her home in the event of a fire is not eligible for Protective Supervision based on that behavior (or lack of appropriate response/behavior) alone.

Routine Child Care

Protective Supervision cannot be authorized for routine child care or supervision. This policy is based on the requirement that Protective Supervision must be related to the functional limitations of the child as set forth in WIC § 12300(e)(4). This policy is also supported by MPP § 30-763.456(d), and it is CDSS' interpretation that this criteria applies to all providers, not just parent providers.

Environmental Modifications/Safety-Proofing to Eliminate Need for Protective Supervision

Environmental modifications such as removing knobs from stove or adding safety latches can be used, and should be encouraged, to eliminate the need for Protective Supervision. If the modification eliminates the hazard, then there is no longer a need for Protective Supervision and Protective Supervision should not be authorized.

Fluctuating/Episodic Behavior

Per MPP § 30-757.173, "Protective Supervision is only available under the following conditions as determined by social service staff:

> (a) At the time of the initial assessment or reassessment, a need exists for twenty four-hours-a-day of supervision in order for the recipient to remain at home safely."

Protective Supervision requires a 24/7 need, so if the behavior in question is considered predictable, and the need for supervision is at certain times of the day, there is no Protective Supervision eligibility because there is not a 24 hour-a-day need. Alternatively, unpredictable episodic behavior does meet the 24/7 requirement, as the need for supervision is constant. The unpredictable episodic behavior must be frequent and long enough that constant supervision is necessary.

It is CDSS' policy that leaving a recipient alone for some fixed short period of time, is not, by itself, a reason to deny Protective Supervision. Although this concept is derived from language from the *Garrett* court order, discussed below, it is CDSS' policy that this should apply to adults and minors alike; therefore, an adult or a child may be eligible for Protective Supervision in order to safeguard them from dangerous and fluctuating/episodic behavior, even if that behavior allows the person to be left alone for short periods of time.

Actual Injury vs. Propensity to Harm Self

It is CDSS' policy that a person does not have to suffer *actual* injury to be eligible for Protective Supervision, but only have a history of a propensity for placing him/herself in danger.

For example:

- A person with a documented history of nonself-direction, who has a tendency to open the front door and start walking away, does not necessarily have to make it into the street in order for this to be considered potentially hazardous behavior.

Other evidence of a propensity for placing him/herself in danger may come from doctor evaluations, Individualized Education Plans (IEPs), etc.

When reassessing for Protective Supervision, changes in a recipient's physical mobility may impact their eligibility for Protective Supervision. Also, changes in a recipient's behavior or condition which indicates that s/he no longer has the same propensity to engage in potentially dangerous activities may impact their eligibility for Protective Supervision.

When the county discontinues Protective Supervision, it must establish the factual basis for the discontinuance.

Assessing Children for Protective Supervision

Based on the settlements of the *Garrett v. Anderson* and the *Lam v. Anderson* superior court cases, county social workers must always:

1. assess all IHSS eligible minors for a mental impairment/mental illness, and request the parent or guardian obtain available information and documentation about the existence of a minor's mental impairment/mental illness;
2. evaluate a mentally ill/mentally impaired minor in the functions of memory, orientation, and judgment, on an individualized basis;
3. evaluate a mentally ill/mentally impaired minor even if there are no previous injuries;
4. evaluate a mentally ill/mentally impaired minor regardless of age;
5. assess whether the minor needs more supervision because of his/her mental impairment than a minor of the same age without such an impairment;
6. evaluate a mentally ill/mentally impaired minor even if the minor can be left home alone for a fixed period of time;
7. review any relevant information provided by the parent;
8. advise parents or guardians of the availability of, and the conditions for receiving Protective Supervision; and
9. not presume that services, which are otherwise compensable, will be provided voluntarily by a parent or guardian or anyone else.

As stated above, the counties must assess all eligible minors, which include anyone up to the age of 18 years old, for a mental impairment/ mental illness. If the child is mentally impaired/mentally ill, the following provides a four-step process for counties to use when applying the terms of the *Garrett v. Anderson* stipulated judgment:

1. Is the minor nonself-directing due to the mental impairment/mental illness? If the answer is no, then the minor is not eligible for Protective Supervision pursuant to *Calderon v. Anderson* and *Marshal v. McMahon*, and Protective Supervision should not be granted. The county should document that because the child is self-directing, the minor does not meet the Garrett criteria of needing more supervision than another minor of the same age without a mental impairment/ mental illness. Counties should also document the underlying facts which are basis for this determination. If the answer is yes, then move to question 2;

2. If the minor is mentally impaired/mentally ill and nonself-directing, is he/she likely to engage in potentially dangerous activities? Consider here whether the minor retains the physical ability to put him/herself at risk of harm. If the answer is no,

then the minor is not eligible for Protective Supervision under the *Calderon v. Anderson* court decision, and Protective Supervision should not be granted. The county should document that because the child is not likely to engage in potentially dangerous activities, the minor does not meet the Garrett criteria of needing more supervision than another minor of the same age without a mental impairment/mental illness. If the answer is yes, then move to question 3;

3. Does he/she also need more supervision than a minor of comparable age who is not mentally impaired/mentally ill pursuant to the *Garrett v. Anderson* court order? "More supervision" can be more time, more intensity, or both. The additional supervision required must be significantly more than routine child care, and not only be related to the functional limitations of the child, but also allow the child to remain safely in their own home with this assistance. If the answer is no, then the minor is not eligible for Protective Supervision under the *Garrett v. Anderson* court order, and Protective Supervision should not be granted. The county should document that because the child does not need more supervision than another child of the same age without a mental impairment/mental illness, the minor does not meet the Garrett criteria of needing 24 hours-a-day of supervision. If the answer is yes, then move to question 4;

4. When it is found that "more supervision" is needed, is 24 hour-a-day supervision needed in order for the minor to remain at home safely pursuant to MPP § 30-757.173? If the answer is no, then the minor is not eligible for Protective Supervision and it should not be granted. If the answer is yes, the minor qualifies for Protective Supervision, if otherwise eligible.

    - Remember that a 24-hour care plan is needed to enumerate how the recipient will be protectively supervised for any hours above those that are provided by IHSS or Alternative Resources.

It is recommended that counties document in the case involving a person up to the age of 18 years old that these *Garrett v. Anderson* requirements have been met in all appropriate cases. The above 4-step process can be used as a template in the case narrative.

Next Steps
To ensure the Protective Supervision regulations accurately reflect CDSS policy and relevant court cases, CDSS is currently working on updating the Protective Supervision regulations.

If you have any questions regarding this ACL, please call the Policy and Quality Assurance Branch, Policy and Operations Bureau at (916) 651-5350, or send an email to APDPolicy@dss.ca.gov.

Sincerely,

Original Document Signed By:

EILEEN CARROLL
Deputy Director
Adult Programs Division

c: CWDA

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY CALIFORNIA DEPARTMENT OF SOCIAL SERVICES

PROTECTIVE SUPERVISION
24-HOURS-A-DAY COVERAGE PLAN

PLEASE PRINT

NAME OF IHSS RECIPIENT:	RECIPIENT'S TELEPHONE #:
ADDRESS OF IHSS RECIPIENT:	
NAME OF PRIMARY CONTACT RESPONSIBLE:	CONTACT'S TELEPHONE #:
RELATIONSHIP TO RECIPIENT:	

As the primary contact for arranging the 24-hour-a-day coverage plan for the above named Recipient, I acknowledge my understanding of the following:

- A 24-hour-a-day coverage plan has been arranged and is in place.

  The continuous 24-hour-a-day coverage plan can be met regardless of paid In-Home Supportive Service (IHSS) hours along with various alternate resources (i.e.; Adult or Child Day Care Centers, community resource centers, Senior Centers, respite centers, etc.)

- The 24-hour-a-day coverage plan will be provided at all times.

- If there is any change to the 24-hour-a-day coverage plan (i.e. hospitalization, attendance in day-care programs, travel, etc.) I will immediately **notify the IHSS social worker.**

- The above name Recipient has an established need for 24-hour-a-day Protective Supervision if he/she is to remain safely in the home. The IHSS social worker has also discussed with me the appropriateness of out-of-home care as an alternative to 24-hour-a-day Protective Supervision.

NAME OF CARE PROVIDER (1):	CONTACT PHONE #:
NAME OF CARE PROVIDER (2):	CONTACT PHONE #:
NAME OF CARE PROVIDER (3):	CONTACT PHONE #:

Describe the implementation of the Protective Supervision 24-Hour-A-Day Coverage Plan:

SIGNATURE OF PRIMARY CONTACT RESPONSIBLE:	DATE:
SIGNATURE OF IHSS SOCIAL WORKER:	CONTACT PHONE #:

State of California – Health and Human Services Agency
IN-HOME SUPPORTIVE SERVICES (IHSS)
PROTECTIVE SUPERVISION
24-HOURS-A-DAY COVERAGE PLAN (SOC 825)

INSTRUCTIONS

The IHSS Protective Supervision 24-Hours-A-Day Coverage Plan (SOC 825) is an optional form for County use. The SOC 825 is intended to ensure that recipients who need Protective Supervision have the 24-hours of care needed for their health and safety 24 hours a day. The recipient's social service worker and the IHSS care provider(s), whether a family member, friend, or no relation at all, should discuss together a plan or schedule of 24 hours a day of coverage for the recipient.

NAME OF IHSS RECIPIENT: Enter the full name of the IHSS recipient.

RECIPIENT'S TELEPHONE NUMBER: Enter the contact telephone number for the recipient.

ADDRESS OF IHSS RECIPIENT: Enter the recipient's home address where the majority of the 24-hours-a-day coverage will be performed.

NAME OF PRIMARY CONTACT RESPONSIBLE: Enter the name of the person with primary responsibility for coordinating the recipient's 24-Hours-A-Day Coverage Plan.

PRIMARY CONTACT'S TELEPHONE NUMBER: Enter the telephone number for the primary contact responsible.

RELATIONSHIP TO RECIPIENT: Enter the relationship of the primary contact to the recipient, (i.e., family member, IHSS care provider, friend, etc.).

NAME OF CARE PROVIDER(S) (1), (2), (3), and CONTACT TELEPHONE NUMBER(S): Enter the name(s) of each care provider responsible for the recipient's care during the 24 hours a day of coverage. Enter a contact telephone number for each care provider.

If more than three (3) care providers are responsible for this recipient, an additional sheet of paper can be attached with name(s) and contact telephone number(s).

Describe the implementation of the Protective Supervision 24-Hours-A-Day Coverage Plan:

Enter the planned schedule, or explanation of the plan in which the above provider(s) will ensure the recipient is cared for the entire 24-hour period. An additional sheet of paper can be attached if more space is needed to describe the 24-Hours-A-Day Coverage Plan.

SIGNATURE OF PRIMARY CONTACT RESPONSIBLE and DATE: Once the 24-Hours-A-Day Coverage Plan is developed, the primary contact responsible will sign and date the form when the Plan is discussed with the social worker authorizing the need for Protective Supervision.

SIGNATURE OF IHSS SOCIAL WORKER and CONTACT TELEPHONE NUMBER:
When the 24-Hours-A-Day Coverage Plan is discussed and signed and dated by the primary contact, the county social service worker will sign the form and add their contact telephone number.

A copy of the form is to be provided to the primary contact and retained in the County case file.

STATE OF CALIFORNIA - HEALTH AND HUMAN SERVICES AGENCY

CALIFORNIA DEPARTMENT OF SOCIAL SERVICES

ASSESSMENT OF NEED FOR PROTECTIVE SUPERVISION FOR IN-HOME SUPPORTIVE SERVICES PROGRAM

■ Release of Information Attached

Attending	PATIENT'S NAME:	PATIENT'S DOB: / /
Physician's /	MEDICAL ID#: (IF AVAILABLE)	COUNTY ID#:
Medical Professional's	IHSS SOCIAL WORKER'S NAME:	
mailing address	COUNTY CONTACT TELEPHONE #:	COUNTY FAX #:

Your patient is an applicant/recipient of **In-Home Supportive Services** (IHSS) and is being assessed for the need for Protective Supervision. Protective Supervision is available to safeguard against accident or hazard by observing and/or monitoring the behavior of non self-directing, confused, mentally impaired or mentally ill persons. This service is <u>not available</u> in the following instances:

(1) When the need for protective supervision is caused by a physical condition rather than a mental impairment;
(2) For friendly visitation or other social activities;
(3) When the need for supervision is caused by a medical condition and the form of supervision required is medical;
(4) In anticipation of a medical emergency (such as seizures, etc.);
(5) To prevent or control antisocial or aggressive recipient behavior.

Please complete this form and return it promptly. Thank you for your assisting us in determining eligibility for Protective Supervision.

(Welfare and Institutions Code §12301.21)

DATE PATIENT LAST SEEN BY YOU:	LENGTH OF TIME YOU HAVE TREATED PATIENT:
DIAGNOSIS/MENTAL CONDITION:	PROGNOSIS: ■ Permanent ■ Temporary - Timeframe:__________

PLEASE CHECK THE APPROPRIATE BOXES

MEMORY

■ No deficit problem ■ Moderate or intermittent deficit (explain below) ■ Severe memory deficit (explain below)

Explanation:

ORIENTATION

■ No disorientation ■ Moderate disorientation/confusion (explain below) ■ Severe disorientation (explain below)

Explanation:

JUDGMENT

■ Unimpaired ■ Mildly Impaired (explain below) ■ Severely Impaired (explain below)

Explanation:

1. Are you aware of any injury or accident that the patient has suffered due to deficits in memory, orientation or judgment? ■ Yes ■ No
   If Yes, please specify:
2. Does this patient retain the mobility or physical capacity to place him/herself in a situation which would result in injury, hazard or accident? ■ Yes ■ No
3. Do you have any additional information or comments?

CERTIFICATION

I certify that I am licensed to practice in the State of California and that the information provided above is correct.

SIGNATURE OF PHYSICIAN OR MEDICAL PROFESSIONAL:	MEDICAL SPECIALTY:	DATE:
ADDRESS:	LICENSE NO.:	TELEPHONE: ( )

RETURN THIS FORM TO: COUNTY'S MAILING ADDRESS, CITY, CA,: ATTN; SW-NAME

STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY PETE WILSON, *Governor*

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

October 30, 1998

Reason For This Transmittal

[ ] State Law Change
[ ] Federal Law or Regulation Change
[X] Court Order or Settlement Agreement
[ ] Clarification Requested by one or More Counties
[ ] Initiated by CDSS

ALL-COUNTY LETTER NO.98-87

TO: ALL-COUNTY WELFARE DIRECTORS

SUBJECT: CLARIFYING PROCEDURES FOR ASSESSING A MINOR'S NEED FOR PROTECTIVE SUPERVISON IN THE IN-HOME SUPPORTIVE SERVICES PROGRAM

This All-County Letter informs counties of a clarification in the In-Home Supportive Service (IHSS) Program, which resulted from the settlements of the Garrett v. Anderson and Lam v. Anderson court cases. The clarification covers procedures for assessing a minor's need for protective supervision (PS) under Manual of Policies and Procedures (MPP) § 30-757.17.

Under the terms of the judgment and ACL No. 98-58, we are citing the state regulations, and statutes which this ACL clarifies.

Counties should apply the substantive standards for protective supervision in MPP § 30-757.17 while following the assessment procedures clarified in this ACL.

ASSESSING MENTAL FUNCTIONING OF MINORS

A county social worker should always assess an IHSS eligible minor for mental functioning MPP § 30-756.1, 756.2, 761.261; Welfare & Institutions Code (WIC) § 12300(d)(4), 12301.1, 12309, (b)(1)(2)(c) The following steps must be taken when assessing a minor's mental functioning:

> The county social worker must review a minor's mental functioning on an individualized basis and must not presume a minor of any age has a mental functioning score of "1." MPP § 30-756.372; WIC § 12301(a), 12301.1.

A county social worker must assess all eligible minors for a mental impairment. In doing so, the worker must request the parent or guardian to obtain available information and documentation about the existence of a minor's mental impairment. MPP § 30-756.31, 756.32. For example, is the minor SSI eligible based on mental impairment? Or is the minor eligible for regional center services based on mental retardation, autism, or a condition like mental retardation or needs services like someone with mental retardation?

A county social worker must evaluate a mentally impaired minor in the functions of memory, orientation, and judgement. MPP § 30.756.372.

The county social worker should review the information, and documentation provided by the parent or guardian. A county social worker is not required to independently obtain such information and documentation, but should ask parents or guardians to do so if they can.

ADVISING PARENTS OF THE CONDITIONS FOR A MINOR TO RECEIVE PROTECTIVE SUPERVISON

A county social worker must advise parents or guardians of a minor with a mental impairment of the conditions for receiving PS.

A county social worker must advise parents or guardians of the availability of PS. A parent or guardian does not have to specifically request this information. MPP § 30-760.21, 760.23, 760.24; WIC § 10061, 12301.1, 12309(c)(1).

A county social worker is not to presume that services, which are otherwise compensable, will be provided voluntarily by a parent or guardian or anyone else in accordance with MPP § 30-763.622.

ASSESSING A MINOR'S NEED FOR PROTECTIVE SUPERVISION

A county social worker must assess the minor's need for PS under MPP § 30-757.17, if the minor has a mental impairment.

A county social worker must assess each minor with a mental impairment for PS based on individual need. MPP § 30-756.1, 756.2, 761.261; WIC § 12300(d)(4), 12301.1, 12309(b)(1), (2)(C). In doing so, request the parent or guardian to obtain available information and documentation about a minor's mental impairment, including other agency records like those from regional centers with the written consent of parents or appropriate persons, and then review such information and documentation. (MPP 30-761.26). A county is not required to independently obtain such information and documentation, but must ask the parent or guardian to do so.

A county social worker must determine whether a minor needs more supervision because of his/her mental impairment than a minor of the same age without such impairment. WIC § 12300(d)(4).

A minor must not be denied PS based solely on age. WIC § 12301.1.

A minor must not be denied PS based solely on the fact that the minor has had no injuries at home due to the mental impairment so long as the minor has the potential for injury by having the physical ability to move about the house (not bedridden). MPP § 761.26, MPP § 30-763.1; WIC § 12300.

A minor must not be denied PS solely because a parent leaves the child alone for some fixed period of time, like five minutes. MPP § 30-761.26, 30-760.24, 30-763.1; WIC § 12301.1.

A county social worker must consider factors such as age, lack of injuries and parental absence, together with all the other facts, in determining whether or not a minor needs PS. WIC § 12301.1.

Any additional questions or clarification pertaining to this court case or the ACL may be directed to the Operations and Technical Assistance Units and the analyst assigned to your county at (916) 229-4000.

Sincerely,

Original Document Signed By
Donna L. Mandelstam on 10/30/98

DONNA L. MANDELSTAM
Deputy Director
Disability and Adult Programs Division

Attachment: Superior Court Order

SUPERIOR COURT OF CALIFORNIA

SAN DIEGO COUNTY

DOSSIE M. GARRETT and DANIEL A. GARRETT, by his guardian ad litem DOSSIE M. GARRETT., Plaintiffs-Petitioner	)	Case No.: No. 712208
	)	STIPULATION FOR ENTRY OF FINAL JUDEMENT AND JUDGMENT
v.	)	
ELOISE ADERSON, Director,, California Department of, Social Serivces, and, CALIFORNIA DEPARTMENT OF, SOCIAL SERVICES, Defendents-Respondent	))	Dept: 43 Judge: Hon J. Michael Bollman Filed: July 9, 1997 Trial: June 12, 1998

Plaintifs-Petitioners Dossie M. Garrett and Daniel A. Garrett by his guardian ad litem Dossie M. Garrett t through their attorney Charles Wolfinger. and defendents-respondents Eloise Anderson, in her capacity as Director of the California Department of Social Services and the California Department of Social Services (collectively "Social Services"), by their attorneys Daniel E. Lungren, Attorney General of the State of California by Deputy Donald P. Cole, have met and conferred concerning the issues presented by this lawsuit. To avoid the expense and uncertainty of future litigation, the parties have agreed to settle the matter in dispute between them.

In the interests of a prompt and final settlement consistent with the public interest and responsibilities of Social services.

THE PARTIES STIPULATE AS FOLLOWS:

1. The parties have reached a mutually acceptable resolution of their dispute and agree to entry of judgment against Social Services. This judgment shall order a permanent injunction against Social Services that may be modified by any lawful means, including:

A) Noticed motion or

B) In the case in which a statutory or regulatory change would operate to change the injunction, Social Services shall give 30 days written notice to Charles Wolfinger at his last address of record in this matter before such changes are implemented

2. No term of this agreement shall be construed as an adjudication or admission of fact or law.

3. The Court may issue a mandatory injunction against defendants-respondents Social Services that no later than 12O days after service of a conformed copy of this judgment all on counsel of record for Social Services, Social Services will issue an All County Letter instructing counties about the procedures for assessing whether a minor eligible for In-home Supportive Services (IHSS) needs protective supervision, which shall include all the following points, but not necessarily in the exact language, with appropriate citations to the Welfare and Institutions Code ("WIC") and Manual of Policies and Procedures (“MPP”):

A) A county must assess mental functioning of all IHSS eligible minors including by taking the following steps:

(1) Assess an IHSS eligible minor for a mental impairment. (WIC §§ 12300, subd. (d)(4), 12301.1, 12309, subd. (b) (1) (2) (C); MIPP §§ 30-756.1, 765.2; 761.261.)

(2) Request the parent or guardian to obtain available information and documentation about the existence of a minor's mental impairment, including about whether a minor is SSI eligible based an mental impairment or eligible for regional center services based on mental retardation. autism or a condition like mental retardation or needs services like someone with mental retardation, and then review such information and documentation. (MIPP §§ 30-756.31, 756.32.) A county is not required to

independently obtain such information and documentation, but must ask the parent or guardian to do so.

(3) For minors with some mental impairment, assess mental functioning as provided for in the regulations. (MPP §§ 30-736.1, 756-2.)

(4) A county may not automatically assign a “1” to mental functioning for a minor of any age; mental functioning must be reviewed based on an individualized evaluation. (WIC §§ 12301. subd. (a), 12301.1; MPP § 30-756.372.)

B) A county must advise parents of a minor with a mental impairment of the conditions for receiving protective supervision including by taking the following steps:

(1) Do not presume that parents will provide otherwise needed services voluntarily. (MPP § 30-763.622.)

(2) Advise parents of the availability of protective supervision; parents do not have to specifically request it. (WIC §§ 10061, 12301.1, 12309, subd. (c)(1); MPP §§ 30-760-21, 760.23, 760-24.)

C) A county must assess the minor's need for protective supervision if minor has a mental impairment including by taking the following steps:

(1) Assess each minor with a mental impairment for protective supervision based on individual need. (WIC §§ 12300, subd. (d) (4), 12301.1, 12309, subd. (b) (1), (2) (C); MPP §§ 30-756.1, 756.2, 761.261.)

(2) Request the parent or guardian to obtain available information and documentation about a minor's mental impairment, including other agency records like those from regional centers with the written consent of parents or appropriate persons, and then review such information and documentation. (MPP § 30-761.26.) A county is not required to independently obtain such information and documentation, but must ask the parent or guardian to do so.

(3) Determine whether a child needs more supervision because of his mental impairment than a child of the same age without such an impairment. (WIC § 12300, subd. (d) (4).)

(4) A county may not deny a minor protectivesupervision based solely on age. (WIC § 12301.1.)

(5) A county may not deny a minor protective supervision based solely on the fact that the minor has had no injuries at home due to the mental impairment so long as the minor has the potential for injury by having the physical ability to move about the house (not bedridden). (WIC § 12300; MPP § 30-763.1.)

(6) A county may not deny a minor protective supervision solely because a parent leaves the child alone some fixed period of time, like five minutes. (§ 12301.1.)

4. Social Services will set aside the Director's Alternate Decision, dated November 13, 1996. In the Matter of Hearing. #96208113, for Claimant Dossie M. Garrett, issue a new decision consistent with the terms stipulated above, finding Daniel A. Garrett eligible for protective supervision retroactive to April 10. 1996 and pay plaintiff Dossie M. Garrett retroactive IHSS with prejudgment interest from April 10, 1996 through November 1, 1997.

5. Plaintiffs-petitioners’ counsel, Charles Wolfinger, is entitled to reasonable attorney fees and costs, the amount to be agreed on or determined after a noticed motion filed within 60 days from the date of entry of judgment.

FOR PLAINTIFFS-PETITIONERS

Dated: 6/8/98

BOSSIE M . GARRETT, Plaintiff and
Guardian ad Litem for Plaintiff
DANIEL A. GARRETT

Dated: 6/10/98

CHARLES WOLFINGER
Attorney for Plaintiffs-Petitioners
FOR DEFENDANTS-RESPONDENTS

Dated: June 10, 1998

LAWRENCE B. B. BOLTON
Deputy Director, Legal, Division
Department of Social Services

Daniel E. LUNGREN, Attorney General
of the State of California
John H. SANDERS Supervising
Deputy Attorney General

Dated: 6/11/98

DONALD P. COLE, Deputy
Attorney General
Attorneys for Defendants-Respondents
Eloise Anderson, Director, and
California Department of Social
Services

JUDEMENT

Having read and considered the foregoing terms, THIS COURT HEREBY ORDERS that the above stipulation at the parties is the final Judgment of the court.

Dated:

HON J. MICHAEL BOLLMAN, JUDGE
San Diego County Superior Court

STATE OF CALIFORNIA—HEALTH AND WELFARE AGENCY PETE WILSC

DEPARTMENT OF SOCIAL SERVICES
744 P Street, Sacramento, California 95814

ERRATA

TO: ALL COUNTY WELFARE DIRECTORS

SUBJECT: CORRECTION TO ALL COUNTY LETTER NO. 98-87

This replaces the Superior Court Order attached to All County Letter 98-87. There were several errors due to scanning, which resulted in typographical errors.

F I L E D
KENNETH E. MARTONE
Clerk of the Superior Court

JUNIO 1998

By: A. DEWHUHST, Deputy

SUPERIOR COURT OF CALZPORNZA

SAN DIEGO COUNTY

DOSSIE M. GARRETT and DANIEL A. GARRETT, by his guardian ad litem DOSSIE M. GARRETT,

Plaintiffs-Petitioners,

v.

ELOISE ANDERSON, Director, California Department of Social Services, and CALIFORNIA DEPARTMENT OF SOCIAL SERVICES,

Defendants-Respondents.

CASE NO. 712208

STIPULATION FOR ENTRY OF FINAL JUDGMENT AND JUDGMENT

Dept: 43
Judge: Hon. J. Michael Bollman
Filed: July 9, 1997
Trial: June 12, 1998

Plaintiffs-Petitioners Dossie M. Garrett and Daniel A. Garrett by his guardian ad litem Dossie M. Garrett through their attorney Charles Wolfinger, and defendants-respondents Eloise Anderson, in her capacity as Director of the California Department of Social Services and the California Department of Social Services (collectively "Social services"), by their attorneys Daniel E. Lungren, Attorney General of the State of California, by Deputy Donald *P.* Cole, have met and conferred concerning the issues presented by this lawsuit. To avoid the expense and uncertainty of future litigation, the parties have agreed to settle the matter in dispute between them.

In the interests of a prompt and final settlement, consistent with the public interest and responsibilities of Social Services,

THE PARTIES STIPULATE AS FOLLOWS:

l. The parties have reached a mutually acceptable resolution of their dispute and agree to entry of judgment against social Services. This judgment shall order a permanent injunction against Social Services that may be modified by any lawful means, including:

A) Noticed motion or

B) In the case in which a statutory or regulatory change would operate to change the injunction, Social Services shall give 30 days written notice to Charles Wolfinger at his last address of record in this matter before such changes are implemented.

2. No term of this agreement shall be construed as an adjudication or admission of fact or law.

3. The court may issue a mandatory injunction against defendants-respondents Social Services that no later than 120 days after service of a conformed copy of this judgment on counsel of record for Social Services, Social services will issue an All County Letter instructing counties about the procedures for assessing whether a minor eligible for In-Home Supportive Services (IHSS) needs protective supervision, which shall include all the following points, but not necessarily in the exact language, with

appropriate citations to the Welfare and Institutions Code ("WIC") and Manual of Policies and Procedures ("MPP"):

A) A county must assess mental functioning of all IHSS eligible minors including by taking the following steps:

(1) Assess an IHSS eligible minor for a mental impairment. (WIC §§ 12300, subd. (d)(4), 1.2301.1, 12309, subd. (b)(1)(2)(C); MPP §§ 30-756.1, 765.2; 761.261.)

(2) Request the parent or guardian to obtain available information and documentation about the existence of a minor's mental impairment, including about whether a minor *is* SSI eligible based on mental impairment or eligible for regional center services based on mental retardation, autism or a condition like mental retardation or needs services like someone with mental retardation, and then review such information and documentation. (MPP §§ 30-756.31, 756.32.) A county is not required to independently obtain such information and documentation, but must ask the parent or guardian to do so.

(3)For minors with some mental impairment, assess mental functioning as provided for *in* the regulations. (MPP §§ 30-756.1, 756.2.)

4) A county may not automatically assign a "1" to mental functioning for a minor of any age; mental functioning must be reviewed based on an individualized evaluation; (WIC §§ 12301, subd. (a}, 12301.1.; MPP § 30-756.372.)

B) A county must advise parents of a minor with a mental impairment of the conditions for receiving protective supervision including by taking the following steps:

(1) no not presume that parents will provide otherwise needed services voluntarily. (MPP § 30-763.622.)

(2) Advise parents of the availability of protective supervision; parents do not have to specifically request it. (WIC §§ 10061, 12301.1, 12309, subd. {c) {1); MPP §§ 30-760.21, 760.23, 760.24.)

C) A county must assess the minor's need for protective supervision if minor has a mental impairment including by taking the following steps:

(1) Assess each minor with a mental impairment for protective supervision based on individual need. (WIC §§ 12300, subd. (d)(4), 12301.1, 123051, subd. (b} (1), (2)(C); MPP §§ 30-756.1, 756.2, 761.261.)

(2)Request the parent or guardian to obtain available information and documentation about a minor's mental impairment, including other agency records like those from regional centers with the written consent of parents or appropriate persons, and then review such information and documentation. (MPP § 30-761.26.) A county is not required to independently obtain such information and documentation, but must ask the parent or guardian to do so.

(3) Determine whether a child needs more supervision because of his mental impairment than a child of the same age without such an impairment. (WIC § 12300, subd.(d) (4).)

(4) A county may not deny a minor protective supervision based solely on age. (WIC § 12301.1.)

(5) A county may not deny a minor protective supervision based solely on the fact that the minor has had no

injuries at home due to the mental impairment so long as the minor has the potential for injury by having the physical ability to move about the house {not bedridden). (WIC § 12300; MPP § 30-763.1.)

(6) A county may not deny a minor protective supervision solely because a parent leaves the child alone some fixed period of time, like five minutes. (§ 12301.1.)

4. Social Services will set aside the Director's Alternate Decision, dated November 13, 1996, In the Matter of Hearing #96208113, for Claimant Dossie M. Garrett, issue a new decision consistent with the terms stipulated above, finding Daniel A. Garrett eligible for protective supervision retroactive to April 10, 1996 and pay plaintiff Dassie M. Garrett retroactive IHSS with prejudgment interest from April 10, 1996 through November 1, 1997.

5. Plaintiffs-petitioners' counsel, Charles Wolfinger, is entitled to reasonable attorney fees and costs, the amount to be agreed on or determined after a noticed motion filed within 60 days from the date of entry of judgment.

FOR PLAINTIFFS-PETITIONERS

Dated: 6/8/98

DOSSIE M. GARRETT, Plaintiff and
Guardian ad Litem for Plaintiff
DANIEL A. GARRETT

Dated: 6/10/98

CHARLES WOLFINGER
Attorney for Plaintiffs-Petitioners

FOR DEFENDANTS-RESPONDENTS

Dated: June 10, 1998

Lawrence B. Bolton
Deputy Director, Legal Division
Department of Social Services

DANIEL E. LUNGREN, Attorney General
of the State of California
JOHN H. SANDERS, Supervising
Deputy Attorney General

Dated:

6-12-98

DONALD P. COLE, Deputy
Attorney General
Attorneys for Defendants-Respondents
Eloise Anderson, Director, and
California Department of Social
Services

JUDGMENT

Having read and considered the foregoing terms, THIS COURT HEREBY ORDERS that the above stipulation of the parties *is* the final judgment of the court.

Dated:

JUN 10 1998

J. MICHAEL BOLLMAN

HON. J. MICHAEL BOLLMAN, JUDGE
san Diego County Superior Court

CASE SCENARIO – JASON
CONSUMER WITH DME

Jason is a 20-year-old male who is a paraplegic as a result of an automobile accident two years ago. He lives with his parents in a small, seven room, single-story home in the center of Bakersfield. Jason has a bedroom and bathroom that have been adapted to meet his needs. He has a roll-in shower in the bathroom and a lightweight wheelchair that he uses to move around the house and to participate in wheelchair track events. The house has a portable ramp on the front steps. Laundry facilities are in the kitchen and include a large front-load washer and dryer. Jason's mother and father are employed and work very long hours. Previously they had insurance which covered all of Jason's medical expenses and home care. The insurance paid for someone to come in during the day to help Jason with his personal care (bathing, grooming, and dressing), clean his room, and cook meals while his parents were out of the home. As the policy dollar limits have been reached, private insurance is not available and Jason's parents have applied for IHSS for their son. They would like to have a provider perform the same services covered by the private insurance.

At the time of the home visit, Jason is at home with his mother. He is observed to be a well-nourished young adult who is able to move around the house with agility. He has one portion of his room set up for weight lifting which he says he does for approximately two hours per day to maintain his upper extremity strength. Jason indicates that he is able to perform most ADLs and IADLs without help from another person. His mother indicates that it takes her an hour each weekend just to clean his room and another two to clean the rest of the home. Jason says that he does not have time to clean his own room because he is busy with other activities. He states that he has never had to clean his own room, even before the accident. Jason's mother expresses that he needs to have someone cook his meals during the day because he will only eat junk food all day if no one cooks for him and will not clean up the kitchen after he cooks. She states that she cooks all the family meals on weekends, but when you ask, expresses that she does not wish to be paid for anything she does for Jason. She also indicates that he needs to have range of motion exercises performed once per day and this is done with the assistance of a therapist who comes to the house every day for one hour. Jason's mother says that he is able to dress himself, but does not always dress appropriately for the occasion and therefore needs reminding regarding clothing selection. She states as an example that he frequently wears t-shirts and shorts to church. You observe him to be neatly and appropriately dressed.

You ask to speak to Jason alone. He tells you that it is difficult being 20 years old and still living by his parents' rules. He expresses that he should be able to eat what he wants and dress as he wishes. You discuss with him what help he thinks he needs. He admits that he could perform some aspects of the housework but would still have difficulty with tasks that are beyond his reach, such as changing the linens on his bed. He states that his chair is manual so it requires both of his hands to move himself forward, making carrying some objects and activities which require him to utilize his hands while moving his chair impossible. He indicates his activities are further limited because many items are stored out of his reach.

Jason says he is able to bathe independently and can reach all areas of his body adequately. He indicates he can dress himself but thinks his mother hangs his clothes high so that she can select what he wears.

As for meals, he expresses that he can feed himself with simple meals such as fruit loops and milk for breakfast and a sandwich and chips for lunch, but cannot reach the stove or the microwave to make any "real" dinners. He says he can do simple clean-up in the kitchen but is unable to reach anything in high cupboards in the back of cupboards.

Task:
Use the functional limitations and abilities Jason and his mother have described as a basis for analyzing his need, rank, and possible authorization. Refer to each task listed in MPP 30-757 .11 and the Annotated Assessment Criteria. Determine his abilities or limitations to complete the identified task in whole or in part.

1. **Identify the need for each task within the category (use AAC as your guide) and then determine the appropriate Functional Index ranking for Domestic Services.**

Domestic Services Tasks	y/n	Notes
Sweeping		
Vacuuming		
Washing / waxing		
Clean kitchen counters		
Clean sinks		
Clean the bathroom		
Storing food and supplies		
Taking out the garbage		
Dusting		
Picking up		
Cleaning stove and oven		
Clean /defrost refrigerator		
Bring in fuel for cooking		
Changing bed linen		
Changing light bulbs		
Wheelchair cleaning		
Wheelchair recharging		

Functional Index Rank: _________

2. **Assess time for Meal Prep. Record answers on the grid below.**

Total Assessed Need	Adjustments	Individual Assessed Need	Alternative Resources/ Refused/Voluntary	Net Adjusted Need

3. **How would you authorize the time for Range of Motion exercises? Record answers on the grid below.**

Total Assessed Need	Adjustments	Individual Assessed Need	Alternative Resources/ Refused/Voluntary	Net Adjusted Need

4. **What other tasks might Jason need based on his abilities?**

CASE SCENARIO – EMILY
ASSESSING NEED

Emily:

Emily is a 38-year-old consumer who lives with her husband Bobby and their two children (13-year-old Jill and 8-year-old Jordan). Emily was diagnosed with Multiple Sclerosis approximately two years ago and her disease has progressed rapidly. Bobby works during the day and provides some of Emily's care during the evenings and weekends, but he chooses not to be paid. Her 18-year-old daughter Amy, who does not live in the home, provides the rest of her care. In addition to Multiple Sclerosis, Emily has high blood pressure and Type I diabetes, which requires two daily insulin injections and periodic blood sugar testing. She takes multiple pills for her blood pressure and MS twice daily. Emily has an electric wheelchair that she is able to use independently to get around the home. When she goes out for her medical appointments, she requires assistance getting from the house to the car and from the car into the doctor's office. She also requires assistance transferring from the wheelchair to the car and from the car to the wheelchair. The home is equipped with a Hoyer lift, which is used to move her in and out of bed. Emily requires assistance with all Domestic and Related services and with personal care including Bowel and Bladder care. Emily is completely unable to bathe herself. Her daughter Amy states that it is difficult to hold her mother up in the shower, requiring a longer time than usual to perform this task. Emily is also at risk of choking because she is unable to chew solid food. For this reason, Amy must puree her mother's food. Emily has no strength in her hands and is unable to grasp utensils. Every Saturday, Emily's mother, Bertha, comes over to dress and bathe her and to make a day's worth of meals for Emily and her family. Emily's husband, Bob, is afraid to leave his wife unattended at any time and is angry because he states that Emily requires 24-hour care and supervision. He is afraid that, if left unattended, she could be harmed by an intruder or could choke on something. He is requesting Protective Supervision.

Bob:

Bob is 40 years old and has been married to Emily for 19 years. She is his one and only true love, but her illness has been hard on him over the last two years and at times he does not know if he can take it anymore. Bob wants the maximum of 283 hours of care for Emily. Bob does not understand that service hours are based on assessed needs. He believes that someone needs to be with his wife at least 8 hours per day, 7 days per week, which is why he is requesting Protective Supervision. Bob can get pretty upset when speaking with the social worker because he believes no one understands the situation and that IHSS is not providing his wife with the hours she needs.

Amy:

Amy is Emily's 18-year-old daughter who recently graduated from high school. She had been accepted to Stanford University but decided to give up school to take care of her mother. Amy feels guilty that she resents her mother at times, but knows that one day she will be able to go off to school. Amy knows that the situation is hard on the whole family, but she wants to be able to move on with her life. Amy made the comment, "I want to be my mom's little princess again." Amy lives in a small studio apartment a few doors from her parents' home. Amy claims that it was nice that her father fixed up the apartment for her, but that she does not have any freedom. She is out of the main house, but she spends all day taking care of her mother and then runs her younger brother and sister around. By the time Saturday arrives, she is so tired physically and mentally that all she does is sleep. Amy speaks about the dreams she had of becoming a teacher and about traveling to Europe this summer with her friends, neither of which she will be able to do. Amy talks about the many nights she and her mother spent discussing those dreams before her mother became sick. For Amy, life is not about dreams anymore, but instead about making it through one more day.

Task:

Discuss how you would approach this case and address the interviewing challenges.

a. How would you approach the interview? What information would be the most difficult to assess?
b. What questions could you ask that would be helpful to clarify the situation?
c. What further information you would like to have?
d. What sensitive areas will need to overcome your discomfort in order to ask the right questions?

MENTAL DISORDER CASE SCENARIOS

Gary – Obsessive-Compulsive Disorder

Gary is a 38-year-old male who lives in a small, one-bedroom apartment. When you arrive at 10:00 a.m., you immediately notice a smell of alcohol on Gary's breath. He is cordial but seems mentally scattered. He lets you in the apartment but does not pay much attention to you. You explain that you are from Social Services and there to assess his In-Home Supportive Services needs. He immediately states that he does not want someone coming in to rearrange any of his things. As you look around, you feel that he could use some help in cleaning. He has piles of newspapers in one corner, stacks of beer bottles in another, and electronic parts stashed in a closet that are spilling out into the hallway.

Gary sits down on a chair and appears to be muttering to himself as he is watching television. The TV is extremely loud so you ask him to turn it down. He puts it on mute, but then appears to be more fidgety. His clothes appear to be tattered and soiled, and he is unshaven with greasy hair. Although you do not ask about it, you notice he is wearing gloves. You find it odd, considering that it is rather warm in the apartment. Physically, he does not appear to have impairments, and is able to ambulate well. He has a relatively empty refrigerator and a stack of unopened bills on his kitchen counter.

In talking with Gary, you believe that he is not actively depressed or psychotic. Although he appears distracted and sad, he does not talk of delusions. You are puzzled, believing he could do a better job with his daily needs. However, based on the number of beer bottles in the apartment, you conclude that his drinking is making him lazy. You are also frustrated with the interview because he seems to be totally focused on something else and uninterested with the purpose of your visit.

To get Gary's attention, you decide to ask him about his collection of electronic parts. When you ask him if he collects certain parts, he seems distracted. You walk over to his pile and pick up an old pocket radio. You ask him if it still works. He appears to freeze for a second, but then comes over quickly and snatches it out of your hands. He puts it back in the pile and explains that his hobby is collecting parts. After a couple of minutes, you shift your focus to the pile of bills on his counter.

Gary explains that he is late in paying his rent and electric bill, and that he stopped paying his phone bill a few months ago. You ask how he contacts friends or family. He tells you that his family lives in Oregon and he does not like socializing with others much. You walk over to his pile of bills, trying to find his electric bill. As you begin to shuffle through his papers, he says, "Please stop rearranging my things! I want you to leave now. I'm busy anyway."

Group Tasks:

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The <u>characteristics</u> of Gary's obsessive-compulsive disorder.
2. Gary's IHSS <u>functional limitations</u>.
3. <u>Techniques</u> that would help in working with Gary.

Characteristics	Functional Limitations
Techniques for Interaction	

Maryann – Borderline Personality Disorder

Maryann is a 60-year-old female with limited mobility. She had been hit by a bus 10 years ago, forcing her to use a walker. She complains about public transportation in the city, saying she is hated by all the bus drivers since she is slow. For this reason, she tells you that she rarely uses public transportation. Maryann is overweight and does not appear to exercise often. She appears to be a heavy smoker and uses her oxygen tank occasionally.

As you walk in, you notice fast food wrappers lying around and a smell of cat urine. When you enter the living room, you notice that she has two cats, and the room is cluttered with papers and other trash. She does not have much food in the refrigerator, and states that she mainly eats fast food because there is a McDonalds next door to her apartment. Maryann also appears dirty, is wearing stained clothes, and has matted hair.

Maryann explains that she does not get out often because people are rude and mean to her. She talks poorly about her neighbors and her family. She then says, “I bet you can’t do anything for me. I’m a hopeless case.” In talking with her, you feel sorry for her and believe people have given up on her. You mention that you can help with her home care needs, and that you can get her approved immediately. She tells you that you are an “angel” and she would write a recommendation to your boss for being so great.

A week later, you telephone Maryann to explain that services will not start as quickly as you predicted. Immediately, she yells into the phone, becomes vulgar and calls you names. She blames you for her “terrible life” and says “I don’t need this anymore. I am going to just slit my wrists. Goodbye!” She abruptly hangs up. You are upset that she would say such awful things to you, since you really wanted to help her.

Group Tasks:

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The characteristics of Maryann's borderline personality disorder.
2. Maryann's IHSS functional limitations.
3. Techniques that would help in working with Maryann.

<table>
<tr><td>Characteristics</td><td>Functional Limitations</td></tr>
<tr><td colspan="2">Techniques for Interaction</td></tr>
</table>

Svetlana – Depressive Disorder

Svetlana is a 75-year-old woman whose spouse passed away six months ago. Her spouse had been in a nursing home for about a year following a stroke, just before his death. The consumer is feeling guilty about the decision to place her husband, thinking that it contributed to his death. Although she is physically functioning well, using no assistive device to walk, she appears impaired in her activities of daily living. She has little contact with her children, accusing them of not caring about her or visiting her often enough. Her grandson calls you, concerned that she needs help with housekeeping.

When you knock at Svetlana's door at 1:00 in the afternoon, she sticks her head out of the upstairs window, telling you that she was asleep. She tells you to come back later. After making another visit in the neighborhood, you come back to interview her at 3:00 p.m. When she lets you in, she is dressed in a dirty and worn nightgown. She walks slowly, stooped over, with her head down; she doesn't make eye contact. As you approach her kitchen, you notice rotting food all over the kitchen with flies buzzing around it. The bathroom has dirt caked in the sink and toilet and there is trash in the bathtub. She apologizes for the messiness of her home, but explains that she simply can't keep up with it anymore. She reports that she used to walk down the street to pick up groceries when her husband lived with her, but that now she rarely goes. She appears very thin and underweight, and you notice that she appears to have very little muscle or fat.

When you ask about how she is sleeping, she says that she sleeps in spurts and usually sleeps in late. Even though she sleeps late she states she is constantly fatigued and wonders why she is alive. She states that in the past before her husband died they enjoyed playing cards and seeing old movies. She can't seem to get up enough energy to do the things she used to enjoy doing. She stated her daughter called recently because she received a call from the electric company that Svetlana's electricity was going to be shut off for non-payment. Svetlana tearfully stated she had just forgotten to pay the bill. She states although she is resistant to the idea of needing help, she is now realizing that she may need some outside help.

<u>Group Tasks:</u>

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The <u>characteristics</u> of Svetlana's depressive disorder.
2. Svetlana's IHSS <u>functional limitations</u>.
3. <u>Techniques</u> that would help in working with Svetlana.

<table>
<tr><td>Characteristics</td><td>Functional Limitations</td></tr>
<tr><td colspan="2">Techniques for Interaction</td></tr>
</table>

Joan – Hoarding Disorder

Joan is a 65-year-old female who lives alone in a two-bedroom apartment. She has never been married and does not have any friends in the area. She has had multiple referrals to Public Health in the past for fire hazards due to her clutter. During every involvement with Public Health, she has worked with her landlord to clean up just enough so that Public Health is satisfied. However, during the most recent referral to Public Health by a neighbor, Joan was not able to clean up as much. She is suffering from severe asthma and appears to have swelling in her legs, which limits her ambulation. Her appearance of being thin causes you to wonder about her nutrition. Joan's landlord tells you that she will be evicted if she does not clean up her place, putting her at risk of becoming homeless.

When you meet with Joan, she can barely open her door due to the clutter. You can see that there are piles of boxes and trash that line the hallways, piled almost to the ceiling. There is however still room to ambulate throughout the apartment. Joan asks why you are there. You say that you are here for your scheduled appointment and that you are with In-Home Supportive Services, and that you are here to help. You make small talk with her in an effort to establish rapport and gain her trust. She explains that the landlord wants to evict her, probably so he can raise the rent. She asks if IHSS can help her clean up her home so that she will not have to be homeless.

Joan shows you around the small apartment which consists of two bedrooms, one bathroom, a living room and kitchen. The kitchen sink is filled with dishes, the stove is opened and you notice that it is filled with pots and pans. When asked how she uses the stove, she states that she only uses the burners on the stove and a small toaster oven for other cooking. The refrigerator is stuffed full with what must be rotting food as it has a foul odor emanating from it. The bathtub is filled with unused paper products. When you ask how she showers, she explains that she has been meaning to move these items for some time, but that she mostly sponge bathes due to her limited mobility. The bedrooms are also cluttered with many boxes along the walls, many reaching nearly to the ceiling.

Joan states that her belongings are "all I have in the world" and that is why it has been so difficult to get rid of anything. She has no family or friends that can help her. Although she states she has received help in the past, she states she is willing to receive ongoing help from IHSS and is interested in what other services she might be eligible for.

Group Tasks:

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The characteristics of Joan’s hoarding disorder.
2. Joan’s IHSS functional limitations.
3. Techniques that would help in working with Joan.

Characteristics	Functional Limitations
Techniques for Interaction	

Robert – Schizophrenia

Robert is a 50-year-old male who is living independently in a small studio apartment in a complex that serves elderly and mentally ill clients on fixed incomes. Robert, who is diagnosed with schizophrenia, has delusions about other residents. When you meet him, he is slowly pacing in the lobby, muttering to himself. The weather is warm, yet he is wearing a jacket and a sweater. You explain to him that you are from IHSS and here to assess his IHSS needs. You ask if you can see his apartment. After some rambling about how he is being told that he is worthless which you listen to patiently, he lets you see the apartment. You notice a strong odor of rotting trash when he opens his door and you see piles of old fast food wrappers and other trash lying everywhere. He also has a pile of what appears to be dirty laundry in the corner of the room. The landlord has informed you that Robert is at risk of eviction due to the smells in his apartment.

The apartment is sparsely furnished and consists of a greasy overstuffed chair with cigarette burns in it and a bare mattress on the floor with a major dent in the middle and one soiled blanket. The mattress appears to have food and urine stains on it. Robert can ambulate without any assistive devices, but he has a slow gait. If he is not lying in bed, he can usually be found in the lobby area of the apartment complex, speaking to himself and slowly pacing. He thinks that some of his neighbors are spying on him through a crack in his front door, which he has duct taped. You notice the duct tape but are not able to see the crack he is speaking of. You notice foil on many windows which blocks the outside light. He explains this keeps the neighbors from “spying” on him. He tells you that one resident that used to be his friend and brought him food occasionally, tried to poison him recently. After confronting his neighbor, they got into a verbal argument with the other resident spitting at him and calling him a “crazy @#$%”.

Robert appears to be willing to accept an IHSS provider, but he does not want anyone trying to bathe him or make him change his clothes. He gets quite angry when talking about this, beginning to ramble about his neighbor who he believes wants to poison him.

Group Tasks:

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The <u>characteristics</u> of Robert's schizophrenia.
2. Robert's IHSS <u>functional limitations</u>.
3. <u>Techniques</u> that would help in working with Robert.

<table>
<tr><td>Characteristics</td><td>Functional Limitations</td></tr>
<tr><td colspan="2">Techniques for Interaction</td></tr>
</table>

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

Instructions for Activity

Using the tools provided (Annotated Assessment Criteria and PS Regulations):

1. Determine if the following scenarios meet eligibility for IHSS Protective Supervision.
2. Give reasons for your decisions.

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
1.	Robert is an 89-year-old who has Alzheimer's Disease. His daughter who is his provider reports that he does not recognize her or other family members. She states that he is "living in the past" and believes that his mother who died many years ago is still alive. He continually states he wants to visit her and she reports he continually tries to leave the house. She says he also is "obsessed" with fire and continually tries to start fires in the fireplace. She indicates he does not sleep well at night and she often finds him roaming the house in the middle of the night trying to get out. On one occasion he got out and was brought back by the police.			
2.	Bruce is a 64-year-old who resides with his spouse. He has a long history of smoking and is being treated for emphysema and CHF. Bruce has also recently been diagnosed with Alzheimer's. He is ambulatory for short distances. His wife states that recently he has been leaving the house when no one is looking. She says that she has found him in the yard on a couple of occasions, but she is afraid he will get out into the busy street and not know where he is. She said at times he does not recognize her and does not know his address.			

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
3.	Carol is a 65-year-old who resides with her daughter and her two children. Carol had a stroke several years ago and has been receiving IHSS for 5 years. She has been confined to a wheelchair since the stroke due to left-sided paralysis. She has an electric wheelchair that she is able to operate in the house. She is aphasic. At reassessment, her daughter says the doctor has recently diagnosed Carol with dementia. Her daughter is concerned that her mother has recently tried to leave the house in her wheelchair and also continually goes into the kitchen and turns the stove on to cook things. She recently started a small fire when she left something on the stove.			
4.	Jane is an 80-year-old who lives alone in an apartment building. She attends ADHC. Her daughter lives in another state and has contacted IHSS because she thinks that her mother's mental condition is deteriorating and that she may be doing things that may cause harm to her. She says during her last phone call, her mother didn't know who she was. During the assessment, Jane appears to have some mild confusion and acknowledges her memory isn't as good as it used to be. She states that she has her own system for remembering things that she is able to describe in detail. When told that her daughter was concerned about her, Jane laughed and said her daughter was always "meddling in her life and that she needed to mind her own business." She stated that although her daughter does not visit frequently, she has a good support system of friends within the apartment complex and at the ADHC.			

These examples have been created for training purposes only. They are provided to reinforce the use of existing regulations. Each consumer's needs should be individualized to ensure that their Functional Index rankings and needs for tasks are correctly assessed.

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
5.	Henry is a 21-year-old who experienced a traumatic brain injury in a MVA at the age of 18. He resides with his parents. He has received extensive rehabilitation and has a history of serious behavioral problems since the accident. The doctors have told his parents there is nothing further that can be done for him. Henry's parents state that they must constantly watch him because he is unaware of the consequences of his behavior and frequently does things that have in the past caused injury. They indicate that Henry is never left alone and has been asked to leave several programs because of his behavior. Information in the case file from the doctor indicates that he functions at the level of an 8-year-old. Henry's parents report that neighbors have called the police on several occasions because of the behavior.			
6.	John is a 69-year-old who was recently diagnosed with Alzheimer's Disease. His spouse has recently requested IHSS for him based on information she received at a support group. His spouse says that John does pretty well during the day, but recently started having frequent episodes of irritability and agitation during the evening and nighttime. She says she frequently finds him up at all hours of the night and that she is afraid that he will injure himself. She says that she has heard IHSS can provide help and she wants to hire someone to come in and watch him during the night so she can get some sleep without worrying about him.			

These examples have been created for training purposes only. They are provided to reinforce the use of existing regulations. Each consumer's needs should be individualized to ensure that their Functional Index rankings and needs for tasks are correctly assessed.

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
7.	Jeremy is a 21-year-old who has a history of extensive drug and alcohol abuse. He has had several periods of incarceration due to his drug and alcohol abuse. Jeremy lives with his single mother and two younger siblings who are 5 and 7 years old. Jeremy had gang affiliations in the past. Jeremy's mother states that she wants IHSS and PS because she believes that Jeremy has some type of brain damage due to the drug and alcohol abuse. She says he frequently is abusive to his siblings and her when he does not get his way. She says she must watch him constantly because he is always trying to sneak out of the house to get drugs and alcohol and has gotten into several fights with the neighbors. She is afraid that he is going to get injured or access drugs and alcohol if she does not constantly monitor him.			
8.	David is a 65-year-old male who resides with his adult daughter and her family. David has had two major strokes during the last two years that have left him needing 24-hour care. David is in bed most of the day, although his daughter does get him up to go to the bathroom and brings him out in the wheelchair in the living room a couple of times so that he can "have a change of scenery." David has to be pushed everywhere in the wheelchair as he has no use of his upper or lower extremities. David's daughter says that he needs to have Protective Supervision because he can't do anything for himself, and without PS he would not be able to leave the house if there was a fire or other emergency.			

These examples have been created for training purposes only. They are provided to reinforce the use of existing regulations. Each consumer's needs should be individualized to ensure that their Functional Index rankings and needs for tasks are correctly assessed.

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
9.	Mario is a 64-year-old who resides with his spouse. He has a long history of smoking and is being treated for emphysema and CHF. Mario is on oxygen 24 hours a day. Mario has mild dementia and is not able to monitor his oxygen. Mario is not ambulatory and must be moved around the house in a wheelchair. Mario's spouse says she does not sleep at night because she is worried about him and what would happen if for some reason the oxygen did not work. She wants PS because she is afraid he could not survive if his oxygen malfunctions.			
10.	Betty is an 80-year-old who lives alone in a small house. Her two daughters live nearby and both look in on her on a daily basis. Betty has been going to an ADHC five days a week. Recently ADHC staff made an IHSS referral because they were concerned about increased confusion and disorientation. During the assessment, Betty's daughters were both present and agreed that her confusion and disorientation were a problem and seemed to be escalating. They say that Betty does not remember to eat and frequently leaves things on the stove which has resulted in two small fires. They say she dresses inappropriately and frequently will let strangers into her house. They indicate that the doctor thinks she may have had several small strokes. They do not believe that Betty can be left alone at home, and either one of them or one of the grandchildren is now with her when she is not at ADHC.			

PROTECTIVE SUPERVISION ELIGIBILITY SCENARIOS

No.	Information from Assessment	Meets PS Criteria? Yes	No	NOTES
11.	Mark is 35 years old and lives with his older sister. During the interview, they indicate that he reverts to the personality of a 5-year-old when he is under extreme stress. During these periods of regression, he thinks and acts as a five-year-old, leaving him in danger if left alone. They estimate this happens at least 6 times per month and can last as long as an hour. During one recent episode, when left alone, Mark left without telling his sister and failed to lock up the house when he went next door to "play videos" with the 20-year-old neighbor.			
12.	Latecia is a 46-year-old woman who currently lives with her grandparents and her 39-year-old sibling. She has had episodes of hallucinations since her early teens that seem to be increasing in both frequency and aggression. Most recently, she has been having periods where she hears a voice telling her that the family is evil and that she must prevent them from hurting her. During the most recent episode, she attacked her grandfather and attempted to scratch his face and eyes. When she returned to her room, her brother found her mumbling in a corner with scratches on her own face and a clump of her hair in her hand. The family is seeking Protective Supervision because they fear for the safety of the grandparents.			

These examples have been created for training purposes only. They are provided to reinforce the use of existing regulations. Each consumer's needs should be individualized to ensure that their Functional Index rankings and needs for tasks are correctly assessed.

CASE SCENARIO – MARGARET
REMOVING PROTECTIVE SUPERVISION

Margaret is an 87-year-old female who lives in a six-room house with her daughter, son-in-law, and their six and seven-year-old children. She moved in with her daughter and son-in-law after her husband died because her daughter felt that she should not be living alone. Margaret's diagnoses include dementia (which was diagnosed after she came to live with her daughter). Initially, her daughter reported that the dementia only required having to continually remind Margaret about things, such as where she was living and the identities of various family members. However, Margaret was assessed a need for Protective Supervision five years ago when her daughter reported during an assessment that Margaret had began wandering out of the house and trying to cook things on the stove unsupervised, resulting in setting off the fire alarm. At that time, it was reported that the police had to bring Margaret home on two separate occasions. Margaret's current assessment for Memory, Orientation, and Judgment is a "5" in each category.

You have recently taken over the caseload of a social worker who has retired and are doing your first assessment of Margaret. At the time of your visit, Margaret is seated in a wheelchair in the living room. Her daughter is present and answers the questions for Margaret. Her daughter reports that over the last two years she has seen a significant decline in her mother's condition. She states that about two years ago, her mother seemed to lose her will to live. She explains that prior to that time, Margaret would recognize her on occasion and remained ambulatory and active. She states that for about two years now, she must provide total assistance to her mother. She must transfer her from a bed to a wheelchair and push her wheelchair whenever she needs to change locations or move from room to room.

You indicate to Margaret's daughter that you will obtain a PS form from Margaret's physician, but that you feel that she no longer meets the criteria for Protective Supervision. You explain that she no longer places herself at risk for injury, hazard, or accident. Margaret's daughter states that she does not feel that this is correct, as her current condition is the same as it has been for two years, and the prior social worker did not discontinue the PS. She also states that even though Margaret has not placed herself at risk for over two years, she still feels that she should get this service because Margaret is unable to detect danger or get herself out of the house in the event of an earthquake, fire, flood, or other disaster.

Task:
Based on Margaret's story, your group should answer the following questions considering the perspective of the:

SOCIAL WORKER:

1. When you remove PS for Margaret, what is the impact on her family/providers?

2. What questions do you anticipate the family will have when you inform them of the removal of PS, and what answers would you give?

3. What would you need to have documented in the case file if there is a fair hearing?

ALJ:

1. What specific concerns do you have in the removal of Margaret's PS?

2. What information would you need to understand the reasons for removal of PS?

3. What information would you need to have documented in the case file in order to support the removal of PS?

FAMILY:

1. What is the impact of the removal of PS on you and your family?

2. What information would you need from the social worker to understand the reasons for removal of PS? What questions would you have for the social worker?

3. What other resources would you want?

CHILDREN AND PROTECTIVE SUPERVISION SCENARIOS

1. Stephanie, a 3½-year-old, was diagnosed with Prader-Willi Syndrome last month. Her mother noticed that she eats incessantly and throws temper tantrums to get food. She is now able to open the refrigerator and climb on a chair to reach food in the cupboard. She will do anything to get to food; even child locks on the cupboard cannot keep her from getting food. She currently weighs 60 lbs., and her doctor says that she is morbidly obese and at risk of many chronic health conditions and possible death during childhood if her eating is not controlled. Nonetheless, without constant monitoring, she gets into food and eats until the food is gone. If she can't get to food in her house, she goes next door and sneaks to the kitchen to eat their food. She goes so fast that her mother can't leave her unattended at all.

2. Jose, a 5-year-old, is moderately mentally impaired and diagnosed with autism. He is antisocial, ignoring all peers and others around him. His language is repetitive, often rhyming. He gets preoccupied with self-stimulating behaviors such as flapping his hands in front of his face and other repetitive movements. Frequently, when performing these movements in front of his face, he starts running. Often, he runs outside without regard to any person on the sidewalk or car in the street.

3. Jacob is 12 years old. He was diagnosed with autism when he was 3. He spent preschool and all his school years in special classes and has been assigned a 1:1 aide at school. He has always been antisocial and when he was young, he often withdrew to a world of his own. Since his puberty started, his behavior has become much worse. Now, he has frequent outbursts – he yells at others, hits, kicks, or bites his mother or any other person in his vicinity, throws rocks at windows to break them, and bangs his head on the wall. The more frustrated he is, the worse his behavior becomes.

4. Emily, age 6, was born with Cystic Fibrosis. She is very vulnerable to catching germs at school and so far this school year, she has had to spend about a third of the school year at home in bed, usually for a respiratory infection or pneumonia. Every time Emily gets sick, her mother must take off work to care for her. Her mother also cannot be far from her daughter's bed when she is sick because Emily gets so filled with phlegm that her mother must do treatments to help clear her lungs. This needs to be done as necessary, so her mother must be near. Mother is not requesting Protective Supervision all the time, just when her daughter is home and sick. She also wants to be paid for the time she spends away from work because her employer does not pay her when she is home caring for Emily. She is worried that she has missed so much work that she risks being fired.

5. Douglas is 9 years old and moderately mentally impaired. He is good-natured, but every time he has a bowel movement, he smears the feces on the walls. Sometimes he has a bowel movement in the toilet and other times he soils his clothes. He either reaches into the toilet to retrieve the feces or pulls it out of his underpants. His mother has found him playing with feces as if it were clay. Often, he smears the feces on the walls, carpet, and his clothing. Mother is becoming increasingly stressed because she can't always anticipate when he will have a bowel movement and it takes an extraordinarily long time to clean up after Douglas (the carpet is so stained that it will have to be replaced).

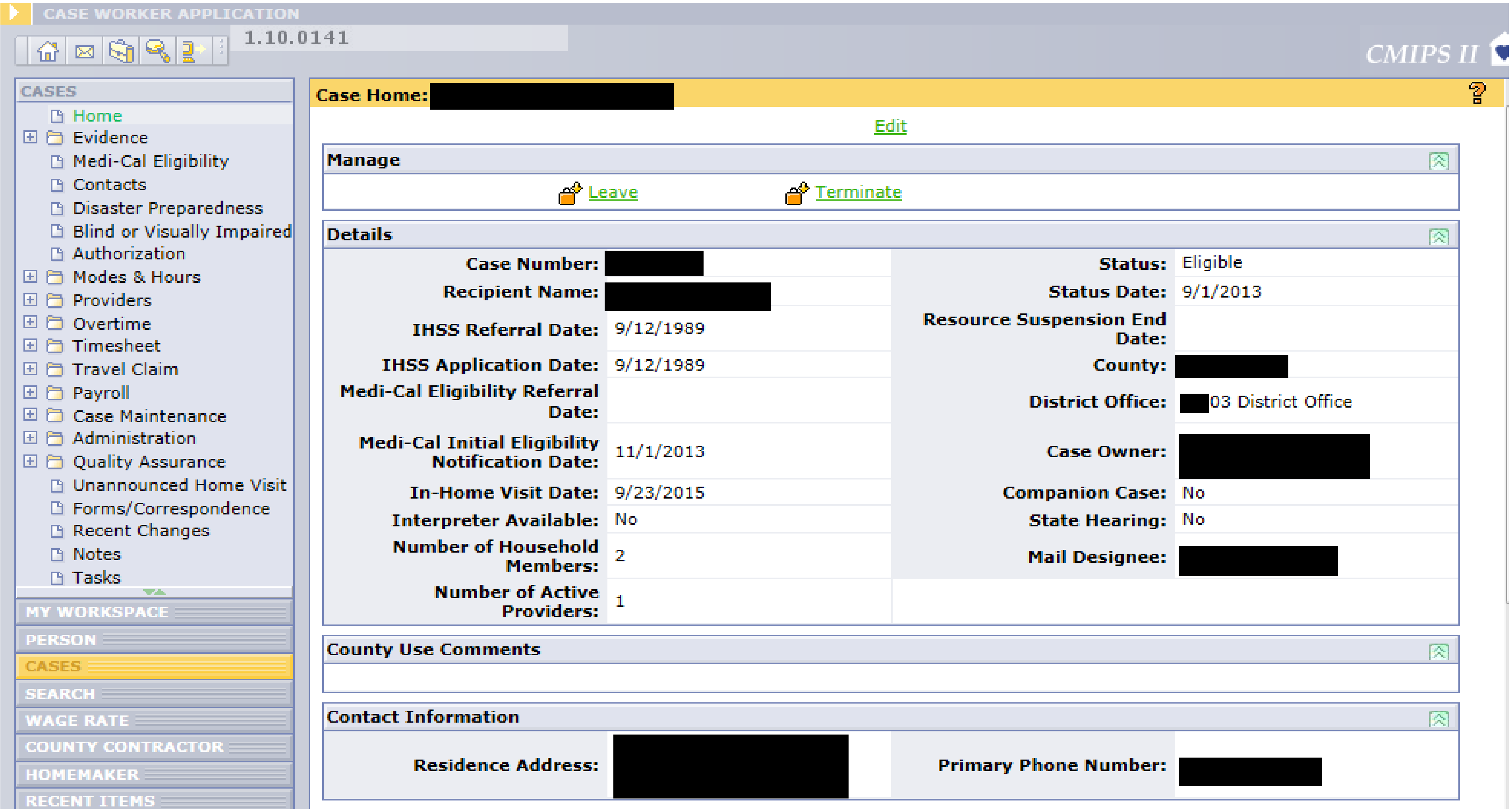
6. Jade is 4 years old and has a moderate mental impairment. She trusts everyone and will open the door to anyone. Her mother is worried that Jade is at elevated risk of abduction because she is more trusting than other 4-year-olds and is unable to form normal personal boundaries.

7. Ethan, age 3, has a mental impairment and Pica. He eats many non-food items such as match heads, cigarette butts, hair, pebbles, string and glass. Whenever he is left unattended, he is drawn to inedible objects that he ingests.

8. Maria, age 9, has autism. Her family moved here from Texas two months ago. They just learned about IHSS. Maria's mother states that she cannot leave her daughter alone because she would run outside the door and keep running. She indicates that on a couple of occasions, Maria got out of the house and started running. She had to call the police to help her find Maria. Maria has severe behavioral problems such as tantrums and throwing things when she is frustrated. When you ask the mother when the last time Maria ran outside, she responds that she hasn't run outside in an unsafe way since she was about 5 years old, but that she has not left her alone since the last time the police brought her home.

9. James is a 16-year-old who lives with his parents and 18-year-old brother and 4-year-old sister. Two years ago, James was in an automobile accident resulting in a brain injury. The family's private insurance is no longer available so they have recently applied for Medi-Cal and IHSS for James. James receives services through the Regional Center and his mother states she has recently been told to apply for IHSS Protective Supervision. She states that James needs this service because he would frequently go into the kitchen and turn on all the burners on the stove. She states that he once burned his hand on the stove. She indicates that he seems obsessed with fire so she has to be careful to make sure he does not have access to matches. When questioned about the last time he turned on the burners, she said he has not done this for about one year because she removed the knobs from the stove. She also states that other than the obsession with fire and some behavior issues which he receives therapy for, James does not place himself at risk.

Case Home



Case Home: [redacted]

Manage

Details

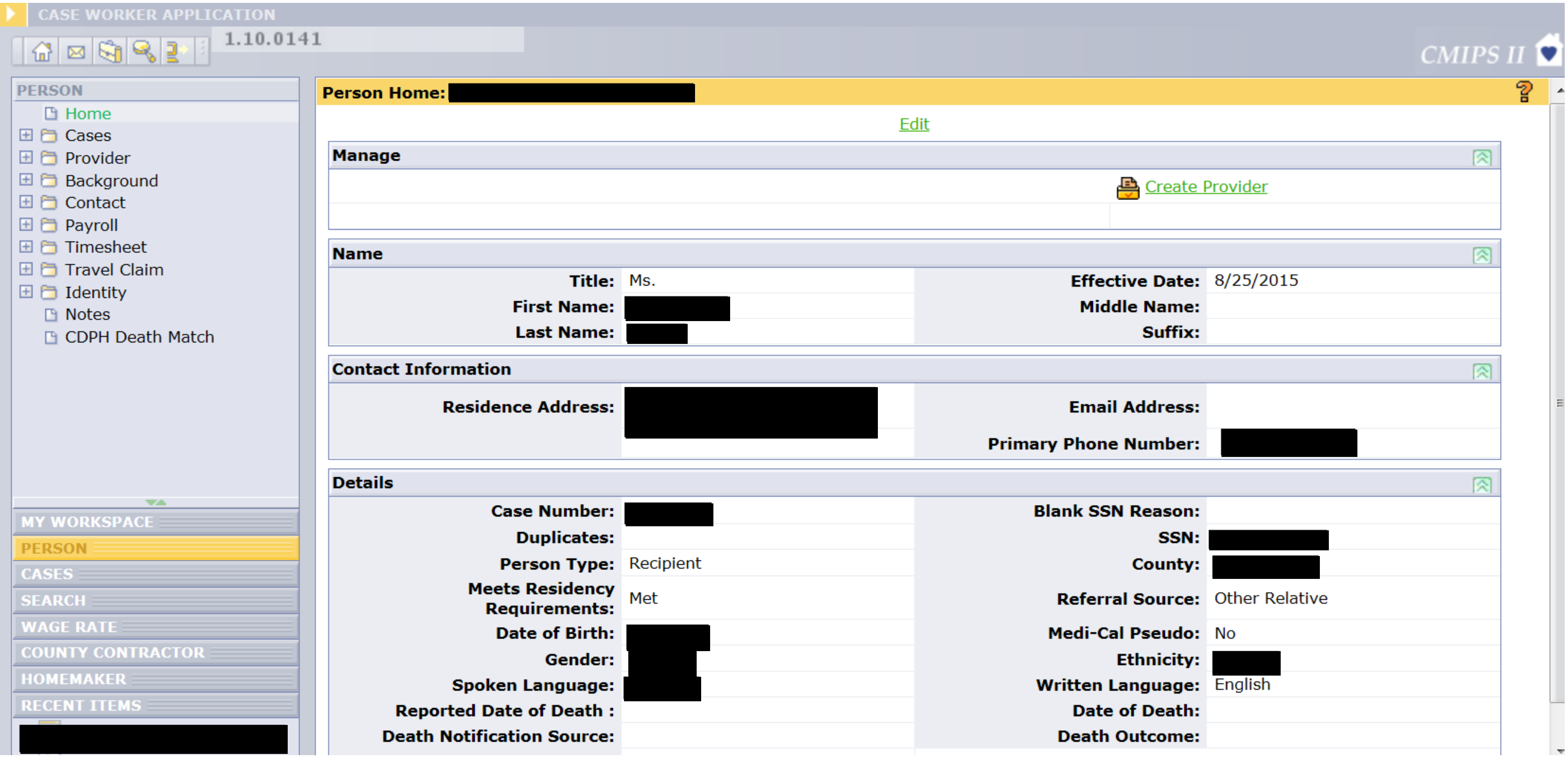
Case Number:	[redacted]	**Status:**	Eligible
Recipient Name:	[redacted]	**Status Date:**	9/1/2013
IHSS Referral Date:	9/12/1989	**Resource Suspension End Date:**	
IHSS Application Date:	9/12/1989	**County:**	[redacted]
Medi-Cal Eligibility Referral Date:		**District Office:**	[redacted]03 District Office
Medi-Cal Initial Eligibility Notification Date:	11/1/2013	**Case Owner:**	[redacted]
In-Home Visit Date:	9/23/2015	**Companion Case:**	No
Interpreter Available:	No	**State Hearing:**	No
Number of Household Members:	2	**Mail Designee:**	[redacted]
Number of Active Providers:	1		

County Use Comments

Contact Information

Residence Address:	[redacted]	**Primary Phone Number:**	[redacted]

Person Home



[redacted]

Person Home: [redacted]

Manage

Name

Title:	Ms.	**Effective Date:**	8/25/2015
First Name:	[redacted]	**Middle Name:**	
Last Name:	[redacted]	**Suffix:**	

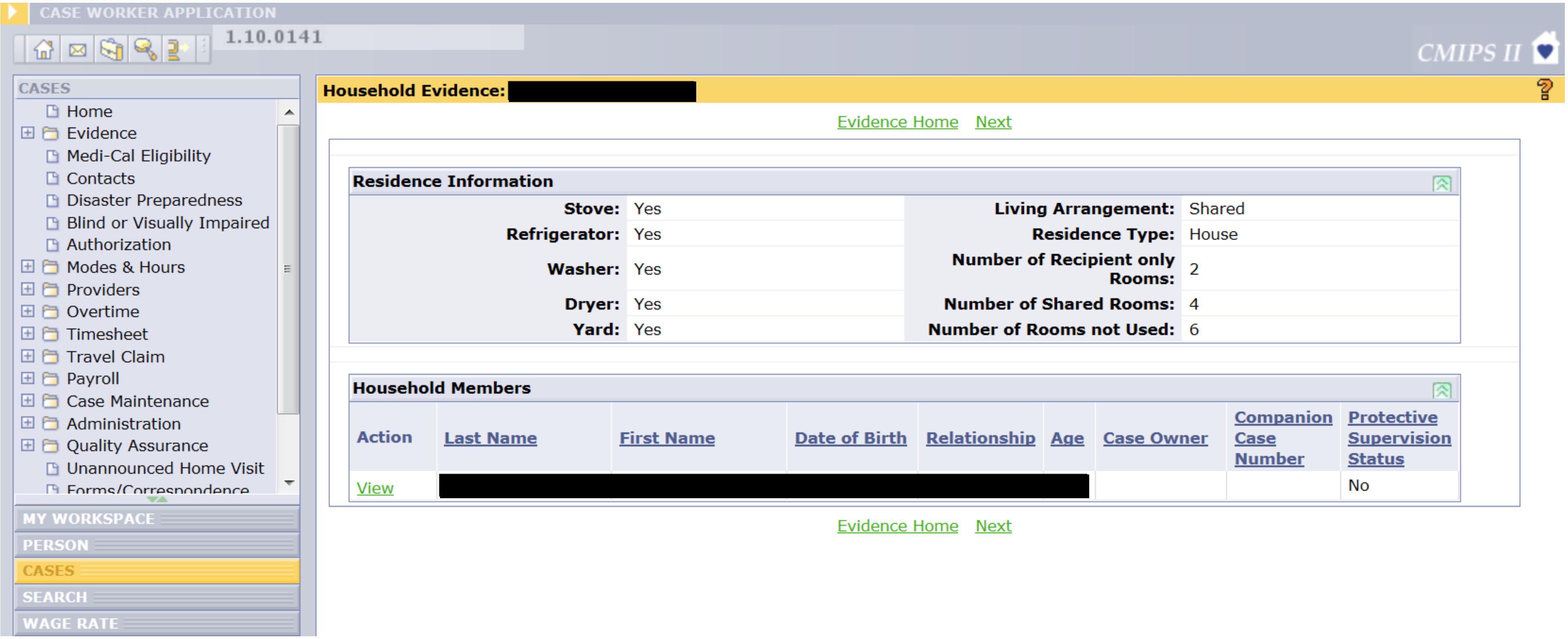
Contact Information

Residence Address:	[redacted]	**Email Address:**	
		Primary Phone Number:	[redacted]

Details

Case Number:	[redacted]	**Blank SSN Reason:**	
Duplicates:		**SSN:**	[redacted]
Person Type:	Recipient	**County:**	[redacted]
Meets Residency Requirements:	Met	**Referral Source:**	Other Relative
Date of Birth:	[redacted]	**Medi-Cal Pseudo:**	No
Gender:	[redacted]	**Ethnicity:**	[redacted]
Spoken Language:	[redacted]	**Written Language:**	English
Reported Date of Death :		**Date of Death:**	
Death Notification Source:		**Death Outcome:**	

Household Evidence



Household Evidence: [redacted]

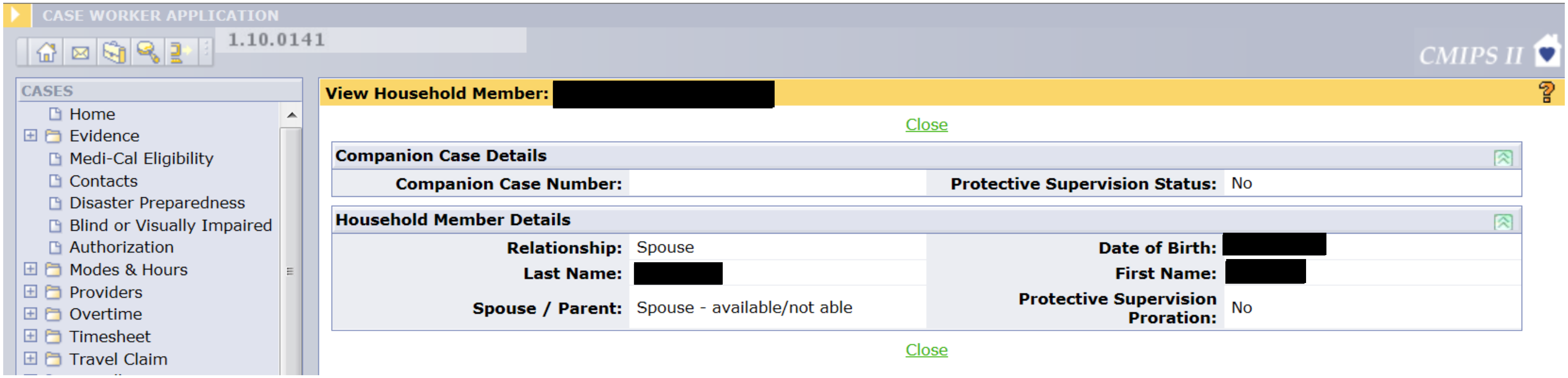
Residence Information

Stove:	Yes	**Living Arrangement:**	Shared
Refrigerator:	Yes	**Residence Type:**	House
Washer:	Yes	**Number of Recipient only Rooms:**	2
Dryer:	Yes	**Number of Shared Rooms:**	4
Yard:	Yes	**Number of Rooms not Used:**	6

Household Members

Action	Last Name	First Name	Date of Birth	Relationship	Age	Case Owner	Companion Case Number	Protective Supervision Status
View	[redacted]							No

Household Member



View Household Member: [redacted]

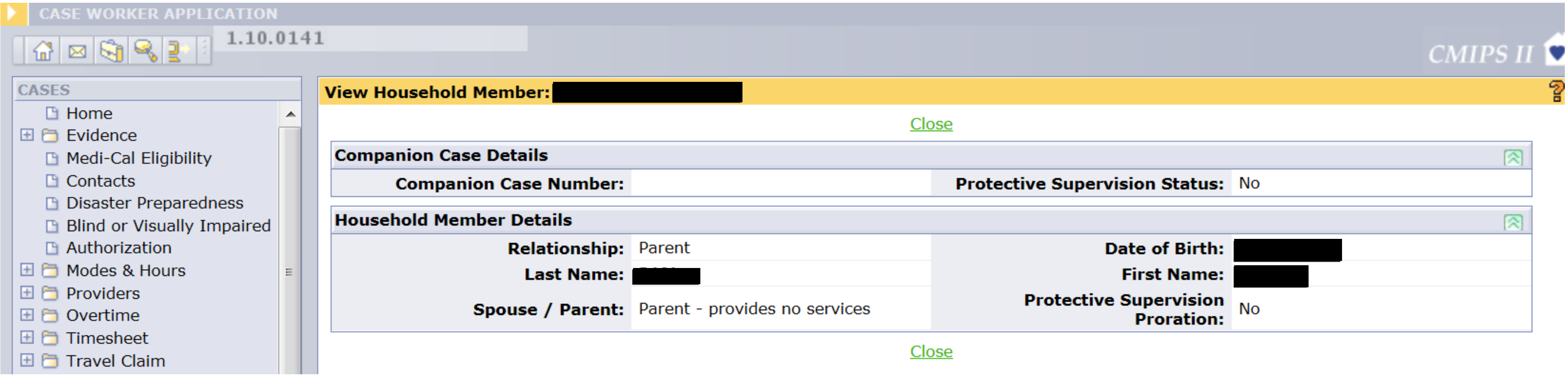
Companion Case Details

Companion Case Number:		**Protective Supervision Status:**	No

Household Member Details

Relationship:	Spouse	**Date of Birth:**	[redacted]
Last Name:	[redacted]	**First Name:**	[redacted]
Spouse / Parent:	Spouse - available/not able	**Protective Supervision Proration:**	No

Household Member - Parent



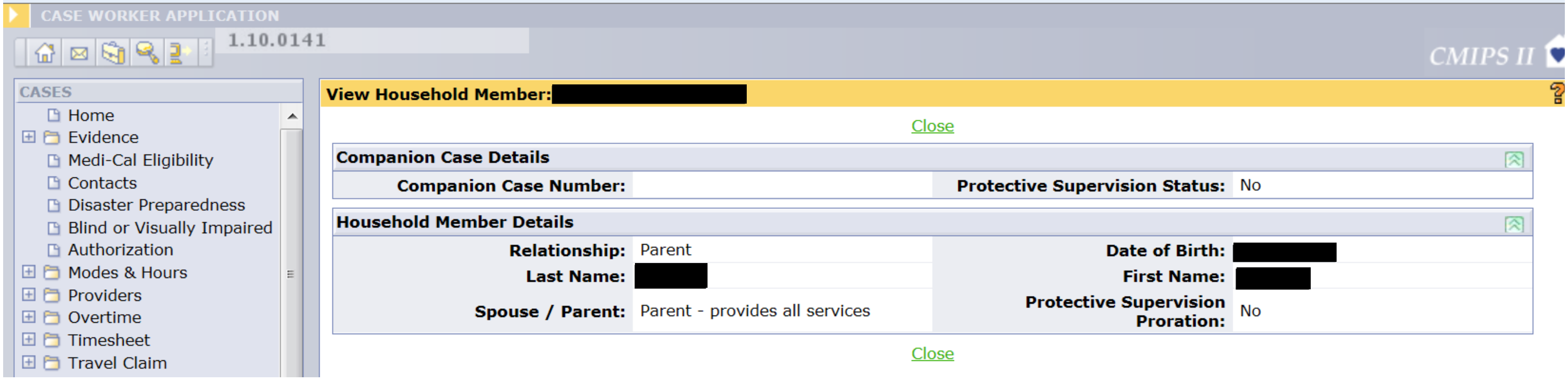
View Household Member: [redacted]

Companion Case Details

Companion Case Number:		**Protective Supervision Status:**	No

Household Member Details

Relationship:	Parent	**Date of Birth:**	[redacted]
Last Name:	[redacted]	**First Name:**	[redacted]
Spouse / Parent:	Parent - provides no services	**Protective Supervision Proration:**	No



View Household Member: [redacted]

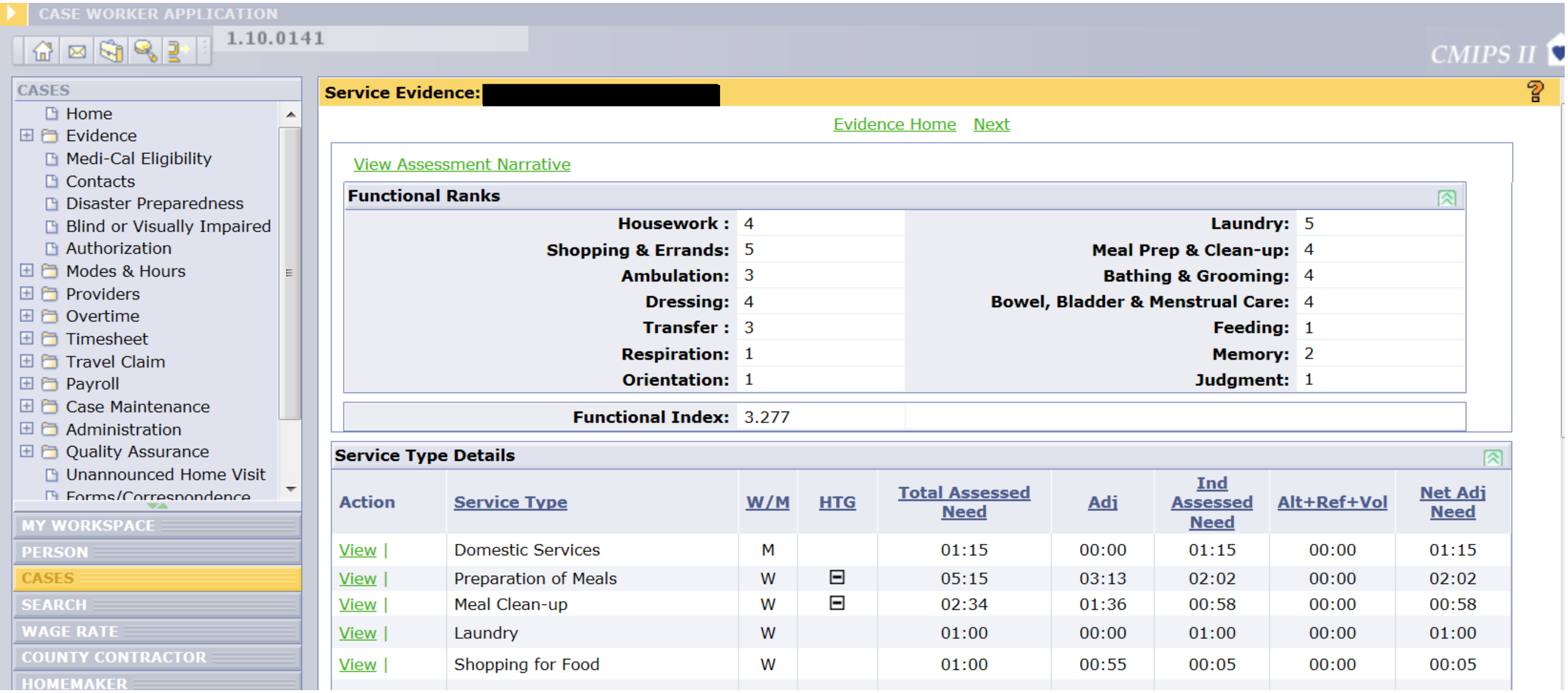
Companion Case Details

Companion Case Number:		**Protective Supervision Status:**	No

Household Member Details

Relationship:	Parent	**Date of Birth:**	[redacted]
Last Name:	[redacted]	**First Name:**	[redacted]
Spouse / Parent:	Parent - provides all services	**Protective Supervision Proration:**	No

Service Evidence



Service Evidence: [redacted]

Functional Ranks

Housework :	4	**Laundry:**	5
Shopping & Errands:	5	**Meal Prep & Clean-up:**	4
Ambulation:	3	**Bathing & Grooming:**	4
Dressing:	4	**Bowel, Bladder & Menstrual Care:**	4
Transfer :	3	**Feeding:**	1
Respiration:	1	**Memory:**	2
Orientation:	1	**Judgment:**	1

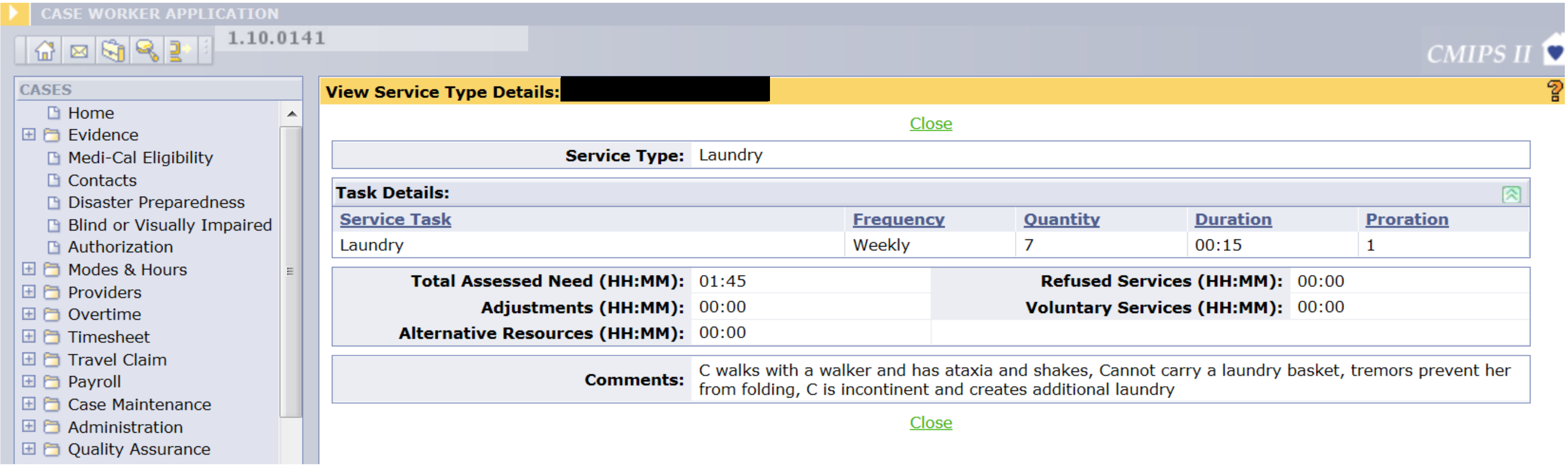
Functional Index: 3.277

Service Type Details

Action	Service Type	W/M	HTG	Total Assessed Need	Adj	Ind Assessed Need	Alt+Ref+Vol	Net Adj Need
View |	Domestic Services	M		01:15	00:00	01:15	00:00	01:15
View |	Preparation of Meals	W	⊟	05:15	03:13	02:02	00:00	02:02
View |	Meal Clean-up	W	⊟	02:34	01:36	00:58	00:00	00:58
View |	Laundry	W		01:00	00:00	01:00	00:00	01:00
View |	Shopping for Food	W		01:00	00:55	00:05	00:00	00:05

Service Type Details

Extraordinary Need for Laundry



View Service Type Details: [redacted]

Service Type: Laundry

Task Details:

Service Task	Frequency	Quantity	Duration	Proration
Laundry	Weekly	7	00:15	1

Total Assessed Need (HH:MM): 01:45

Adjustments (HH:MM): 00:00

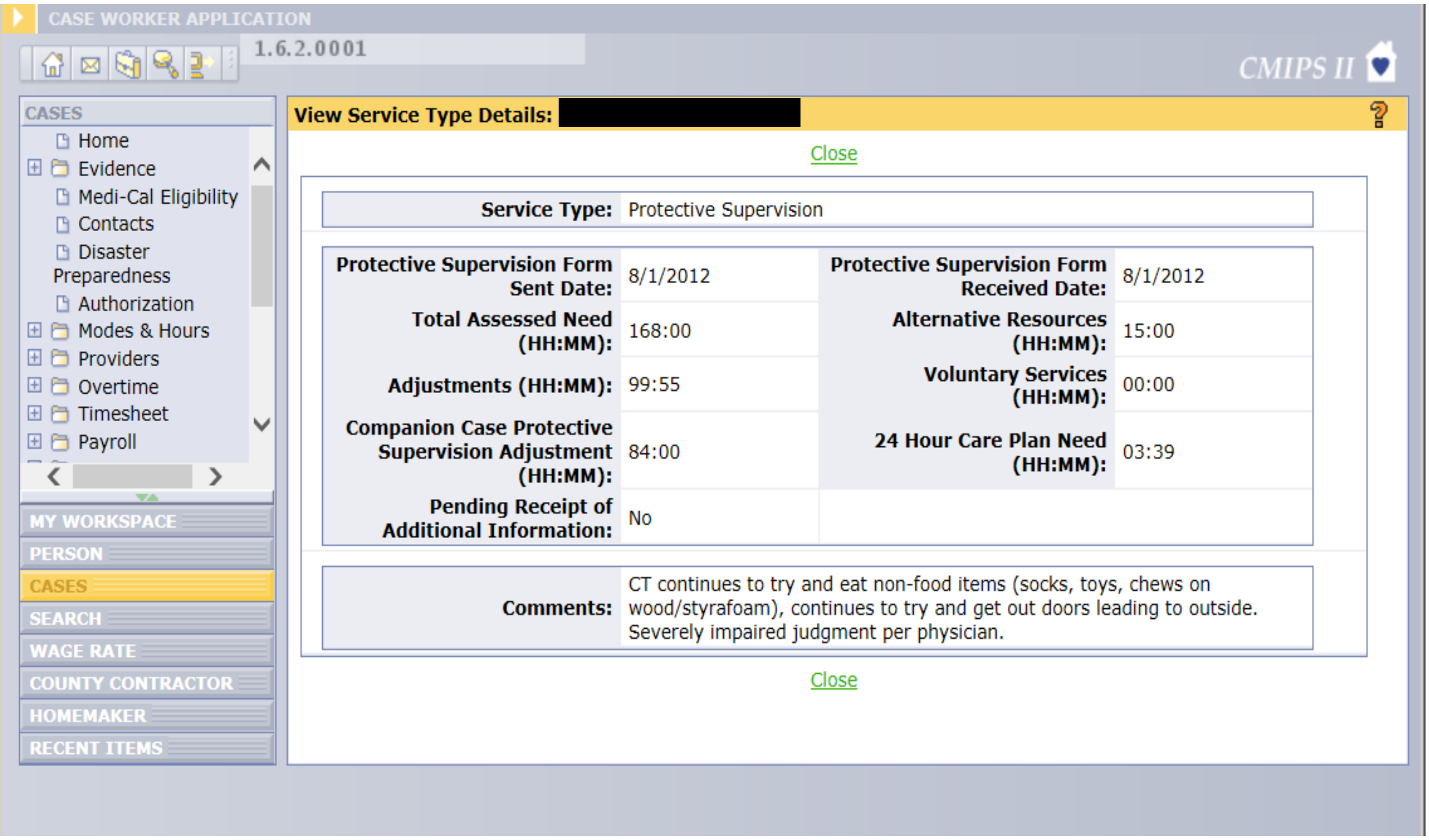
Alternative Resources (HH:MM): 00:00

Refused Services (HH:MM): 00:00

Voluntary Services (HH:MM): 00:00

Comments: C walks with a walker and has ataxia and shakes, Cannot carry a laundry basket, tremors prevent her from folding, C is incontinent and creates additional laundry

Service Type: Protective Supervision



View Service Type Details: [redacted]

Service Type: Protective Supervision

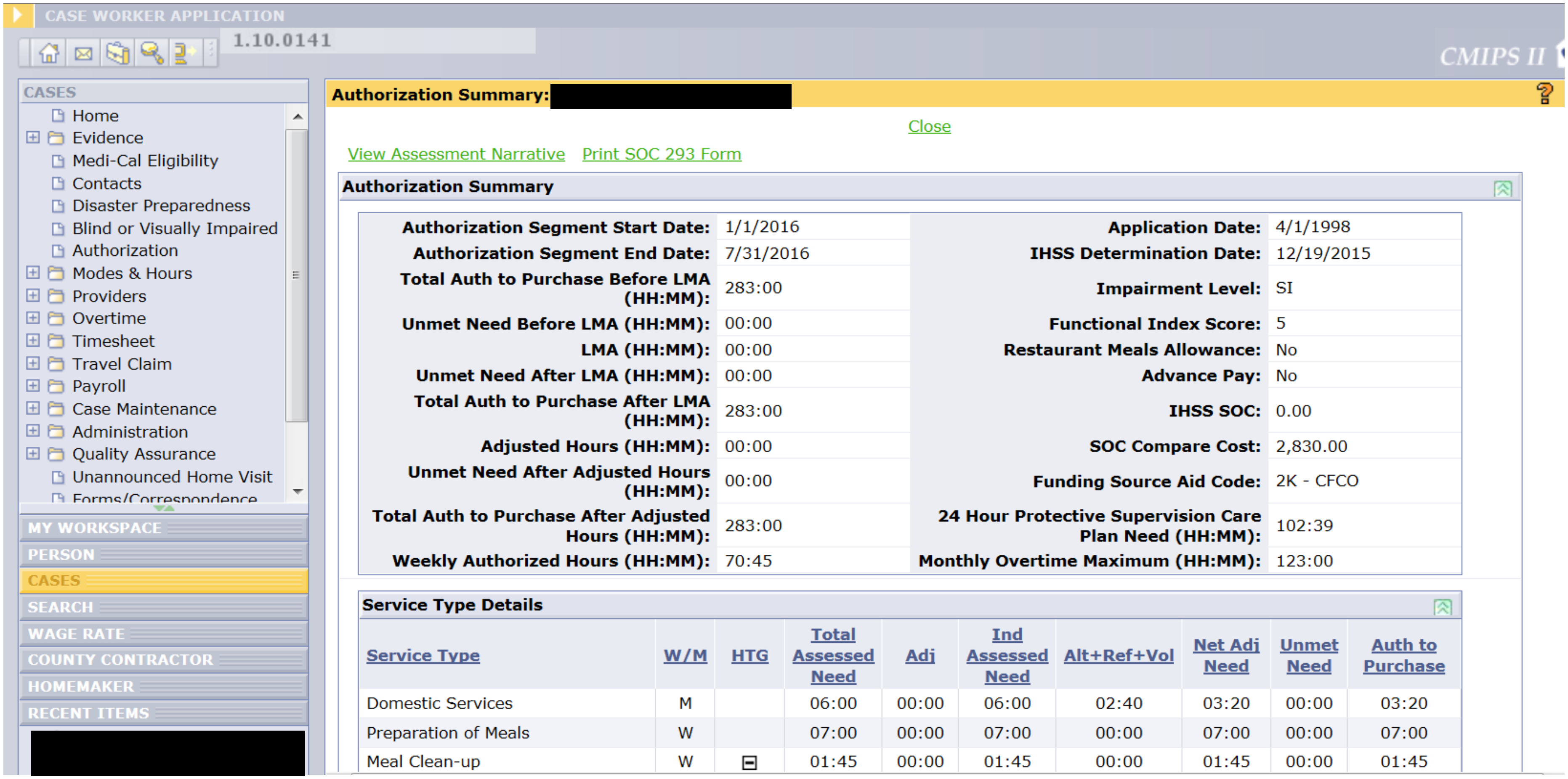
Protective Supervision Form Sent Date:	8/1/2012	**Protective Supervision Form Received Date:**	8/1/2012
Total Assessed Need (HH:MM):	168:00	**Alternative Resources (HH:MM):**	15:00
Adjustments (HH:MM):	99:55	**Voluntary Services (HH:MM):**	00:00
Companion Case Protective Supervision Adjustment (HH:MM):	84:00	**24 Hour Care Plan Need (HH:MM):**	03:39
Pending Receipt of Additional Information:	No		

Comments: CT continues to try and eat non-food items (socks, toys, chews on wood/styrafoam), continues to try and get out doors leading to outside. Severely impaired judgment per physician.

Field Name*	Description*
Protective Supervision Form Sent Date	The date when the Protective Supervision Form (SOC 821) was sent to the physician.
Total Assessed Need	Displays the system-generated total assessed need for Protective Supervision (168 hours). (HH:MM)
Adjustments	System-generated hours of service prorated between the recipient and other members of the household. (HH:MM)
Companion Case Protective Supervision Adjustment	Calculated during Final Determination. (HH:MM)
Pending Receipt of Additional Information	User-entered answer.
Protective Supervision Form Received Date	The date when the Protective Supervision Form (SOC 821) was received from the physician.
Alternative Resources	User-entered Alternative Resources for Protective Supervision. (HH:MM)
Voluntary Services	User-entered voluntary service for Protective Supervision. (HH:MM)
24 Hour Care Plan Need	Calculated during Final Determination. (HH:MM)

*(HH:MM) indicates that the data is displayed in an hours and minutes, rather than a decimal, format.

Authorization Summary



[redacted]

Authorization Summary: [redacted]

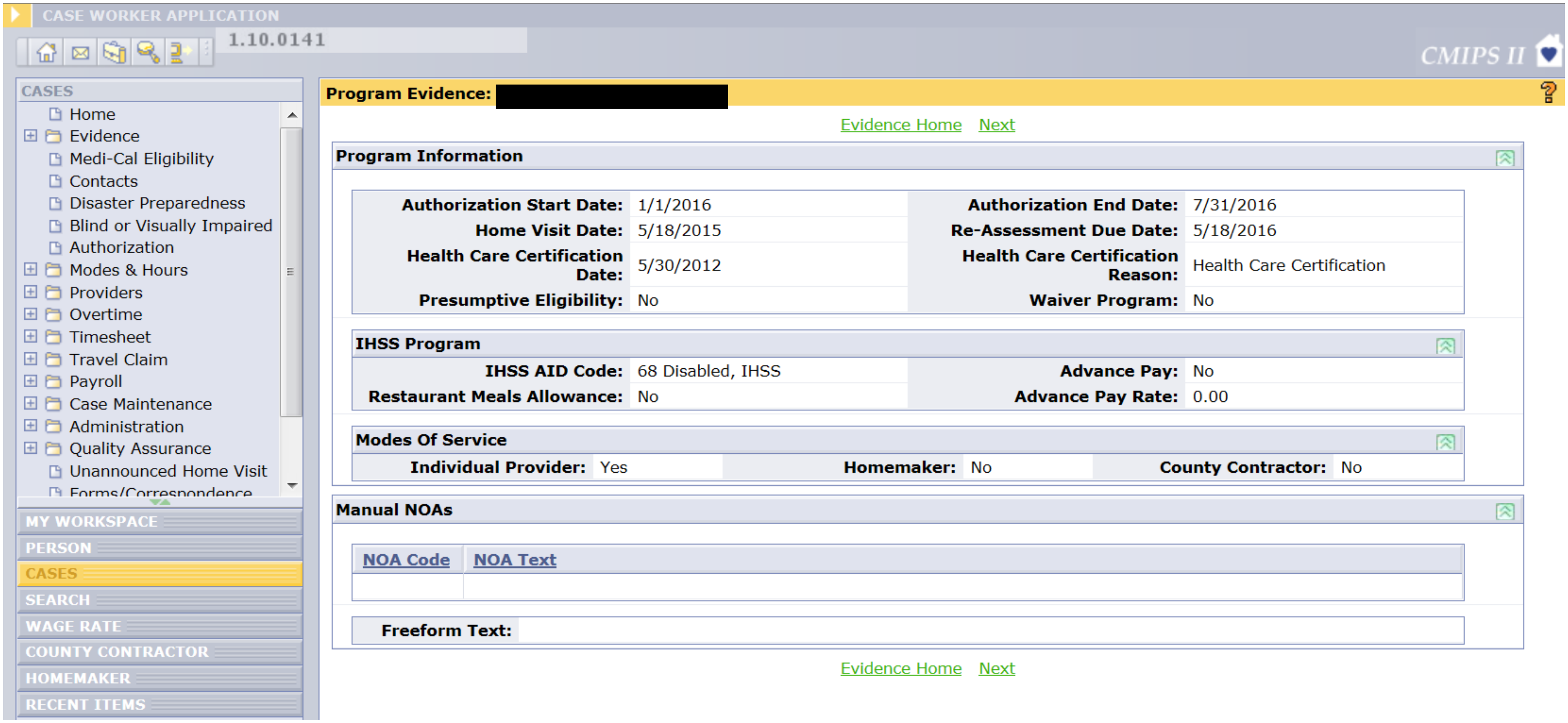
Authorization Summary

Authorization Segment Start Date:	1/1/2016	**Application Date:**	4/1/1998
Authorization Segment End Date:	7/31/2016	**IHSS Determination Date:**	12/19/2015
Total Auth to Purchase Before LMA (HH:MM):	283:00	**Impairment Level:**	SI
Unmet Need Before LMA (HH:MM):	00:00	**Functional Index Score:**	5
LMA (HH:MM):	00:00	**Restaurant Meals Allowance:**	No
Unmet Need After LMA (HH:MM):	00:00	**Advance Pay:**	No
Total Auth to Purchase After LMA (HH:MM):	283:00	**IHSS SOC:**	0.00
Adjusted Hours (HH:MM):	00:00	**SOC Compare Cost:**	2,830.00
Unmet Need After Adjusted Hours (HH:MM):	00:00	**Funding Source Aid Code:**	2K - CFCO
Total Auth to Purchase After Adjusted Hours (HH:MM):	283:00	**24 Hour Protective Supervision Care Plan Need (HH:MM):**	102:39
Weekly Authorized Hours (HH:MM):	70:45	**Monthly Overtime Maximum (HH:MM):**	123:00

Service Type Details

Service Type	W/M	HTG	Total Assessed Need	Adj	Ind Assessed Need	Alt+Ref+Vol	Net Adj Need	Unmet Need	Auth to Purchase
Domestic Services	M		06:00	00:00	06:00	02:40	03:20	00:00	03:20
Preparation of Meals	W		07:00	00:00	07:00	00:00	07:00	00:00	07:00
Meal Clean-up	W	⊟	01:45	00:00	01:45	00:00	01:45	00:00	01:45

Program Evidence



Program Evidence: [redacted]

Program Information

Authorization Start Date:	1/1/2016	**Authorization End Date:**	7/31/2016
Home Visit Date:	5/18/2015	**Re-Assessment Due Date:**	5/18/2016
Health Care Certification Date:	5/30/2012	**Health Care Certification Reason:**	Health Care Certification
Presumptive Eligibility:	No	**Waiver Program:**	No

IHSS Program

IHSS AID Code:	68 Disabled, IHSS	**Advance Pay:**	No
Restaurant Meals Allowance:	No	**Advance Pay Rate:**	0.00

Modes Of Service

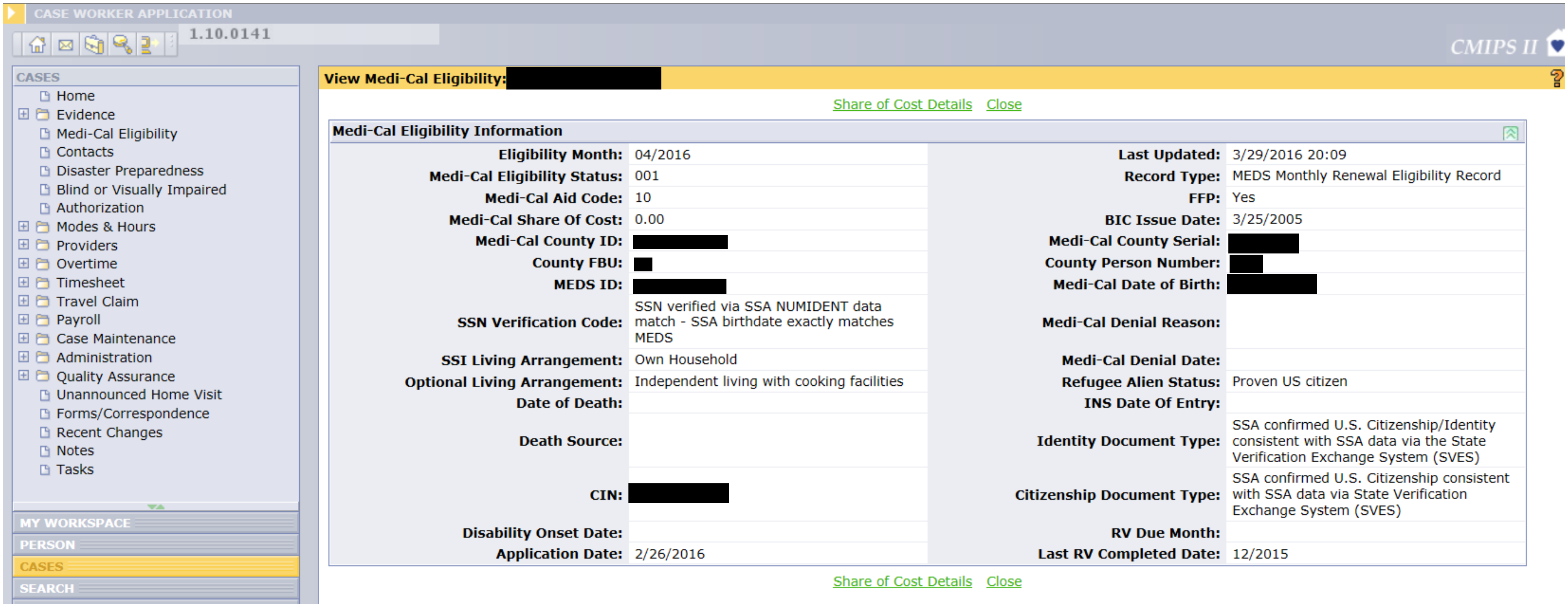
Individual Provider:	Yes	**Homemaker:**	No	**County Contractor:**	No

Manual NOAs

NOA Code	NOA Text

Freeform Text:

Medi-Cal Eligibility

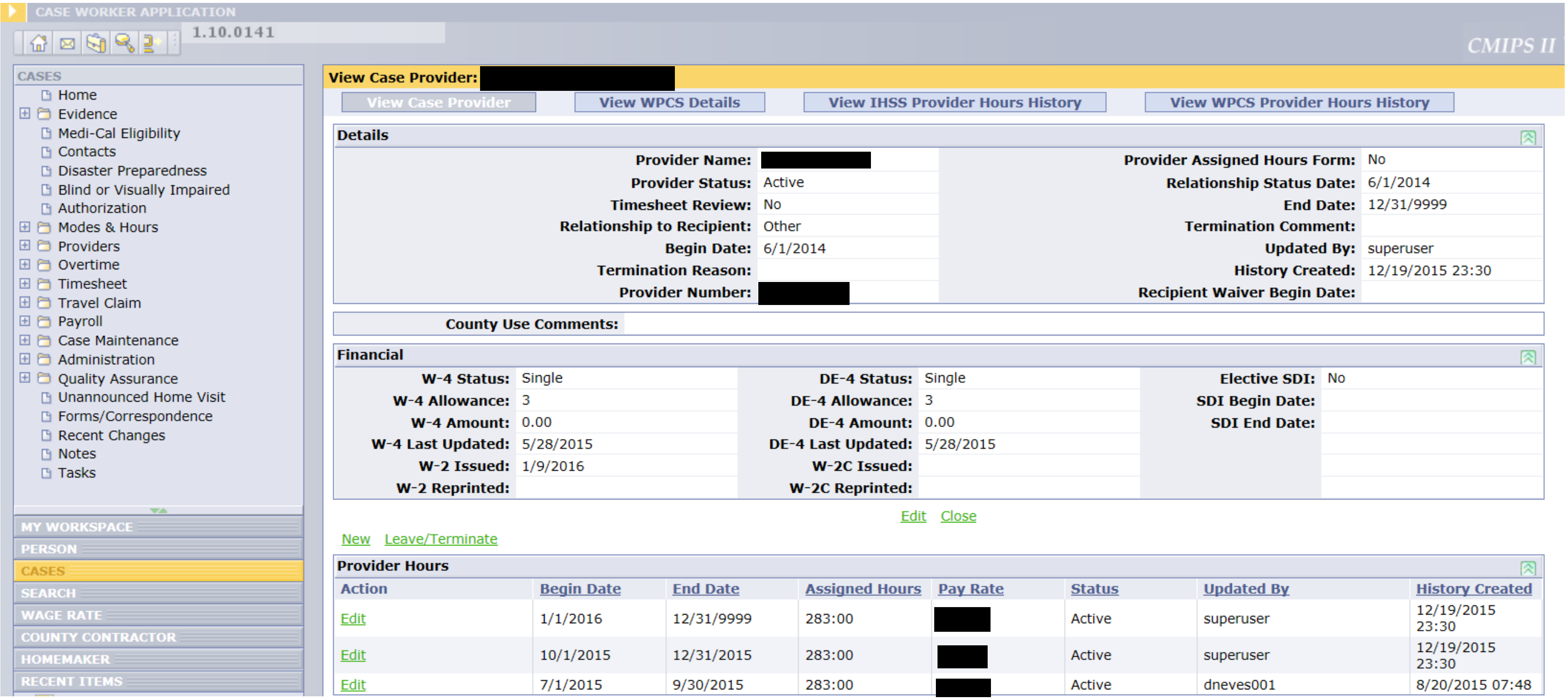


View Medi-Cal Eligibility: [redacted]

Medi-Cal Eligibility Information

Eligibility Month:	04/2016	**Last Updated:**	3/29/2016 20:09
Medi-Cal Eligibility Status:	001	**Record Type:**	MEDS Monthly Renewal Eligibility Record
Medi-Cal Aid Code:	10	**FFP:**	Yes
Medi-Cal Share Of Cost:	0.00	**BIC Issue Date:**	3/25/2005
Medi-Cal County ID:	[redacted]	**Medi-Cal County Serial:**	[redacted]
County FBU:	[redacted]	**County Person Number:**	[redacted]
MEDS ID:	[redacted]	**Medi-Cal Date of Birth:**	[redacted]
SSN Verification Code:	SSN verified via SSA NUMIDENT data match - SSA birthdate exactly matches MEDS	**Medi-Cal Denial Reason:**	
SSI Living Arrangement:	Own Household	**Medi-Cal Denial Date:**	
Optional Living Arrangement:	Independent living with cooking facilities	**Refugee Alien Status:**	Proven US citizen
Date of Death:		**INS Date Of Entry:**	
Death Source:		**Identity Document Type:**	SSA confirmed U.S. Citizenship/Identity consistent with SSA data via the State Verification Exchange System (SVES)
CIN:	[redacted]	**Citizenship Document Type:**	SSA confirmed U.S. Citizenship consistent with SSA data via State Verification Exchange System (SVES)
Disability Onset Date:		**RV Due Month:**	
Application Date:	2/26/2016	**Last RV Completed Date:**	12/2015

Provider Details



View Case Provider: [redacted]

Details

Provider Name:	[redacted]	**Provider Assigned Hours Form:**	No
Provider Status:	Active	**Relationship Status Date:**	6/1/2014
Timesheet Review:	No	**End Date:**	12/31/9999
Relationship to Recipient:	Other	**Termination Comment:**	
Begin Date:	6/1/2014	**Updated By:**	superuser
Termination Reason:		**History Created:**	12/19/2015 23:30
Provider Number:	[redacted]	**Recipient Waiver Begin Date:**	

County Use Comments:

Financial

W-4 Status:	Single	**DE-4 Status:**	Single	**Elective SDI:**	No
W-4 Allowance:	3	**DE-4 Allowance:**	3	**SDI Begin Date:**	
W-4 Amount:	0.00	**DE-4 Amount:**	0.00	**SDI End Date:**	
W-4 Last Updated:	5/28/2015	**DE-4 Last Updated:**	5/28/2015		
W-2 Issued:	1/9/2016	**W-2C Issued:**			
W-2 Reprinted:		**W-2C Reprinted:**			

Provider Hours

Action	Begin Date	End Date	Assigned Hours	Pay Rate	Status	Updated By	History Created
Edit	1/1/2016	12/31/9999	283:00	[redacted]	Active	superuser	12/19/2015 23:30
Edit	10/1/2015	12/31/2015	283:00	[redacted]	Active	superuser	12/19/2015 23:30
Edit	7/1/2015	9/30/2015	283:00	[redacted]	Active	dneves001	8/20/2015 07:48