WELCOME TO THE
IHSS TRAINING ACADEMY

CORE: SPECIAL AREAS IN IHSS

On behalf of the California Department of Social Services (CDSS), we are pleased to offer ***Core: Special Areas in IHSS***. During this two-day training, participants will share best practices and take part in exercises designed to apply the principles covered and practiced during the training which will lead to greater consistency and uniformity in the assessment and authorization of IHSS services. The training curriculum will cover:

- IHSS and Children
- Working with Consumers with Mental Illness
- Protective Supervision
- Assessing the Needs of Consumers with Severe Disabilities

Objectives:

At the end of the program, the participants will be able to:

- Understand and apply regulations and policy for assessing the needs of children who qualify for IHSS
- Apply age appropriate guidelines when selecting the functional index score for children
- Understand who is eligible for Protective Supervision
- Identify factors that affect the calculations of Protective Supervision hours
- Perform accurate assessment of consumers with severe disabilities
- Identify alternative resources for IHSS consumers
- Understand common mental illnesses and how to work with consumers with mental illness

IHSS TRAINING ACADEMY
CORE: SPECIAL AREAS IN IHSS

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Welcome to In-Home Supportive Services Training Academy

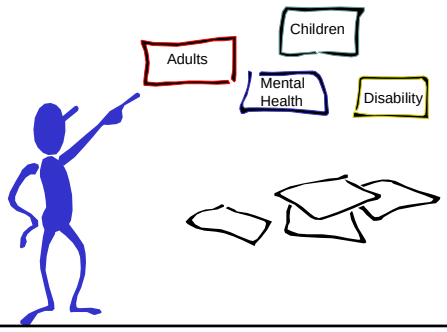
A partnership between...

- California Department of Social Services
- California Welfare Directors' Association
- California State University, Sacramento
  - College of Continuing Education
  - Institute for Social Research

Course Overview: Special Areas in IHSS

- IHSS and Children
- Working with Consumers with Mental Illness
- Protective Supervision
- Assessing Severe Disabilities

Activity – Resources



IHSS and Children

Recipient under 18 years old and living with parent(s).
[MPP 30-763.44]

- IHSS will pay provider other than parent if:
  - Parent(s) is absent because of employment or education or training for vocational purposes.
  - Parent(s) is physically or mentally unable to perform the needed services.
  - Parent is absent because of ongoing medical, dental or other health related treatment.
  - Up to 8 hours weekly to perform shopping and errands essential to the family or for essential purposes related to caring for minor siblings.

Recipient under 18 years old and living with parent(s).
[MPP 30-763.45]

- IHSS will pay parent if ***all*** of the following conditions are met:
  - Parent has left or is prevented from obtaining full-time employment because of need to provide IHSS for child.
  - There is no other suitable provider available.
  - The child who does not receive the listed services may inappropriately require out-of-home placement or may receive inadequate care.

When both parents are in the home.

[MPP 30-763.453]

- IHSS will pay a parent to provide services if:
  - Conditions in Section 30-763.451(a) through (c) have been met.
  - Non-provider parent cannot provide services because of employment, education, or is physically or mentally unable to do so.
  - If the non-provider is unable to provide services because of employment or education purposes, payment is only for services provided during the periods of the non-provider parent's absence.

Services NOT provided when IHSS is provided by parent:

- Domestic
- Heavy cleaning
- Remove grass, weeds, rubbish
- Remove ice, snow

Applying Annotated Assessment Criteria to Children

- If the child is not developmentally appropriate for a task, the Annotated Assessment Criteria is not used for that task.
- Look at all the tasks that the child developmentally would not be able to complete and assign "1" for FI.
- Then assess the rest of the tasks using the Annotated Assessment Criteria as written.

Age Appropriate Guidelines

Assessing Children

- Autism
- Hyperactivity diagnosis
- Drug exposure

1. What are the characteristics of the disorder?
2. What effects can it have on the child's normal functioning?
3. What are some strategies the SW can use when assessing these children?

Alternative Resources

- IHSS Secondary Provider
  - Regulation 30-763.44
- Other services that may be available
  - Regional center
  - School-based resources

Exercise: Assessing Children

Given the Age Appropriate Guidelines and Annotated Assessment Criteria:

- Using your resources and the Annotated Assessment Criteria, answer questions as indicated on your scenario.
- Report the group's responses to the questions as indicated at the bottom of your scenario.

Working with the Consumer with Mental Illness

Important Concepts

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

Stigma of Mental Illness

- Behaviors are controllable.
- The person can overcome illness if had enough will power.
- Mental illness reflects the person's character and intelligence.

Schizophrenia
Characteristics

- Affects around 1 percent 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.

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.**

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

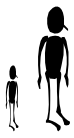
- Mania
  - Severe mania may not feel the need to keep themselves well groomed or his/her apartment clean
  - Risk with physical impairments – taking risks with mania
  - Not taking medications
  - Need for sleep or for eating regularly may become less

Bipolar Disorder
IHSS Functional Limitations

- Depression
  - 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

- Mania
  - **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**



Personality Disorders

People with personality disorders have traits that cause them to feel and behave in socially distressing ways, which often limit their ability to function in relationships and in social situations.

Personality Disorders

- **Cluster A** includes personality disorders marked by ***odd, eccentric behavior***, including paranoid, schizoid and schizotypal personality disorders.
- **Cluster B** personality disorders are those defined by ***dramatic, emotional behavior***, including histrionic, narcissistic, antisocial and borderline personality disorders.
- **Cluster C** personality disorders are characterized by ***anxious, fearful behavior*** and include obsessive-compulsive, avoidant and dependent 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 Illness

- 15% of adults with mental illness also have substance abuse problems
- Substances used to augment medication / treatment
- Need for referrals

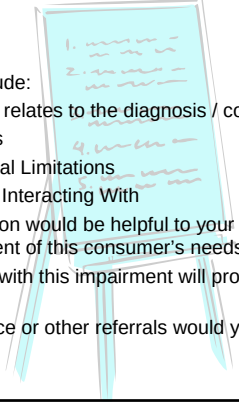
Suicide and Mental Illness

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

Assigning Functional Index

- Determine Functional Index ranking both on physical capabilities and functioning as impacted by mental illness
- Recognize that functioning can be impaired equally by physical impairments and mental illness
- Determine ability to make choices

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.

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

Thanks for your participation!

Characteristic behaviors of autism may or may not be apparent in infancy (18-24 months), but usually become obvious during early childhood (24 months-6 years). The National Institute of Child Health and Human Development (NICHD) lists five behaviors that signal further evaluation is warranted.

1. Child does not babble/coo by 12 months.
2. Child does not gesture (point, wave, grasp) by 12 months.
3. Child does not say single words by 16 months.
4. Child does not say two-word phrases on his/her own by 24 months.
5. Child exhibits any loss of language or social skills at any age.

Medication

Autism is a pervasive developmental disorder (though it is in the DSM-IV). In addition, because we really do not know where autism comes from or how it develops, it is difficult to target what area of the brain or brain chemistry needs medication. Most children who have autism go through some special education and behavioral therapy. There is not a prescription medication for it. Doctors may prescribe medications for physical effects that can be related to autism (e.g. seizures) but it is not a treatment for the autism itself.

Families Experiencing Autism

(Excerpt taken from *Autism Society of America's website:* *http://www.autism-society.org*)

Research indicates that parents of children with autism experience greater stress than parents of children with mental retardation and Down Syndrome. This may be a result of the distinct characteristics that individuals with autism exhibit. An individual with autism may not be able to express their basic wants or needs. Therefore, parents are left playing a guessing game. Is the child crying because he/she is thirsty, hungry, or sick? When the parent cannot determine their child's needs, both are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious behaviors that threaten their safety and the safety of others (e.g. siblings). Stereo-typical and compulsive behaviors often concern parents because they appear peculiar and interfere with functioning and learning.

A child's deficits in social skills, such as the lack of appropriate play, are also stressful for families. Individuals lacking appropriate leisure skills often require constant structure of their time, a task not feasible to accomplish in the home environment. Many families struggle with the additional challenges of getting their child to sleep through the night and everyone else's bedtime routines can be interrupted. Scheduled dinner times may not be successful due to the child's inability to sit appropriately for extended periods of time or lack of wanting to eat a wider variety of foods. All of these deficits and behaviors are physically exhausting for families and emotionally draining.

Autism Resources

- American Psychiatric Association. (2000). I*Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (Text Revision).* APA.
- Autism Society of America: http://www.autism-society.org
- The UC Davis M.I.N.D. Institute: http://www.ucdmc.ucdavis.edu/mindinstitute
- The National Autistic Society: http://www.nas.org.uk/

ADHD
(Attention-Deficit / Hyperactivity Disorder)

ADHD is one of the most common childhood neurobehavioral disorders diagnosed in the United States today. Its symptoms vary depending on the sub-type diagnosis (i.e., Combined Type, Predominantly Inattentive Type and Predominantly Hyperactive-Impulsive Type) and can persist through adolescence and adulthood.

According to the DSM-IV-TR (2000), five criteria make up the clinical definition of ADHD. They are:

Criterion A: The essential feature of attention-deficit/hyperactivity disorder is a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development.

Criterion B: Some hyperactive-impulsive or inattentive symptoms that cause impairment must have been present before age 7 years, although many individuals are diagnosed after the symptoms have been present for a number of years.

Criterion C: Some impairment from the symptoms must be present in at least two settings (i.e., at home and at school or work).

Criterion D: There must be clear interference with developmentally appropriate social, academic, or occupational functioning.

Criterion E: The disturbance does not occur exclusively during the course of a pervasive developmental disorder, schizophrenia, or other psychotic disorder and is not better accounted for by another mental disorder (i.e., mood disorder, anxiety disorder, disassociative disorder, or personality disorder).

ADHD Symptoms

The primary symptoms of ADHD are inattention, hyperactivity, and impulsivity. These symptoms will generally appear early in a child's life and may persist through later childhood, adolescence, and adulthood. Different symptoms may appear in different settings, depending on the demands the situation may pose for the child's self-control. A child who "can't sit still" or is otherwise disruptive will be noticeable in school, but the inattentive daydreamer may be overlooked or seen as "shy" or "withdrawn". The impulsive child who acts before thinking may be considered to have discipline issues, while the child who is passive or sluggish may be viewed as simply unmotivated. Yet both may have different types of ADHD. All children are sometimes fidgety, sometimes act without thinking, and sometimes daydream the time away. When the child's hyperactivity, distractibility, poor concentration, or impulsivity begins to affect performance in school, social relationships with other children, or behavior at home, ADHD may be a plausible diagnosis (National Institute of Mental Health, 2003).

Some signs of **hyperactivity-impulsivity** are:

- Feeling restless, often fidgeting, or squirming while seated
- Running, climbing, or leaving a seat in situations where sitting or quiet behavior is expected
- Blurting out answers before hearing the whole question
- Having difficulty waiting in line or taking turns

Some signs of **inattention** are:

- Often becoming easily distracted by irrelevant sights and sounds
- Often failing to pay attention to details and making careless mistakes
- Often does not seem to listen when spoken to directly
- Rarely following instructions carefully and often losing or forgetting things like toys, or pencils, books, and tools needed for a task
- Often skipping from one uncompleted activity to another

Medication (information taken from the National Institute of Mental Health website)
The medications that seem to be the most effective are a class of drugs known as stimulants. Following is a list of the stimulants, their trade (or brand) names, and their generic names. "Approved age" means that the drug has been tested and found safe and effective in children of that age.

Trade Name	Generic Name	Approved Age
Adderall	amphetamine	3 and older
Concerta	methylphenidate (long acting)	6 and older
Cylert	pemoline	6 and older
Dexedrine	dextroamphetamine	3 and older
Dextrostat	dextroamphetamine	3 and older
Focalin	dexmethylphenidate	6 and older
Metadate ER	methylphenidate (extended release)	6 and older
Metadate CD	methylphenidate (extended release)	6 and older
Ritalin	methylphenidate	6 and older
Ritalin SR	methylphenidate (extended release)	6 and older
Ritalin LA	methylphenidate (long acting)	6 and older

The U.S. Food and Drug Administration (FDA) recently approved a medication for ADHD that is not a stimulant. The medication, Strattera®, or atomoxetine, works on the neurotransmitter norepinephrine, whereas the stimulants primarily work on dopamine. Both of theses neuro-transmitters are believed to play a role in ADHD. More studies will need to be done to contrast Strattera® with the medications already available, but the evidence to date indicates that over
70 percent of children with ADHD given Strattera® manifest significant improvement in their symptoms (National Institute of Mental Health:
http://www.nimh.nih.gov/publicat/adhd.cfm#treat)

Families and Children with ADHD

Many children with ADHD require medication and therapy or skills training in order to learn to maximize their every day functioning. Often, parents and siblings find themselves extraordinarily frustrated with the symptoms of ADHD as they can affect everyday family life and schedules. Families with children who have ADHD are encouraged to help their children develop a daily schedule, organize school notebooks and work as well as everyday items (i.e., clothing, school supplies, etc.).

Families who are having a difficult time managing challenging behaviors may need family counseling/therapy in order to equip themselves in coping with this challenging diagnosis. Mental health practitioners and skills trainers are equipped with tools and strategies to aid parents and families as they learn to appreciate the uniqueness of their child and find new ways of relating to one another.

ADHD Resources

- American Psychiatric Association. (2000). I*Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (Text Revision).* APA.
- National Institute of Mental Health: http://www.nimh.nih.gov/publicat/adhd.cfm
- AdhdNews.Com: http://www.adhdnews.com
- Focus on ADHD: http://www.focusonadhd.com

AUTISM

Autism is a pervasive developmental disorder which, according to the DSM-IV-TR (2000), are disorders characterized by substantial impairment in several areas of development including reciprocal social interaction skills, communication skills, presence of stereotyped behavior, interests and activities.

According to the U.S. Department of Education (1991),

> "Autism is a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age three, that adversely affects educational performance. Characteristics of autism include – irregularities and impairments in communication, engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routine and unusual responses to sensory experiences." [U.S. Department of Education. 1991. Notice of proposed rulemaking. *Federal Register, 56 (160),* p 41271]

The following are symptoms that may or may not be present in children with autism. Due to its nature as a spectrum disorder (a disorder with a range of functioning in several skill areas), specific symptoms may not apply to all affected individuals. Symptoms can be seen in the areas of communication, social skills, learning deficits, unusual sensory reactions, and behaviors.

Communication

- Range from minimal to severe expressive language deficits
- Stereotyped and repetitive use of language
- Resistance to making eye contact
- Unresponsive to verbal cues; acts as if unable to hear, although hearing test results are in normal range

Social Skills

- Preference for being alone
- Failure to develop peer relationships appropriate to developmental level
- Resistance to affection from individuals including caregivers and family
- Unable to engage in imaginative or symbolic play

Learning Deficits

- Unresponsive to typical teaching methods
- Significantly impaired intellectual function (I.Q. < 70)

Unusual Sensory Reactions

- Apparent over or under-sensitivity to pain
- High sensitivity to sounds
- Problems with sensory integration

Stereotyped/Repetitive Behaviors

- Resistant to change in routine or environment
- Engages in repetitious self-stimulating behavior (waving their hands in front of their eyes; physically rocking their body)
- Sustained odd play
- Obsessive attachment to objects
- Absence of fear of danger

DRUG AND ALCOHOL EXPOSURE

Alcohol
Exposure to alcohol during prenatal development can lead to a wide range of affects after a child is born. Developmental damage can be sustained from exposure to alcohol from the point of conception through the end of the third trimester in pregnancy. It is for this reason that women are discouraged from drinking alcoholic beverages from the point at which they are trying to become pregnant in addition to abstaining during pregnancy.

Infants who are exposed to alcohol (as well as other addictive substances) during pregnancy may experience withdrawal effects after birth when the substance is no longer present in their bloodstream. Infants, as a result, may experience the following symptoms:

- Low birth weight
- High levels of irritability
- Problems with sleeping and eating
- Failure to bond

As mentioned previously, the effects of alcohol exposure can be seen in a wide range. The most severe cases of exposure are seen in children with Fetal Alcohol Syndrome (FAS). Symptoms of FAS include:

- Abnormally small head and underdeveloped brain
- Eye abnormalities
- Congenital heart disease
- Joint abnormalities
- Malformations of the face
- Retardation in physical growth and cognitive functioning

The effects of lower levels of alcohol consumption can result in Fetal Alcohol Effects which include more subtle (but measurable) deficits in cognitive and motor functioning. The degree of impact of these effects will vary with both the timing of the exposure to alcohol during pregnancy and the quantity of alcohol consumed during pregnancy.

Marijuana
Currently, in developmental research, there is a debate in regards to developmental effects of marijuana exposure. Some studies have shown that marijuana use during pregnancy leaves the infant at risk for premature birth and low birth weight. In addition, studies in the United States and Canada have associated the following symptoms with marijuana exposure in young children (Cole & Cole, 2001):

- Startle more readily
- Tremors
- Problems with sleeping

Cocaine
Cocaine use is highly dangerous for both mother and fetus. When cocaine enters the mother's body, the mother's and fetus's blood vessels constrict sharply restricting the flow of blood to the fetus. The reduced blood flow results in oxygen deprivation for the fetus which can result in:

- Stillbirth or premature delivery
- Low birth weight and delayed growth
- Increased risk of stroke
- Birth defects affecting the heart, lungs and intestines
- Excessive irritability
- Delayed cognitive functioning
- Delays in senses development (hearing, vision, smell and touch)

In addition, due to the damage of the infant's nerves and nerve endings in the central nervous system, effects of cocaine exposure can extend far into childhood resulting in the following:

- Attention deficit disorders
- Instances of uncontrollable rage or restlessness
- Inability to be comforted

Heroin/Methadone

Infants born to mothers who are addicted to heroin are born addicted to the substance themselves and must be given heroin or methadone in order to ease the life-threatening process of withdrawal. These infants are at risk for the following effects:

- Stillbirth or premature delivery
- Low birth weight
- Vulnerable to respiratory illness and infection
- High levels of irritability
- Tremors
- Abnormal cries
- Sleep disturbances
- Diminished motor control/functioning
- Impaired ability to pay attention (can be a long-term effect)

The Family

Education is extraordinarily important with regards to effects of drug and alcohol exposure on mothers and infants. It is critical that any pregnant woman who is abusing substances during pregnancy seek medical attention and help to refrain from substance use during and after her pregnancy. In addition, proper legal authorities need to be informed in order to protect the fetus/infant from further exposure.

After birth, the family will need resources including education and counseling to learn to adapt to any possible special needs of their child. As seen above, cognitive and behavioral challenges can be a long-term effect to exposure to substances during pregnancy and the family may need a referral for medical, mental health or special education services.

Resources

- Cole, M., & Cole, S. (2001). The Development of Children (4th Edition). New York, New York: Worth Publishing.
- National Institutes of Health: http://www.nih.gov
- National Center for Education in Maternal and Child Health (NCEMCH): http://www.ncemch.org/directory/default.html
- National Organization on Fetal Alcohol Syndrome (NOFAS): http://www.nofas.org

ASSOCIATION OF REGIONAL CENTER AGENCIES
GUIDELINES FOR DETERMINING "5TH CATEGORY" ELIGIBILITY FOR THE CALIFORNIA REGIONAL CENTERS

The California Welfare and Institutions (W&I) Code Section 4512(a) defines a developmental disability as: "...a disability which originates before an individual attains age 18, continues or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation **or** to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature." The California Code of Regulations (CCR) Title 17 Section 54000 defines "developmental disability" as a disability that is attributable to mental retardation, cerebral palsy, epilepsy, autism or other conditions similar to mental retardation that require treatment similar to that required by individuals with mental retardation. The developmental disability shall: 1) originate before age 18; 2) be likely to continue indefinitely; and 3) constitute a substantial handicap for the individual.

Eligibility for Regional Center services under the 5th category requires a determination as to whether an individual functions in a manner that is similar to that of a person with mental retardation **OR** requires treatment similar to that required by individuals with mental retardation.

A recent appellate court decision clarified that the Legislative intent was not to provide a detailed definition of the 5th category in statute, deferring to the professionals of the Regional Center Eligibility Team to make the decision on eligibility after considering information obtained through the assessment process [Mason v OAH (2001) 89 Cal.App.4th 1119]. This opinion also discusses what information should be considered in determining eligibility in the 5th category.

The local eligibility team should consider the following factors when determining eligibility under the 5th category.

I. Does the individual function in a manner that is similar to that of a person with mental retardation?

Mental retardation is defined in the DSM-IV as "significantly subaverage general intellectual functioning...that is accompanied by significant limitations in adaptive functioning..."

General intellectual functioning is measured by assessment with one or more standardized tests. Significantly sub-average intellectual functioning is defined as an intelligence quotient (IQ) of 70 or below.

An individual can be considered to be functioning in a manner that is similar to a person with mental retardation if:

A. The general intellectual functioning is in the low borderline range of intelligence (I.Q. scores ranging from 70-74). Factors that the eligibility team should consider include:

1. Cognitive skills as defined in the California Code of Regulations, Title 17, Section 54002: "...the ability of an individual to solve problems with insight, to adapt to new situations, to think abstractly and to profit from experience."

2. The higher an individual's IQ is above 70, then the less similar to a person with mental retardation is the individual likely to appear. For example, an individual with an IQ of 79 is more similar to a person with low average intelligence and more dissimilar to a person with mild mental retardation.

3. As an individual's intelligence quotient rises above 70, it becomes increasingly essential for the eligibility team to demonstrate that:
   a. there are substantial adaptive deficits, and
   b. such substantial adaptive deficits are clearly related to cognitive limitations.

4. Occasionally, an individual's Full Scale IQ is in the low borderline range (IQ 70-74) but there is a significant difference between cognitive skills. For example, the Verbal IQ may be significantly different than the Performance IQ. When the higher of these scores is in the low average range (IQ 85 or above), it is more difficult to describe the individual's general intellectual functioning as being similar to that of a person with mental retardation. In some cases, these individuals may be considered to function more like persons with learning disabilities than persons with mental retardation.

5. Borderline intellectual functioning needs to show stability over time. Young children may not yet demonstrate consistent rates and patterns of development. For this reason, eligibility for young children in the 5th category should be viewed with great caution.

B. In addition to sub-average intellectual functioning the person also must demonstrate significant deficits in *Adaptive* skills including, but not limited to, communication, learning, self-care, mobility, self-direction, capacity for independent living, and economic self-sufficiency. Factors that the eligibility team should consider include:

1. Adaptive behavior deficits as established on the basis of clinical judgments supplemented by formal Adaptive Behavior Scales (e.g., Vineland ABS, AAMR-ABS) when necessary.

2. Adaptive deficits are skill deficits related to intellectual limitations that are expressed by an inability to perform essential tasks within adaptive domains or by an inability to perform those tasks with adequate judgment.

3. Skill deficits are not performance deficits due to factors such as physical limitations, psychiatric conditions, socio-cultural deprivation, poor motivation, substance abuse, or limited experience.

I. Does the person require treatment similar to that required by an individual who has mental retardation?

In determining whether an individual requires "treatment similar to that required for mentally retarded individuals," the team should consider *the nature of training and intervention* that is most appropriate for the individual who has global cognitive deficits. The eligibility team should consider the following to determine whether the individual requires treatment similar to that required by an individual who has mental retardation.

A. Individuals demonstrating *performance based deficits* often need treatment to increase motivation rather than training to develop skills.

B. Individuals with *skill deficits* secondary to socio-cultural deprivation but not secondary to intellectual limitations need short term, remedial training, which is not similar to that required by persons with mental retardation.

C. Persons requiring *habilitation* may be eligible, but persons primarily requiring *rehabilitation* are not typically eligible as the term rehabilitation implies recovery of previously acquired skills; however, persons requiring rehabilitation may be eligible if the disability is acquired before age 18 and is a result of traumatic brain injury or disease.

D. Individuals who require *long term training* with steps broken down into small, discrete units taught through repetition may be eligible.

E. The eligibility team may consider the intensity and type of *educational supports* needed to assist children with learning. Generally, children with mental retardation need more supports, with modifications across many skill areas.

III. Is the individual substantially handicapped based upon the statewide definition of Substantial Disability/Handicapped?

The W&I Code (Section 4512) defines a *Developmental Disability* as a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a *substantial disability* for that individual.
The CCR Title 17 (Section 54001) defines *substantial handicap* as:

a) Substantial handicap means a condition which results in major impairment of cognitive and/or social functioning. Moreover, a substantial handicap represents a condition of sufficient impairment to require interdisciplinary planning and coordination of special or generic services to assist the individual in achieving maximum potential.

b) Since an individual's cognitive and/or social functioning is many-faceted, the existence of a major impairment shall be determined through an assessment which shall address aspects of functioning including, but not limited to:
   1) Communication skills;
   2) Learning;
   3) Self-care;
   4) Mobility;
   5) Self-direction;
   6) Capacity for independent living;
   7) Economic self-sufficiency.

c) The assessment shall be made by a group of Regional Center professionals of differing disciplines and shall include consideration of similar qualification appraisals performed by other interdisciplinary bodies serving the potential consumer. The group shall include as a minimum a program coordinator, a physician, and a psychologist.

d) The Regional Center professional group shall consult the potential consumer, parents, guardians/ conservators, educators, advocates, and other consumer representatives to the extent that they are willing and available to participate in its deliberation and to the extent that the appropriate consent is obtained.

Regional Centers should use the criteria of three or more limitations in the seven major life activities as used in the federal definition for Developmental Disability. The

determination of substantial handicap for children under 5 years of age should be based upon assessment in five areas of functioning (communication skills; learning; self-care; mobility; and self-direction). For children from 6-18 years of age (and adults ages 18-22 who are in educational programs) the determination should be based upon assessment in six areas of functioning (communication skills; learning; self-care; mobility; self-direction and capacity for independent living).

IV. Did the disability originate before age 18 and is it likely to continue indefinitely?

The eligibility team should provide an opinion regarding the person's degree of impairment in the adaptive functioning domains, identifying skill deficits due to cognitive limitations and considering performance deficits due to factors such as physical limitations, psychiatric conditions, socio-cultural deprivation, poor motivation, substance abuse, or limited experience. Additional information, such as that obtained by a home visit, school or day program observation, or additional testing may be required to make this determination.

Approved by the ARCA Board of Directors on March 16, 2002.

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Department of Developmental Services
Regional Centers

(Colors correspond to areas served by each Regional Center)

Updated: July 1, 2003

State of California
Department of Developmental Services
http://www.dds.ca.gov/RC/Home.cfm

Services Provided By Regional Centers

Regional centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services and supports that are needed because of a developmental disability. There is no charge for the diagnosis and eligibility assessment.

Once eligibility is determined, a case manager or service coordinator is assigned to help develop a plan for services, tell you where services are available, and help you get the services. Most services and supports are free regardless of age or income.

There is a requirement for parents to share the cost of 24-hour out-of-home placements for children under age 18. This share depends on the parents' ability to pay. For further information, see Parental Fee Program (http://www.dds.ca.gov/ParentalFee/Home.cfm). There may also be a co-payment requirement for other selected services. For further information, see Family Cost Participation Program (http://www.dds.ca.gov/FCPP/Index.cfm).

Some of the services and supports provided by the regional centers include:

- Information and referral
- Assessment and diagnosis
- Counseling
- Lifelong individualized planning and service coordination
- Purchase of necessary services included in the individual program plan
- Resource development
- Outreach
- Assistance in finding and using community and other resources
- Advocacy for the protection of legal, civil and service rights
- Early intervention services for at risk infants and their families
- Genetic counseling
- Family support
- Planning, placement, and monitoring for 24-hour out-of-home care
- Training and educational opportunities for individuals and families
- Community education about developmental disabilities

Who Is Eligible For Services?

To be eligible for services, a person must have a disability that begins before the person's 18th birthday, be expected to continue indefinitely and present a substantial disability as defined in *Section 4512* of the *California Welfare and Institutions Code.* Specifically, that is a disability that originates before an individual turns 18, continues or can be expected to continue indefinitely, and constitutes a substantial disability for that individual. The disabilities include mental retardation, cerebral palsy, epilepsy, and autism. It also includes disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature.

"Substantial disability" means the existence of significant functional limitations in three or more of the following areas of major life activity, as determined by a regional center, and as appropriate to the age of the person:

(1) Self-care.
(2) Receptive and expressive language.
(3) Learning.
(4) Mobility.
(5) Self-direction.
(6) Capacity for independent living.
(7) Economic self-sufficiency.

Eligibility is established through diagnosis and assessment performed by regional centers.

Infants and toddlers (age 0 to 36 months) who are at risk of having developmental disabilities or who have a developmental delay may also qualify for services. The criteria for determining the eligibility of infants and toddlers is specified in *Section 95014* of the *California Government Code*(http://www.dds.ca.gov/statutes/GOVSectionView.cfm?Section=95014.htm). In addition, individuals at risk of having a child with a developmental disability may be eligible for genetic diagnosis, counseling and other prevention services. For information about these services, see Early Start

Information About Programs and Services

The Department of Developmental Services is responsible for designing and coordinating a wide array of services for California residents with developmental disabilities. Regional centers help plan, access, coordinate and monitor these services and supports.

A Person-Centered Planning approach is used in making decisions regarding where a person with developmental disabilities will live and the kinds of services and supports that may be needed. In person-centered planning, everyone who uses regional center services has a planning team that includes the person utilizing the services, family members, regional center staff and anyone else who is asked to be there by the individual. The team joins together to make sure that the services that people are getting are supporting their choices in where they want to live, how and with whom they choose to spend the day, and hopes and dreams for the future.

The following is a partial list of supportive services and living arrangements available for persons with developmental disabilities:

Day Program Services

Day programs are community-based programs for individuals served by a regional center. They are available when those services are included in that person's Individual Program Plan (IPP). Day program services may be at a fixed location or out in the community.

- Types of services available through a day program include:
- Developing and maintaining self-help and self-care skills.
- Developing the ability to interact with others, making one's needs known and responding to instructions.
- Developing self-advocacy and employment skills.
- Developing community integration skills such as accessing community services.
- Behavior management to help improve behaviors.
- Developing social and recreational skills.

There are many different types of day programs that provide a diverse range of opportunities for persons with developmental disabilities.

Education Services For Children with Developmental Disabilities

The public school system in California has an important role in providing services to children with developmental disabilities. In recent years, the California State Department of Developmental Services (DDS) and the California Department of Education (CDE) have become strong partners in providing early intervention services to children 0 - 3 years old and special education services to children 3 to 21 years old. Children with special needs who were served by California's Early Start Program (http://www.dds.ca.gov/EarlyStart/home.cfm) are able to enter public school programs as preschoolers if they satisfy the eligibility criteria as a child who can benefit from special education services. Local education agencies provide special education and related services to children with disabilities in environments including the home, school, public or private preschools or child care settings. Regional centers continue to provide some services for children who are eligible under the Lanterman Developmental Disabilities Services Act that are not provided as special education and related services.

More information about educational services for children with special needs can be obtained through local school districts, local education agency or Special Education Local Plan Area.

Work Services Program

The Work Services *(formerly Habilitation)* Program addresses the vocation needs of persons with developmental disabilities through a broad range of services directed toward developing the individual's maximum potential for mainstreaming into generic vocational rehabilitation programs. The Work Services Program provides both sheltered workshop services through Work Activity Programs and supported employment services. Work Services are available only to persons with developmental disabilities who are also Regional Center clients.

Supported Employment Services

Supported Employment (SE) services through the Department of Rehabilitation can be provided either through the vocational rehabilitation program or the HSP. SE services are aimed at finding competitive work in a *community integrated work setting* for persons with severe disabilities who need ongoing support services to learn and perform the work. SE placements can be individual placements, group placements (called enclaves), and work crews, such as landscaping crews. Support is usually provided by a job coach who meets regularly with the individual on the job to help him or her learn the necessary skills and behaviors to work independently. As the individual gains mastery of the job, the support services are gradually phased out.

The Department of Rehabilitation is the main SE service provider for adults with developmental disabilities. However, if they are unable to provide services due to fiscal reasons, the regional center may be able to help individuals served get a job by referring them to other programs that provide SE-like services, if these services are available in their area.

Work Activity Program Services

Work Activity Program (WAP) services through the Department of Rehabilitation include paid work, work adjustment and supportive habilitation services in a *sheltered work shop setting.* WAPs provide paid work in accordance with Federal and State Fair Labor Standards. Work adjustment services may include developing good work safety practices, money management skills, and appropriate work habits. Supportive habilitation services may include social skill and community resource training as long as the services are necessary to achieve vocational objectives.

Supported Services

Support services are provided to persons receiving services from a regional center in order to meet the goals and objectives of the Individual Program Plan (IPP) or the Individual Family Service Program (IFSP) (for children ages 0-3 years). Services may be provided through vendors approved by the regional center or through other resources.

Regional centers have a mandate not only to serve persons with developmental disabilities, but to provide services in the most cost-effective manner possible. They are required by the Lanterman Act to use all other resources or generic resources first before using regional center funds. A generic agency is one which has a legal responsibility to serve all members of the general public and receives public funds for providing those services. Other resources include natural supports, school districts, etc.

In-Home Supportive Services

In-Home Supportive Services (IHSS) provides personal care and domestic services to persons who are aged, blind or disabled and who live in their own homes. IHSS is provided to those who otherwise might be placed in an out-of-home care facility but who can safely remain in their own home if IHSS services are received.

Regional centers have a mandate not only to serve persons with developmental disabilities, but to provide services in the most cost-effective manner possible. They are required by the Lanterman Act to use all other sources of funding and services before using regional center funds to provide services. Persons who receive services from a regional center and are eligible for IHSS are expected to use IHSS services available to them.

The In-Home Supportive Services (IHSS) program is administered by each county with oversight by the California Department of Social Services (CDSS). For application and eligibility information contact local county welfare department, adult services section. Look for them in the county government section of the local telephone directory.

Supported Living Services

Supported Living Services (SLS) consist of a broad range of services to adults with developmental disabilities who, through the Individual Program Plan (IPP) process, choose to live in homes they themselves own or lease in the community. SLS may include assistance with selecting and moving into a home; choosing personal attendants and housemates; acquiring household furnishings; common daily living activities and emergencies; becoming a participating member in community life; managing personal financial affairs, as well as other supports.

These services help individuals exercise meaningful choice and control in their daily lives, including where and with whom to live. SLS is designed to foster individuals' nurturing relationships, full membership in the community, and work toward their long-range personal goals. Because these may be life-long concerns, Supported Living Services are offered for as long and as often as needed, with the flexibility required to meet a persons' changing needs over time, and without regard solely to the level of disability. Typically, a supported living service agency works with the individual to establish and maintain a safe, stable, and independent life in his or her own home. But it is also possible for some individuals to supervise their services themselves, to secure the maximum possible level of personal independence.

The guiding principles of SLS are set down in Section 4689(a) of the Lanterman Act (http://www.dds.ca.gov/Statutes/WICSectionView.cfm?Section=4685-4689.7.htm). The Department's regulations for SLS are found in Title 17, Division 2, Chapter 3, Subchapter 19 (Sections 58600 et seq) (http://www.dds.ca.gov/title17/T17sectiontoc.cfm?SubchapterID=34)of the California Code of Regulations (CCR).

Individuals who choose to live in their own homes, and their agencies or other people who support them, often will need information about affordable housing options, sources of financial support such as Supplementary Security Income (SSI), and how to stretch a limited budget to meet living expenses. These are the ordinary challenges that are inseparable from a truly self-directed life in the community. For the many adults for whom SLS makes great sense, such challenges are often also road signs on the path to a satisfying life.

Family Home Agency

A Family Home Agency (FHA) approves family homes which offer the opportunity for up to two adult individuals with developmental disabilities per home to reside with a family and share in the interaction and responsibilities of being part of a family. The individual with developmental disabilities receives the necessary service and supports from the family, agencies and the community to enable the individual to be a participating member of the family and the community where the family resides. The family home arrangement allows the sharing of food, shelter, experience, responsibilities and love.

The FHA is a private, nonprofit organization under contract to, and vendored by a regional center. FHAs are responsible for recruiting, training, approving and monitoring family homes, as well as providing ongoing support to family homes. Social service staff employed by the FHA make regular visits to the family home to ensure that necessary services and supports are in place, and that the match between the family and the new family member is viable, and continues to be viable.

FHA and family home services and supports are a new option which enables adults with developmental disabilities to enter into partnerships with families that promote self-determination and interdependence.

Independent Living

Independent Living is a service provided to adults with developmental disabilities that offers functional skills training necessary to secure a self-sustaining, independent living situation in the community and/or may provide the support necessary to maintain those skills. Individuals typically live alone or with roommates in their own homes or apartments. These homes are not licensed.

Independent living programs, which are vendored and monitored by regional centers, provide or coordinate support services for individuals in independent living settings. They focus on functional skills training for adults who generally have acquired basic self-help skills or who, because of their physical disabilities, do not possess basic self-help skills, but who employ and supervise aides to assist them in meeting their personal needs.

Foster Family Agency

Foster Family Agencies (FFAs) are residential options for children with developmental disabilities, that represent a collaborative effort between two service systems - developmental disabilities and social services/community care licensing. FFAs are privately operated organizations licensed by the Community Care Licensing Division of the State Department of Social Services to care for children up to age 18 in certified foster family homes. FFAs are responsible for the recruitment, training and certification of families to provide alternative homes for children. FFAs monitor and provide oversight for the homes they have certified, and have the authority to decertify homes when necessary. In addition, through the

use of professional staff such as social workers, FFAs provide ongoing support to certified parent(s) and the children who live with them.

Professional foster care allows the family and/or those who know the child the best to pick and choose the best support system for the child and wrap services around the child rather than have the child fit into whatever services, i.e. group home, are available. The child is living in a "normal" way - the child lives in a family, in a neighborhood and interacts with other children living the same way. The child has as much contact with the family of origin as the family chooses. The foster home, in the most ideal situation, becomes an extension of the family system.

Respite (In-Home) Services

Respite (In-Home) Services means intermittent or regularly scheduled temporary non-medical care and/or supervision provided in the person's home. In-Home Respite services are support services which typically include:

- Assisting the family members to enable a person with developmental disabilities to stay at home;
- Providing appropriate care and supervision to protect that person's safety in the absence of a family member(s);
- Relieving family members from the constantly demanding responsibility of providing care; and
- Attending to basic self-help needs and other activities that would ordinarily be performed by the family member.

Respite (Out-of-Home) Services are provided in licensed residential facilities.

Respite services typically are obtained from a respite vendor, by use of vouchers and/or alternative respite options. Vouchers are a means by which a family may choose their own service provider directly through a payment, coupon or other type of authorization.

Transportation services

Transportation services are provided so persons with a developmental disability may participate in programs and/or other activities identified in the IPP. A variety of sources may be used to provide transportation including: public transit and other providers; specialized transportation companies; day programs and/or residential vendors; and family members, friends, and others. Transportation services may include help in boarding and exiting a vehicle as well as assistance and monitoring while being transported.

Community Care Facilities

Community Care Facilities (CCFs) are licensed by the Community Care Licensing Division of the State Department of Social Services to provide 24-hour non-medical residential care to children and adults with developmental disabilities who are in need of personal services, supervision, and/or assistance essential for self-protection or sustaining the activities of daily living. Based upon the types of services provided and the persons served, each CCF vendored by a regional center is designated one of the following service levels:

- SERVICE LEVEL 1: Limited care and supervision for persons with self-care skills and no behavior problems.

- SERVICE LEVEL 2: Care, supervision, and incidental training for persons with some self-care skills and no major behavior problems.

- SERVICE LEVEL 3: Care, supervision, and ongoing training for persons with significant deficits in self-help skills, and/or some limitations in physical coordination and mobility, and/or disruptive or self-injurious behavior.

- SERVICE LEVEL 4: Care, supervision, and professionally supervised training for persons with deficits in self-help skills, and/or severe impairment in physical coordination and mobility, and/or severely disruptive or self-injurious behavior. Service Level 4 is subdivided into Levels 4A through 4I, in which staffing levels are increased to correspond to the escalating severity of disability levels.

Intermediate Care Facilities and Program Types (ICF/DD, ICF/DD-H, ICF/DD-N, ICF/DD-CN)

Intermediate Care Facilities (ICF) are health facilities licensed by the Licensing and Certification Division of the California Department of Health Services to provide 24-hour-per-day services. The four types of ICFs providing services for Californians with developmental disabilities in the community are:

ICF/DD (Developmentally Disabled)
"Intermediate care facility/developmentally disabled" is a facility that provides 24-hour personal care, habilitation, developmental, and supportive health services to developmentally disabled clients whose primary need is for developmental services and who have a recurring but intermittent need for skilled nursing services.

ICF/DD-H (Habilitative)
"Intermediate care facility/developmentally disabled-habilitative" is a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, habilitation, developmental, and supportive health services to 15 or fewer developmentally disabled persons who have intermittent recurring needs for nursing services, but have been certified by a physician and surgeon as not requiring availability of continuous skilled nursing care.

ICF/DD-N (Nursing)
"Intermediate care facility/developmentally disabled-nursing" is a facility with a capacity of 4 to 15 beds that provides 24-hour personal care, developmental services, and nursing supervision for developmentally disabled persons who have intermittent recurring needs for skilled nursing care but have been certified by a physician and surgeon as not requiring continuous skilled nursing care. The facility shall serve medically fragile persons who have developmental disabilities or demonstrate significant developmental delay that may lead to a developmental disability if not treated.

ICF/DD-CN (Continuous Nursing) Pilot Program
These facilities provide services similar to ICF/DD-N services with the addition of 24-hour skilled nursing services (licensed vocational nurse and registered nurse) for those consumers whose medical conditions require continuous nursing care and observation. The ICF/DD-CN facilities provide these services for 4-15 consumers in a community-based living arrangement, with preference given to facilities serving 4-6 individuals. The pilot project is currently limited to selected participants and no new facilities are currently being developed.

Source: California Health & Safety Code, Chapter 2. Health Facilities, Article 1, Section 1250-1263: www.leginfo.ca.gov

National Institutes of Health
The Nation's Medical Research Agency

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 as well.

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.[2]

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.

National Institutes of Health
The Nation's Medical Research Agency

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.

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The Nation's Medical Research Agency

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National Institutes of Health
The Nation's Medical Research Agency

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:

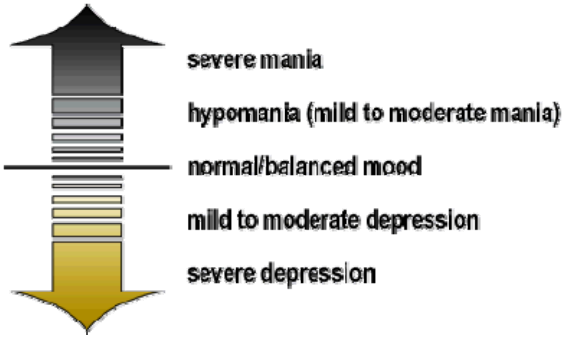
- Lasting sad, anxious, or empty mood
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Loss of interest or pleasure in activities once enjoyed, including sex
- Decreased energy, a feeling of fatigue or of being "slowed down"
- Difficulty concentrating, remembering, 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.

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.

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) .

National Institutes of Health
The Nation's Medical Research Agency

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.

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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

The information is presented to inform IHSS social workers about mental illness conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

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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

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For More Information

Depression Information and Organizations from NLM's MedlinePlus
http://www.nlm.nih.gov/medlineplus/depression.html (also in Spanish)

NIH Publication No. 4593
Revised April 2007

The information is presented to inform IHSS social workers about mental illness conditions. It is not meant to contradict any information the consumer may receive from their personal physician. **All IHSS assessments should be individualized and are not diagnosis specific.**

Personality Disorder Types

The personality disorders defined by *DSM-IV* are as follows:

Paranoid
Patients with paranoid personality disorder are characterized by suspiciousness and a belief that others are out to harm or cheat them. They have problems with intimacy and may join cults or groups with paranoid belief systems. Some are litigious, bringing lawsuits against those they believe have wronged them. Although not ordinarily delusional, these patients may develop psychotic symptoms under severe stress. It is estimated that 0.5-2.5% of the general population meet the criteria for paranoid personality disorder.

Schizoid
Schizoid patients are perceived by others as "loners" without close family relationships or social contacts. Indeed, they are aloof and really do prefer to be alone. They may appear cold to others because they rarely display strong emotions. They may, however, be successful in occupations that do not require personal interaction. About 2% of the general population has this disorder. It is slightly more common in men than in women.

Schizotypal
Patients diagnosed as schizotypal are often considered odd or eccentric because they pay little attention to their clothing and sometimes have peculiar speech mannerisms. They are socially isolated and uncomfortable in parties or other social gatherings. In addition, people with schizotypal personality disorder often have oddities of thought, including "magical" beliefs or peculiar ideas (for example, a belief in telepathy or UFOs) that are outside of their cultural norms. It is thought that 3% of the general population has schizotypal personality disorder. It is slightly more common in males. Schizotypal disorder should not be confused with schizophrenia, although there is some evidence that the disorders are genetically related.

Antisocial
Patients with antisocial personality disorder are sometimes referred to as sociopaths or psychopaths. They are characterized by lying, manipulativeness, and a selfish disregard for the rights of others; some may act impulsively. People with antisocial personality disorder are frequently chemically dependent and sexually promiscuous. It is estimated that 3% of males in the general population and 1% of females have antisocial personality disorder.

Borderline
Patients with borderline personality disorder (BPD) are highly unstable, with wide mood swings, a history of intense but stormy relationships, impulsive behavior, and confusion about career goals, personal values, or sexual orientation. These often highly conflictual ideas may correspond to an even deeper confusion about their sense of self (identity). People with BPD frequently cut or burn themselves, or threaten or attempt suicide. Many of these patients have histories of severe childhood abuse or neglect. About 2% of the general population have BPD; 75% of these patients are female.

Histrionic
Patients diagnosed with this disorder impress others as overly emotional, overly dramatic, and hungry for attention. They may be flirtatious or seductive as a way of drawing attention to themselves, yet they are emotionally shallow. Histrionic patients often live in a romantic fantasy world and are easily bored with routine. About 2-3% of the population is thought to have this disorder. Although historically the disorder has been more associated with womenin clinical settings, there may be bias toward diagnosing women with the histrionic personality disorder.

Narcissistic
Narcissistic patients are characterized by self-importance, a craving for admiration, and exploitative attitudes toward others. They have unrealistically inflated views of their talents and accomplishments, and may become extremely angry if they are criticized or outshone by others. Narcissists may be professionally successful but rarely have long-lasting intimate relationships. Fewer than 1% of the population has this disorder; about 75% of those diagnosed with it are male.

Avoidant
Patients with avoidant personality disorder are fearful of rejection and shy away from situations or occupations that might expose their supposed inadequacy. They may reject opportunities to develop close relationships because of their fears of criticism or humiliation. Patients with this personality disorder are often diagnosed with dependent personality disorder as well. Many also fit the criteria for social phobia. Between 0.5-1.0% of the population have avoidant personality disorder.

Dependent
Dependent patients are afraid of being on their own and typically develop submissive or compliant behaviors in order to avoid displeasing people. They are afraid to question authority and often ask others for guidance or direction. Dependent personality disorder is diagnosed more often in women, but it has been suggested that this finding reflects social pressures on women to conform to gender stereotyping or bias on the part of clinicians.

Obsessive-compulsive

Patients diagnosed with this disorder are preoccupied with keeping order, attaining perfection, and maintaining mental and interpersonal control. They may spend a great deal of time adhering to plans, schedules, or rules from which they will not deviate, even at the expense of openness, flexibility, and efficiency. These patients are often unable to relax and may become "workaholics." They may have problems in employment as well as in intimate relationships because they are very stiff and formal, and insist on doing everything their way. About 1% of the population has obsessive-compulsive personality disorder; the male/female ratio is about 2:1.

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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.

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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)

http://understanding_ocd.tripod.com/hoarding.html

Frost & Hartl's ('96) 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 which results in people keeping large amounts of items that to the outside world are considered excessive or worthless/useless. It is also still being researched much and surrounded with much secrecy and shame.

Is important to realize however that Hoarding isn't solely linked or associated to OCD, and can be found independently but cause equal distress.

Many Elderly people deal with Hoarding and may have had a life- time of accumulating stuff that gradually got worse as they got older. Often this leaves the by then grown- up children to deal or face with the actions of their elderly parents.

- Hoarding & Saving Symptoms are found in 18% to 42% of OCD patients. But 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, such as.: Anorexia Nervosa, Dementia and sometimes Psychotic Disorders.
  The differences between these types are not known yet.

- 4 keywords that are found when talking about Hoarding are: Indecisiveness, Perfectionism, Procrastination, and Avoidance.

- This is a symptom that is known to be difficult to treat, especially if there is little willingness to change.

- The usual medications that can help with/for many other OCD- symptoms seem to be less effective for treating hoarding. Same goes for the ERP that is traditionally used to treat OCD when it comes to therapies. But an adapted form of ERP is being developed of which the results will still have to be looked in to more thoroughly.

- The primary reasons for Hoarding are biologically based rather than psychological. But studies (By Dr. Randy Frost.) have shown that no real cause can be determined yet.
- BT (Behavior Therapy.) does prove to show some benefits. But like mentioned above, do Hoarders not benefit greatly from the traditional treatments for OCD.

For those who hoard, it creates a vicious circle in which they almost literally become trapped. The mess will or can become so dominant that their self- esteem and social life will/may suffer from it. Simple things such as no longer feeling they can invite people over and with that, an important motivation for people to keep their house clean will disappear.

Of course, Hoarding like any other aspects of OCD, exists in different degrees.
But the severe cases of Hoarding may truly devastate a person's life if no help is sought.

They feel shame and this shame will gradually evolve into isolation.
Hiding one's behavior seems to be the only possible solution. But how do you hide sometimes very omni- present and visible clutter/mess from the outside world. You can't, so you have to resort to blocking out the outside world from your inside world.

Living amongst "junk" is not accepted in our society. Hoarding labels a person to be without any discipline, a person that is messy and it's not just that.

This is a real disorder, not someone that is just unwilling because they are lazy.

(Living in a messy surrounding will in most cases means something isn't going right. This may be a depression, a lack of self- respect or no reason for caring anymore. So looking into the Why's of excessive mess may be helpful.).

THE DIFFERENCE BETWEEN A HOARDER AND A CLUTTERER.

While both terms are used to denote someone who accumulates many things to the point of it becoming a problem there still is a difference.

Hoarder:

- Someone who Hoards has psychiatric condition that affects less than 1 % of the population.
- The person obsesses over his 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. They will not take out trash and will often keep about anything.

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. They will be able to take out trash and throw things away if given enough reason.

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THE POSSIBLE CAUSES OF OCHD.

People easily jump to the conclusion that people who Hoard must have some background in which they have been deprived of material things, which would seem logical or rather give an explanation 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, they did find that there seems to be a tendency for Hoarders to report some material deprivation. Since the studies were unable to make a clear enough relationship between both it is considered to be only a minor factor.

There is also a whole range or reasons of why people Hoard, such as finding it difficult to make decisions, finding it difficult to categorize, finding it difficult to give a clear value to an object.

What could be a plausible factor are the parents displaying some Hoarding Problems. It also appears that OCD can be prevalent in families. Whether this adds up to Hoarding being Genetically determined is not yet proven, nor whether it's a Learned Behavior or the combination of both.

In all, this is clearly a disorder that has yet to be thoroughly researched. Little is really known in a factual way but people are trying to find out more and more about the whys and as importantly about how help can be given.

WHY PEOPLE HOARD.

Simplified Hoarding is about the fear of throwing something away that you might need someday, of not being able to remember it perfectly or that if thrown away it will cause a problem or that something bad may happen.

While many people keep things around them for a variety of reasons, is Hoarding a normal behavior become excessively present, creating more discomfort than it could/should be creating comfort.

The accumulation of material goods doesn't create material comfort but will instead result in a discomfort that may disrupt their life on all levels. People will often say: “Typical, just after I finally threw that item away I found a use for it or needed it a few days later." But rarely do they end up living in a house where small paths have to be created to be able to walk around.

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The following reasons of why people Hoard are all closely linked, but although similar they still have distinct differences.

SENTIMENTAL VALUE.

- Now you would expect for these things that are kept to have a purpose, to be meaningful or valuable. But for the person that Hoards, **the usefulness and/or value may lay in the most unexpected things. Sentimental value** is only 1 of the criteria to keep just about anything. This value is also about feeling the item is part of "you", not just an independent object.
  MISCONCEPTION: The moment I discard of this item I discard a part of myself.

DECISION MAKING.

- The "What If's" that are so typical of OCD are found here too. 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 1 day? Where is the harm in keeping just this 1 extra thing?"

  Not having to make the decision of discarding something literally means that they can't make any mistakes while doing so. Sounds simple enough, but how better to avoid making mistakes than to yes, avoid doing things, making decisions.
  You can't do anything wrong if you don't do anything. Those who don't try can't fail.
  MISCONCEPTION: The moment I decide to throw something away I may be making the wrong choice.

ORGANIZING.

- There is also the difficulty with knowing how to organize objects, not being able to see how you would possibly store them in a logical fashion (Which is ironic considering the visual chaos that is created by the Hoarder). But while this chaos may be painfully apparent for outsiders, the hoarder himself often finds some logic in this. To him a pile of junk may very well be the only way he can sense some control and order. If only because the pile will literally be created by stacking what is most important 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.

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RESPONSIBILITY.

- As you may see in OCD, you also have a tendency for people 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 being carried around with them at all times. For example: Hauling a huge purse around that could easily knock anybody out.
- But you also have the obligation of HAVING to use a certain item. Discarding seems to be wasting something and this is why so many items will later on be categorized under "Recycling", "Giving Away" and so on.
  MISCONCEPTION: The moment my object has a use, I have to keep/use it so it doesn't get wasted.

CONTROL/PERFECTION.

- Then you have **the issue of Control/Perfectionism**, again so present when looking at OCD. The fact that when you throw something away, it's gone and once the trash will be picked up you will never be able to find this item again.
  MISCONCEPTION: The moment you decide to throw something away, you no longer are the person in control and what happens to this item will be in the hands of others.

SCARED OF FORGETTING/PERFECTION.

- Because of **the fear of forgetting** and the inability to accept that we can't be in total control, items will be kept so that with written/printed material for instance, it can be re- read at all times.

  Some will find themselves looking through the garbage, checking if they haven't thrown out something they shouldn't have or resort in writing information down what they see in every- day life, such as license- plate #'s, to make sure the information won't be forgotten. The inability to remember all, becomes the behavior of keeping all within "arm- reach".

- Hoarders have been noted to have a greater sense of Perfection than non- Hoarders and will even *expect* this Perfection whereas others may *strive* for Perfection.
  MISCONCEPTION: The moment you throw something away, you may forget it's content or the way it looked and it will be gone forever.

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LETTING GO OF THINGS.

- A motivation to Hoard can be the **fear of letting go, of 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 loosing things that had even a remotely sentimental value to me, scared me. Because there would be no turning back, 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.
  All part of being afraid of death."

- Letting go of things in life is so needed if we want to experience some sense of freedom, but for someone with OCD this means letting go of the control wanted so badly.
  Items became part of who the person is, thus letting go would be letting go of them self.
  MISCONCEPTION: The moment you throw something away, you let go of that specific part of your life, however insignificant it may be.

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

By Jason Adamek, MSW, LCSW

2005

Introduction

What is a mental illness? It is defined by the American Psychiatric Association as being a "clinically significant behavioral or psychological syndrome or pattern that occurs in an individual and that is associated with present distress or disability or with a significantly increased risk of suffering death, pain, disability, and/or important loss of freedom" (APA, 2000).

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 illness 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 depression, 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 depression may exhibit different deficits. One person with depression 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 depression can be related to a physical condition. For instance, someone who can not go shopping because they are physically disabled may also be depressed because of the impairment. As a consequence, this person's depression may affect their ability to do simple tasks such as cooking and grooming.

There is great stigma attached to mental illness. Much of society believes that mental illness 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 illnesses 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 illness the consumer is experiencing.

Substance Abuse and Mental Illness 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 illness also have a substance abuse problem (National Mental Health Association, n.d.) A person who use 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 depression, 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 depression 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 can not 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 Disorder

Bipolar Disorder, otherwise known as manic-depression, is a mental disorder that consists of depressive and manic episodes. The American Psychiatric Association classifies people with bipolar symptoms in four different categories (American Psychiatric Association, 2000). 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 elevated or irritable mood for at least a week. This mood may include a decreased need for sleep, an inflated self-esteem, 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 be dangerous, such as buying sprees, gambling, or sexual activity abnormal for this person (American Psychiatric Association, 2000). When this manic episode bottoms out, the consumer will usually be depressed. This depression 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 illness 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 state 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, it can be worse than for a person with general depression. This depression 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 state 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 depression 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). 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 express 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 Disorder

Characteristics

- Consumer will have both manic and depressive episodes.
- Mania includes elevated or irritable mood, racing thoughts, and possible hallucinations or delusions.
- Someone who is manic may start unreasonable projects or engage in unsafe behavior. He/she may be charming or hostile.
- A person with mania 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 mania, or make mania worse.
- Eventually, mania turns into depression 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 severe mania may not have the ability or feel the need to keep their homes or their person clean.
- An elder consumer with mania may ambulate beyond their normal abilities, causing a risk of falling.
- A consumer with mania 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 mania drops out and becomes depression, consumers will have problems with more ADL/IADLS.
- Depression 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.

Depression

Depression 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. This depression can be observable by other people, noticing the person may be tearful or even irritable. The person has limited interest in activities and he/she may have difficulty sleeping or may be sleeping to an excessive amount. A person may have a loss of appetite which causes weight loss, have difficulty concentrating, and have a diminished ability to make decisions. A person may also have feelings of worthlessness or express excessive guilt about a certain action. In addition, they may appear to either be physically restless or slowed down (American Psychiatric Association, 2000).

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 illness, 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 depression 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 depression 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 depression, 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 Depression

Though your job as an IHSS worker is not to provide therapy to a client with depression, 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.

Depression

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 control over his/her emotions (American Psychiatric Association, 2000). 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 gambling, spending, sex, or substance abuse (American Psychiatric Association, 2000). 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.

IHSS Functional Limitations

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 illnesses. 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 Behaviors

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

Characteristics

- Hoarding behavior can occur at any age, but may be related to more than just obsessive-compulsive traits as a person ages.
- 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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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 1997. 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 denied 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 denied Protective Supervision 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 cannot be denied 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.

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:	PATIENT'S DOB: / /
	MEDICAL ID#: (IF AVAILABLE)	COUNTY ID#:
	IHSS SOCIAL WORKER'S NAME:	
	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:	MEDICAL SPECIALTY:	DATE:
ADDRESS:	LICENSE NO.:	TELEPHONE: ( )

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

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.

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

(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]).

IHSS Training Academy
Special Areas in IHSS

Day 2

Protective Supervision Eligibility

Regulations

[MPP 30-757-.17]

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

Regulations

[MPP 30-757.171 (a)(1-3)]
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; and
(3) Voluntary resources.

[MPP 30-757.174]

- 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 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.

Protective Supervision is NOT available under the following conditions:

[MPP 30-757.172 (a-e)]

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.

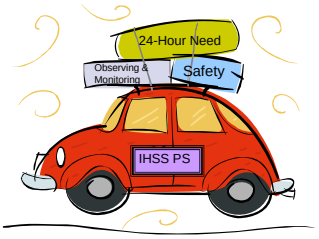
Lawsuits that Affect PS

- 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

Memory/Orientation/Judgment

- FI 5 in all three areas does not necessarily mean consumer will need PS.
- CMIPS will give soft edit if total of the 3 is 7 or more.
- This is a question for consideration – not a hard edit.

Remember: The Need for Protective Supervision is *NOT* Diagnosis Driven



Assessment of Need for Protective Supervision Form [MPP 30-757.173(a)(1-4)]


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

Factors that Affect Calculation of Protective Supervision Hours

- PCSP / Waiver / Residual
- NSI and SI
- Number of recipients in household
- Number of recipients receiving PS
- Alternative resources

Calculation of Protective Supervision Hours

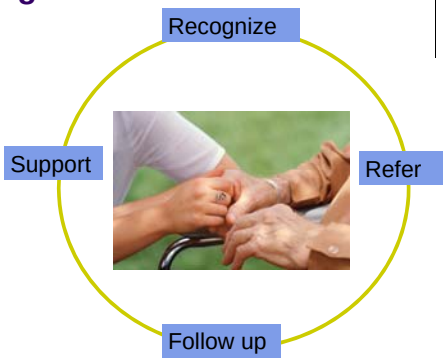
Removing Services

- 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.

Other Resources for People Who Do Not Qualify for Protective Supervision

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

Caregiver Issues



Activity: Protective Supervision

Assessing the Needs of People with Severe Disabilities

- Asking the hard questions (digging for the actual need)
- Screening for other issues
- Assessing need for alternative resources

Exercise: Complex Medical

- Within your group, read and discuss the scenario and questions.
- Report the group's responses to the questions.
- Include further actions / needs for referral in your response.

PUZZLE EXERCISE

Thanks For Your Participation!

Please complete the evaluation.

IHSS Training Academy

GUIDE TO CALCULATING PROTECTIVE SUPERVISION HOURS

This guide is intended to provide guidance on the calculation of PS hours in the most common types of cases. If further guidance is required on types of cases not contained in this guide, designated county staff should contact the California Department of Social Services (CDSS) Policy Analyst assigned to their county.

Table of Contents

Protective Supervision Concepts

- A 24-hour need exists for PS.

  - ***168 hours per week =*** 24 hours per day x 7 days per week.
  - Total Need Column on SOC 293 will always be 168.

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

- Entire 24-hour need must be met by combination of IHSS and alternative resources.

  - Unmet Need Column on SOC 293 will always be zero.

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00					**0**	

- Adjustment Column is total of **all** other authorized services to the household.

  - If recipients live alone, total Domestic and Other services are added and put in the Adjustment Column.
  - If recipient lives with one or more recipients who do not receive PS, **all** Domestic and Other service hours of **all** recipients are added and put in the Adjustment Column.

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**Total All Other IHSS Services**				0	

- No need for PS exists during time provider is in home to provide other IHSS services. [MPP 30-763.332]

  - This is why the Adjustments are subtracted to calculate the Individual Need and the Authorized for Purchase amounts.

- When two or more recipients are living together and both require PS, the total need shall be treated as a common need and prorated accordingly. [MPP 30-763.331]

Components for Exercise	
Severely Impaired	Consumer who receives 20.00 or more hours per week of services identified with * on grid portion of SOC 293.
Non-Severely Impaired	Consumer who receives fewer than 20.00 hours per week of services identified with * on grid portion of SOC 293.
PCSP	Services which are available for federal financial participation. PCSP Program became effective in 1993. In 2004, CDSS received federal approval to add Protective Supervision (unless provided by parent of minor child or spouse of recipient) and cases with only Domestic and Related Services authorized to PCSP services.
IPW	Cases that receive federal financial participation through a Waiver granted by the Centers for Medicaid and Medicare in 2004 and include one or more of the following components: • Advance pay • Providers who are parents of minor children recipients • Providers who are spouses of recipients • Restaurant meal allowance
Residual	Cases that are not eligible for federal financial participation.

Factors that Affect Protective Supervision Calculation of Hours

- PCSP / IPW / Residual
- NSI and SI
- Number of recipients in the household
- Number of recipients receiving Protective Supervision in the household
- Alternative Resources (voluntary and/or formal)

Maximum IHSS Hours Available For Persons Who Need Protective Supervision

	Non Severely Impaired **(NSI)**	Severely Impaired **(SI)**
PCSP	195 hours monthly for PS ***Plus*** Other IHSS service hours up to a total of **283 hours monthly**	**283 hours monthly**
IPW or IHSS Residual	**195 hours monthly**	**283 hours monthly**

Important Numbers to Remember When Calculating PS

- 195 hours monthly = 45.03 hours weekly
- 283 hours monthly = 65.36 hours weekly
- 283 hours – 195 hours = 88 hours monthly
- 88 hours monthly = 20.32 hours weekly

Converting Monthly Hours To Weekly Hours

(Domestic, Heavy Cleaning, Remove Grass/Rubbish and Remove Ice/Snow)

- **It is necessary to convert monthly hours to weekly hours to complete the Adjustments Column of WW Line of SOC 293.**

Divide Individual Need by 4.33 or
Use Table Below When Appropriate

Monthly	Weekly
6.00	1.38
5.00	1.15
4.00	0.92
3.00	0.69
2.00	0.46
1.00	0.23
195.00	45.03
283.00	65.36
283.00 – 195.00 = 88.00	20.32

Example 1

- **One Consumer In Household Receiving IHSS**

- **This Consumer is NSI Residual or IPW**
  - Eligible for a total of **195 hours monthly (45.03 weekly)** services for *both* PS and other services.

- **This Consumer has the following Other Authorized Services:**
  - 3.00 hours per month for Domestic
  - 15.00 hours per week of other tasks

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - Convert 3.00 hours monthly Domestic to weekly hours [3.00 ÷ 4.33 = .69]
   - Add to 15.00 hours weekly Other non-PS IHSS services [.69 +15.00 = 15.69]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**15.69**					

3. **Calculate Individual Need**
   - Total Need - Adjustment = Individual Need [168.00 – 15.69 = 152.31]
   - This represents the amount of weekly hours this consumer will need to meet the need for 24-hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	15.69	**152.31**				

4. Calculate PS <u>Authorized To Purchase</u>

- Since this consumer is eligible for a total of **195** hours monthly of IHSS, the number of weekly hours available is **45.03** per week.
- Since regulations provide that no need for PS exists during time provider is in the home to provide other services [MPP 30763.332], the other IHSS hours are subtracted from 45.03 to arrive at PS hours authorized to purchase.
- Maximum IHSS Hours – Adjustments = Authorized to Purchase
  [45.03 – 15.69 = 29.34]

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	15.69	152.31		**29.34**		

Note: PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 152.31.
- IHSS is authorizing 29.34 PS to purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [152.31 – 29.34 = 122.97]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	15.69	152.31	**122.97**	29.34		

6. Enter <u>Unmet Need</u>

- Unmet Need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	15.69	152.31	122.97	29.34	**0**	

Note: The case file should contain documentation regarding how the 24-hour need is being met.

Example 2

- **One Consumer In Household Receiving IHSS**

- **This Consumer is NSI PCSP**
  - Eligible for a total of 195 hours PS ***Plus*** Other IHSS hours up to a total of **283 hours per month (65.36 weekly)**

- **This Consumer has the following Other Authorized Services:**
  - 3.00 hours per month for Domestic
  - 15.00 hours per week of other tasks

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - Convert 3.00 hours monthly Domestic to weekly hours [3.00 ÷ 4.33 = .69]
   - Add to 15.00 hours weekly Other non-PS IHSS services [.69 +15.00 = 15.69]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**15.69**					

3. **Calculate Individual Need**
   - Total Need - Adjustment = Individual Need [168.00 – 15.69 = 152.31]
   - This represents the amount of weekly hours this consumer will need to meet the need for 24-hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	15.69	**152.31**				

4. Calculate PS <u>Authorized To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Since this consumer is eligible for a total of 195 monthly hours of PS ***plus*** other IHSS hours up to a total of 283 monthly, **45.03** weekly hours of PS are available ***in addition*** to other services.
- This consumer can receive 15.69 hours of other IHSS <u>plus</u> 45.03 weekly hours of PS, for a total of 60.72 weekly, or 263 monthly hours of IHSS.
- Therefore, you enter 45.03 in the Authorize to Purchase Column.

Note:

- Most NSI PCSP will receive between 195 – 283 total hours IHSS.
- If a NSI PCSP consumer has greater than 20.32/week of other IHSS services in the Adjustments Column of the WW line, it will mean that they will receive 283/month of IHSS.
- If a NSI PCSP consumer has greater than 20.32/week in Adjustments Column, follow instructions for calculating hours for SI Consumers.

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	15.69	152.31		**45.03**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 152.31.
- IHSS is authorizing 45.03 weekly hours PS to purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [152.31 – 45.03 = 107.28]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	15.69	152.31	**107.28**	45.03		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	15.69	152.31	107.28	45.03	**0**	

Note: The case file should contain documentation regarding how the 24-hour need is being met.

Example 3

- **One Consumer In Household Receiving IHSS**

- **This Consumer is SI (PCSP, IPW or Residual)**
  - Eligible for a total of **283 hours monthly (65.36 hours weekly)**
  - When consumer is SI, the program does not matter; total hours available is always 283 hours monthly.

- **This Consumer has the following Other Authorized Services:**
  - 3.00 hours per month for Domestic
  - 35.00 hours per week of other tasks

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - Convert 3.00 hours monthly Domestic to weekly hours [3.00 ÷ 4.33 = .69]
   - Add to 35.00 hours weekly Other non-PS IHSS services [.69 +35.00 = 35.69]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**35.69**					

3. **Calculate Individual Need**
   - Total Need - Adjustment = Individual Need [168.00 – 35.69 = 132.31]
   - This represents the amount of weekly hours this consumer will need to meet the need for 24-hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	35.69	**132.31**				

4. Calculate PS <u>Auth. To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resources hours necessary to meet 24-hour need can be determined.)

- Since this consumer is eligible for a total of **283** hours monthly of IHSS, the number of weekly hours available is **65.36** per week.
- Since regulations provide that no need for PS exists during time provider is in the home to provide other services [MPP 30763.332], the other IHSS hours are subtracted from 65.36 to arrive at PS hours authorized for purchase.
- Maximum IHSS Hours – Adjustments = Authorized to Purchase
  [65.36 – 35.69 = 29.67]

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	35.69	132.31		**29.67**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 132.31.
- IHSS is Authorizing 65.36 weekly hours PS for purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [132.31 – 29.67 = 102.64]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	35.69	132.31	**102.64**	29.67		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	35.69	132.31	102.64	29.67	**0**	

Note: The case file should contain documentation regarding how the 24-hour need is being met.

Example 4

- **Two or More Consumers In Household Receiving IHSS**

- **Only One Consumer Receiving PS**

- **This Consumer is NSI IPW or Residual**
  - Eligible for a total of **195 hours monthly (45.03 weekly)** services for *both* PS and other services.
  - Resides with another IHSS NSI IPW consumer who *does not* receive PS.

- **This example assumes both consumers receive care from One Provider.**

- **Other Authorized Services for this example:**
  - PS Consumer (A)
    - 2.00 hours of Domestic services
    - 15.00 hours of other IHSS
  - Non-PS Consumer (B)
    - 2.00 hours of Domestic services
    - 12.00 hours of other IHSS

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments –**
*****Differs from One Consumer Living In Household*****
   - The Adjustments Column should include the other IHSS hours of all other consumers in the household.
   - Regulations provide that no need for PS exists during time provider is in the home to provide other services [MPP 30763.332].
   - The number in the Adjustments Column is the result of adding Consumer A's total IHSS weekly hours to Consumer B's total IHSS weekly hours [15.46 +12.46 = 27.92]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**27.92**					

Note: If both Consumer A and Consumer B had their own providers, Consumer B's IHSS hours would not be included in the Adjustments column.

3. Calculate <u>Individual Need</u>

- Total Need - Adjustment = Individual Need [168.00 – 27.92 = 140.08]
- This represents the amount of weekly hours this consumer will need to meet the need for 24 hour/day Protective Supervision.
- Hours for Both Consumer A and B are subtracted because these are the total hours someone is already in the house providing services.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	27.92	**140.08**				

4. Calculate PS <u>Auth. To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Consumer A is eligible for a total of **195** hours monthly of IHSS, the number of weekly hours available is **45.03** per week.
- Only Consumer A's other IHSS hours are subtracted from 45.03 to arrive at PS hours authorized for purchase.
- Maximum IHSS Hours – Adjustments = Authorized to Purchase
  [45.03 – 15.46(Consumer A) = 29.57]

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	27.92	140.08		**29.57**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 140.08.
- IHSS is authorizing 29.57 weekly hours PS to purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [140.08 – 29.57 = 110.51]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	27.92	140.08	**110.51**	29.57		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	27.92	140.08	110.51	29.57	**0**	

Note: The case file should contain documentation regarding how the 24-hour need is being met.

Example 5

- **Two Consumers in Household both receiving IHSS with PS**

- **Both Consumers are NSI IPW**
  - **Each consumer** is eligible for a total of **195 hours monthly (45.03 weekly)** services for *both* PS and other services.

- **The Consumers are both minor children who receive services only from their parent.**

- **This example assumes that both consumers are receiving services from One Provider.**

- **Other Authorized Services for this example:**
  - PS Consumer A
    - 15.00 hours per week of non-PS tasks
  - PS Consumer B
    - 12.00 hours of non-PS tasks.
  - **Note:** Per the Age Appropriate Guideline Tool, minor children are F1 ranking and therefore should not receive domestic and related services.

Calculations to Complete the WW Line of SOC 293 for Consumer A:

(Consumer B's PS Hours would be calculated in the same manner as Consumer A's.)

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - When two or more recipients are living together and both require PS, the total need shall be treated as a common need and prorated accordingly. [MPP 30-763.331]
   - Divide Total Need (168) by the number of Consumers in the household –one household will not have more that 168 hours weekly Total Need
   - Add Consumer A's total weekly non PS hours (15.00) to one half of Total Need for Protective Supervision.
     [168.00 ÷ 2 = 84.00 + 15.00 = 99.00]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**99.00**					

3. Calculate <u>Individual Need</u>

- Total Need - Adjustment = Individual Need [168.00 – 99.00 = 69.00]
- This represents the amount of weekly hours this consumer will need to meet the need for 24 hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	99.00	**69.00**				

4. Calculate PS <u>Auth. To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Consumer A is eligible for a total of **195 hours monthly** of IHSS, the number of weekly hours available is **45.03** per week.
- Regulations provide that no need for PS exists during time provider is in the home to provide other services (MPP 30-763.332),
- *Only* Consumer A's other IHSS hours (15.00) are subtracted from 45.03 to arrive at PS hours authorized for purchase. This allows Consumer A to receive up to maximum services allowed.
  [45.03 – 15.00 = 30.03]

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	99.00	69.00		**30.03**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 69.00.
- IHSS is authorizing 30.03 weekly hours PS to purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [69.00 – 30.03 = 38.97]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	99.00	69.00	**38.97**	30.03		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	99.00	69.00	38.97	30.03	**0**	

Note: As illustrated in this example, a second consumer in the household receiving services from the same provider does not result in the consumers receiving fewer PS hours authorized for purchase than they would receive if they were the only consumer. After completing calculations, the end result is that there are fewer hours which must be provided without compensation (met through an Alternative Resource).

Example 6

- **Two Consumers in Household both receiving IHSS with PS**

- **Both Consumers are SI (PCSP, IPW or IHSS Residual)**
  - Each consumer eligible for a total of **283 hours monthly (65.36 hours weekly)**

- **This example assumes that both consumers are receiving services from the One Provider.**

- **Other Authorized Services for this example:**
  - PS Consumer A
    - 2.00 hours per month Domestic services
    - 25.00 hours per week of non-PS tasks
  - PS Consumer B
    - 2.00 hours per month of Domestic services
    - 25.00 hours of non-PS tasks

Calculations to Complete the WW Line of SOC 293 for Consumer A:

(Consumer B's PS Hours would be calculated in the same manner as Consumer A's.)

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168.

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - When two or more recipients are living together and both require PS, the total need shall be treated as a common need and prorated accordingly. [MPP 30-763.331]
   - Divide Total Need (168) by the number of Consumers in the household –one household will not have more that 168 hours weekly Total Need.
   - Add Consumer A's total weekly non PS hours (25.46) to one half of Total Need for Protective Supervision.
     [168.00 ÷ 2 = 84.00 + 25.46 = 109.46]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**109.46**					

3. Calculate <u>Individual Need</u>

- Total Need - Adjustment = Individual Need [168.00 – 109.46 = 58.54]
- This represents the amount of weekly hours this consumer will need to meet the need for 24-hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	109.46	**58.54**				

4. Calculate PS <u>Auth. To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Consumer A is eligible for a total of **283 hours monthly** of IHSS, the number of weekly hours available is **65.36** per week.
- Regulations provide that no need for PS exists during time provider is in the home to provide other services (MPP 30-763.332),
- *Only* Consumer A's other IHSS hours (25.46) are subtracted from 65.36 to arrive at PS hours authorized for purchase. This allows Consumer A to receive up to maximum services allowed.
  [65.36 – 25.46 = 39.90]

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	109.46	58.54		**39.90**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.
- This consumer's Individual Need for PS (Total Need minus Adjustments) is 58.54.
- IHSS is Authorizing 39.90 weekly hours PS for purchase.
- Individual Need - Authorized to Purchase = Alternative Resources
  [58.54 – 39.90 = 18.64]

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	109.46	58.54	**18.64**	39.90		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	109.46	58.54	18.64	39.90	**0**	

Note: As illustrated in this example, a second consumer in the household receiving services from the same provider does not result in the consumers receiving fewer PS hours authorized for purchase than they would receive if they were the only consumer. After completing calculations, the end result is that there are fewer hours which must be provided without compensation (met through an Alternative Resource).

Alternative Resources Concepts

- **Since PS is a 7 day per week, 24-hour need and IHSS covers only approximately 9 hours per day of services, alternative resources must provide some of the PS.**

- **Alternative resources can be Formal or Informal.**

  - Examples of Formal Alternative Resources include, but are not limited to, the following:

    - Adult Day Health Care programs
    - School
    - Sheltered Workshops
    - Senior Day Care

  - Examples of Informal Alternative Resources

    - Voluntary PS provided by a relative, neighbor or friend

- **The availability of formal alternative resources will usually not reduce the number of PS hours authorized for purchase.**

  - Even with the availability of formal alternative resources, family members or others will usually still have to provide hours without compensation. (See examples for exception)

- **If there are formal alternative resources available, or if the consumer has a large number of informal alternative resources, an additional step will be necessary to determine whether the existence of alternative resources will reduce the number of PS hours authorized for purchase.**

General Process for Calculations when Consumer has Alternative Resources for PS

1. **Add up Actual hours of available Alternative Resource(s).**

2. **Compare Actual to "Calculated" amount.**
   - Individual Need - Authorized to Purchase = Alternative Resources

3. **Use the larger of the two numbers in Alternative Resources Column.**

Example 7

- **One Consumer in Household Receiving IHSS with Alternative Resources for PS**

- **This Consumer is NSI PCSP**
  - Eligible for a total of 195 hours PS ***Plus*** Other IHSS hours up to a total of **283 hours per month (65.36 weekly)**

- **This Consumer has the following Other Authorized Services:**
  - 3.00 hours per month Domestic services
  - 11.00 hours per week of other tasks

- **This Consumer has the following Alternative Resources for PS:**
  - Attends Adult Day Health Care 6 hours per day, 3 days per week, and
  - is on the ADHC van an additional 45 minutes each way

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - Convert 3.00 hours monthly Domestic to weekly hours [3.00 ÷ 4.33 = .69]
   - Add to 11.00 hours weekly Other non-PS IHSS services [.69 +11.00 = 11.69]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**11.69**					

3. **Calculate Individual Need**
   - Total Need - Adjustment = Individual Need [168.00 – 11.69 = 156.31]
   - This represents the amount of weekly hours this consumer will need to meet the need for 24 hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	11.69	**156.31**				

4. Calculate PS <u>Authorized To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Since this consumer is eligible for a total of 195 monthly hours of PS ***plus*** other IHSS hours up to a total of 283 monthly, **45.03** weekly hours of PS are available ***in addition*** to other services.
- This consumer can receive 11.69 hours of other IHSS <u>plus</u> 45.03 weekly hours of PS, for a total of 56.72 weekly, or 246 monthly hours of IHSS.
- Therefore you enter 45.03 in the Authorize to Purchase Column

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	11.69	156.31		**45.03**		

5. Calculate <u>Alternative Resources</u>

This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.

- Because of the availability of formal alternative resources (ADHC), an **additional step** must be performed in the calculation process to determine whether the existence of alternative resources will reduce the hours authorized for purchase.

  1. **Add up Actual hours of available Alternative Resource(s)**
  2. **Compare Actual to "Calculated" amount**
     Individual Need - Authorized to Purchase = Alternative Resources
  3. **Use the larger of the two numbers in Alternative Resources Column**

- **Actual Hours**: Consumer spends 18 hours per week at ADHC, with an additional 4.50 hours per week spent being transported to and from ADHC. Therefore, total **Formal Alternative Resource hours available = 22.50 hours per week**.

- **Calculated Hours**: This consumer's Individual Need for PS (Total Need minus Adjustments) is 156.31. IHSS is Authorizing 45.03 weekly hours PS for purchase.
  Individual Need - Authorized to Purchase = Alternative Resources
  [156.31 – 45.03 = 111.28]

  - To determine whether the availability of formal resources will reduce the number of hours authorized for purchase, compare Formal Alternative Resource hours (22.50) to Alternative Resource hours necessary without considering ADHC hours (111.28).
  - **The larger of the two numbers, 111.28** should be entered in the Alternative Resource column of the WW line of the SOC 293 and the WW line should be calculated without regard to the hours available through ADHC.
  - **Hours Authorized for Purchase column stays the same –no recalculation of hours Authorized to Purchase is necessary.**

Total Need	Adj.	Individual Need	**Alt. Resources**	Auth. Purchase	Unmet Need	County Use
168.00	11.69	156.31	**111.28**	45.03		

6. Enter <u>Unmet Need</u>

- Unmet need must always = ZERO

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	**Unmet Need**	County Use
168.00	11.69	156.31	111.28	45.03	**0**	

Note: The case file should contain documentation regarding how the 24-hour need is being met. In this case the file should indicate the number of hours through ADHC (22.50 per week) as well as who is providing the other alternative resources necessary to meet the 24-hour need.

Example 8

- **One Consumer In Household Receiving IHSS with Large Number of Voluntary Alternative Resources for PS**

- **This Consumer is NSI PCSP**
  - Eligible for a total of 195 hours PS ***Plus*** Other IHSS hours up to a total of **283 hours per month (65.36 weekly)**

- **This Consumer has the following Other Authorized Services:**
  - 3.00 hours per month Domestic services
  - 11.20 hours per week of other tasks

- **This Consumer has the following Voluntary Alternative Resource for PS:**
  - Lives with daughter who is willing to provide Protective Supervision and other IHSS voluntarily when she is home from work.
  - Daughter works 6 hours per day, 5 days per week, and commutes an additional 30 minutes each way per day.
  - Another provider provides IHSS while she is at work –total of 11.89 hours of other tasks

Calculations to Complete the WW Line of SOC 293:

1. **Enter Total Need = 168.00**
   - Always 168 hours weekly because 24-hour care, 7 days a week = 168

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00						

2. **Calculate Adjustments**
   - Convert 3.00 hours monthly Domestic to weekly hours [3.00 ÷ 4.33 = .69]
   - Add to 11.20 hours weekly Other non-PS IHSS services [.69 +11.20 = 11.89]

Total Need	**Adj.**	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	**11.89**					

3. Calculate <u>Individual Need</u>

- Total Need - Adjustment = Individual Need [168.00 – 11.89 = 156.11]
- This represents the amount of weekly hours this consumer will need to meet the need for 24 hour/day Protective Supervision.

Total Need	Adj.	**Individual Need**	Alt. Resources	Auth. Purchase	Unmet Need	County Use
168.00	11.89	**156.11**				

4. Calculate PS <u>Authorized To Purchase</u>

(PS Hours Authorized to Purchase must be calculated <u>before</u> number of Alternative Resource hours necessary to meet 24-hour need can be determined.)

- Since this consumer is eligible for a total of 195 monthly hours of PS ***plus*** other IHSS hours up to a total of 283 monthly, **45.03** weekly hours of PS are available ***in addition*** to other services.
- This consumer can receive 11.89 hours of other IHSS <u>plus</u> 45.03 weekly hours of PS, for a total of 56.92 weekly or 246 monthly hours of IHSS.
- Therefore you enter 45.03 in the Authorize to Purchase Column

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	11.89	156.11		**45.03**		

5. Calculate <u>Alternative Resources</u>

- This is the number of hours which must be provided by Alternative Resources to meet the 24-hour PS Individual Need.

- Because of the availability of Voluntary Alternative Resources, **additional step** must be performed in the calculation process to determine whether the existence of alternative resources will reduce the hours authorized for purchase.

  1. **Add up Actual hours of available Alternative Resource(s)**
  2. **Compare Actual to "Calculated" amount**
     Individual Need - Authorized to Purchase = Alternative Resources
  3. **Use the larger of the two numbers in Alternative Resources Column**

- **Actual Hours**: Daughter works 6 hours per day, 5 days per week, and commutes an additional 30 minutes each way per day. Her total time out of the home each week is 35.00 hours. Total **Voluntary Alternative Resource hours available = 133.00 hours per week**. [168.00 – 35.00 = 133.00]

- **Calculated Hours**: This consumer's Individual Need for PS (Total Need minus Adjustments) is 156.11. IHSS would Authorize 45.03 weekly hours PS for purchase. Individual Need - Authorized to Purchase = Alternative Resources
  [156.11 – 45.03 = 111.08]

- To determine whether the availability of Alternative Resources will reduce the number of hours authorized for purchase, compare Voluntary Alternative Resource hours (133.00) to Alternative Resource hours necessary without considering those hours (111.08).
  - **The larger of the two numbers, 133.00** should be entered in the Alternative Resource column of the WW line of the SOC 293 and the Authorized for Purchase hours should be recalculated utilizing the hours available through the Alternative Resource.
  - **Hours Authorized for Purchase column would change to reflect the hours that the daughter wishes to provide voluntarily without compensation.**
  - Total Need minus the sum of Adjustments and Alternative Resources = the new Hours Authorized to Purchase.
    [168 – (11.89+133.00) = 23.11]

The WW line of the SOC 293 would then reflect the following:

Total Need	Adj.	Individual Need	Alt. Resources	**Auth. Purchase**	Unmet Need	County Use
168.00	11.89	156.11	133.00	**23.11**	0	

Note: The case file should contain documentation regarding how the 24-hour need is being met. In this case the file should indicate the number of hours that the daughter is providing voluntarily. A SOC-450 should be obtained from the daughter acknowledging that she is providing the services voluntarily and does not wish to be paid for them and placed in the case file.

Protective Supervision Calculations
Training Example 1

	Auth to Purch
AA Domestic	3.00
BB Meal Prep	3.50
CC Meal Cleanup	1.50
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	3.00
JJ Feeding	
KK Bed Bath	
LL Dressing	1.50
MM Menstrual	
NN Ambulation	1.00
OO Transfer	
PP Bathing	3.00
QQ Rubbing	
RR Prosthesis	
SS AccompMD	
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N
PCSP Y/N	N
IHSS to Comp/Wk.	
# PS Hsmates	
AltRes for PS	

Enter SI or NSI

This is the companion's total auth.
Number of housemates authorized PS
Hours/week PS AR

For ProtSup	On line WW, enter the following
Total Need	168
Adjustments	15.69
IndNeed	152.31
AltResource	122.97
Purchase	29.34

Protective Supervision Calculations
Training Example 2

	Auth to Purch
AA Domestic	3.00
BB Meal Prep	3.50
CC Meal Cleanup	1.50
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	3.00
JJ Feeding	
KK Bed Bath	
LL Dressing	1.50
MM Menstrual	
NN Ambulation	1.00
OO Transfer	
PP Bathing	3.00
QQ Rubbing	
RR Prosthesis	
SS AccompMD	
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N
PCSP Y/N	Y
IHSS to Comp/Wk.	
# PS Hsmates	
AltRes for PS	

Enter SI or NSI

This is the companion's total auth.
Number of housemates authorized PS
Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	15.69
IndNeed	152.31
AltResource	107.28
Purchase	45.03

Protective Supervision Calculations
Training Example 3

	Auth to Purch
AA Domestic	3.00
BB Meal Prep	3.50
CC Meal Cleanup	1.50
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	7.00
JJ Feeding	
KK Bed Bath	
LL Dressing	3.50
MM Menstrual	
NN Ambulation	3.50
OO Transfer	
PP Bathing	5.50
QQ Rubbing	3.50
RR Prosthesis	3.50
SS AccompMD	2.00
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	Y
PCSP Y/N	Y
IHSS to Comp/Wk.	
# PS Hsmates	
AltRes for PS	

Enter SI or NSI

This is the companion's total auth.
Number of housemates authorized PS
Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	35.69
IndNeed	132.31
AltResource	102.64
Purchase	29.67

Protective Supervision Calculations
Training Example 4

	Auth to Purch
AA Domestic	2.00
BB Meal Prep	3.50
CC Meal Cleanup	1.00
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	3.50
JJ Feeding	
KK Bed Bath	
LL Dressing	3.50
MM Menstrual	
NN Ambulation	2.00
OO Transfer	
PP Bathing	
QQ Rubbing	
RR Prosthesis	
SS AccompMD	
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N
PCSP Y/N	N
IHSS to Comp/Wk.	12.46
# PS Hsmates	
AltRes for PS	

Enter SI or NSI

This is the companion's total auth.

Number of housemates authorized PS

Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	27.92
IndNeed	140.08
AltResource	110.51
Purchase	29.57

Protective Supervision Calculations
Training Example 5

	Auth to Purch
AA Domestic	
BB Meal Prep	
CC Meal Cleanup	
DD Laundry	
EE Food Shop	
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	3.50
JJ Feeding	1.00
KK Bed Bath	
LL Dressing	3.50
MM Menstrual	
NN Ambulation	2.00
OO Transfer	1.00
PP Bathing	3.50
QQ Rubbing	
RR Prosthesis	
SS AccompMD	0.50
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N	Enter SI or NSI
PCSP Y/N	N	
IHSS to Comp/Wk.		This is the companion's total auth.
# PS Hsmates	1	Number of housemates authorized PS
AltRes for PS		Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	99.00
IndNeed	69.00
AltResource	38.97
Purchase	30.03

Protective Supervision Calculations
Training Example 6

	Auth to Purch
AA Domestic	2.00
BB Meal Prep	3.50
CC Meal Cleanup	1.00
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	3.50
JJ Feeding	
KK Bed Bath	
LL Dressing	1.75
MM Menstrual	
NN Ambulation	2.00
OO Transfer	3.50
PP Bathing	3.50
QQ Rubbing	2.00
RR Prosthesis	1.00
SS AccompMD	1.75
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	S
PCSP Y/N	Y
IHSS to Comp/Wk.	
# PS Hsmates	1
AltRes for PS	

Enter SI or NSI

This is the companion's total auth.
Number of housemates authorized PS
Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	109.46
IndNeed	58.54
AltResource	18.64
Purchase	39.90

Protective Supervision Calculations
Training Example 7

	Auth to Purch
AA Domestic	3.00
BB Meal Prep	3.50
CC Meal Cleanup	1.50
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	
JJ Feeding	
KK Bed Bath	
LL Dressing	1.50
MM Menstrual	
NN Ambulation	
OO Transfer	
PP Bathing	3.00
QQ Rubbing	
RR Prosthesis	
SS AccompMD	
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N	Enter SI or NSI
PCSP Y/N	Y	
IHSS to Comp/Wk.		This is the companion's total auth.
# PS Hsmates		Number of housemates authorized PS
AltRes for PS	22.5	Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	11.69
IndNeed	156.31
AltResource	111.28
Purchase	45.03

Protective Supervision Calculations
Training Example 8

	Auth to Purch
AA Domestic	3.00
BB Meal Prep	3.50
CC Meal Cleanup	1.50
DD Laundry	1.00
EE Food Shop	0.50
FF Errands	
GG Heavy Clean	
HH Respiration	
II Bowel&Bladder	
JJ Feeding	
KK Bed Bath	
LL Dressing	1.50
MM Menstrual	
NN Ambulation	
OO Transfer	
PP Bathing	3.20
QQ Rubbing	
RR Prosthesis	
SS AccompMD	
TT AccompOther	
UU Grass	
VV Ice	
XX T&D	
YY Paramedical	

Form Completion Instruction to Automate Authorization of Protective Supervision

Enter the number of hours authorized to be purchased for each task, as reflected on the 293. The calculation for line WW is below.

SI/NSI	N
PCSP Y/N	Y
IHSS to Comp/Wk.	
# PS Hsmates	
AltRes for PS	133

Enter SI or NSI

This is the companion's total auth.
Number of housemates authorized PS
Hours/week PS AR

For ProtSup — On line WW, enter the following

Total Need	168
Adjustments	11.89
IndNeed	156.11
AltResource	133.00
Purchase	23.11

PS CALCULATION ACTIVITY
EXAMPLE 2

1. Determine the factors that affect calculation of hours for this example:

   PCSP / IPW / Residual (circle one)

   NSI and SI (circle one)

   Number of recipients in the household: _____

   Number of recipients receiving Protective Supervision: _____

   Alternative Resources (voluntary and/or formal): _____
   _____
   _____

2. When figuring the **Authorized to Purchase** amount for this example, how does the NSI PCSP maximums affect the amount you enter?

3. How does this process differ from the example shown in class?

4. If NSI consumer has more that 20.32 hours of other IHSS services, how does this affect total hours authorized (PS and non-PS)?

5. What does the **Alternative Resources** column number represent?

6. How do you figure out if you have calculated Zero **Unmet Need**?

7. Fill in the WW line:

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use

PS CALCULATION ACTIVITY
EXAMPLE 4

1. Determine the factors that affect calculation of hours for this example:

   PCSP / IPW / Residual (circle one)

   NSI and SI (circle one)

   Number of recipients in the household: _____

   Number of recipients receiving Protective Supervision: _____

   Alternative Resources (voluntary and/or formal): _____
   _____
   _____

2. Explain how to calculate the **Adjustment** column when there are two IHSS recipients in the household with only one receiving PS.

3. Explain the reason for the method used to calculate the Adjustments.

4. Explain the resulting **Individual Need** – what does it represent?

5. When calculating the hours **Authorized to Purchase,** what numbers do you use and why?

6. Fill in the WW line:

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use

PS CALCULATION ACTIVITY
EXAMPLE 5

1. Determine the factors that affect calculation of hours for this example:

   PCSP / IPW / Residual (circle one)

   NSI and SI (circle one)

   Number of recipients in the household: _____

   Number of recipients receiving Protective Supervision: _____

   Alternative Resources (voluntary and/or formal): _____
   _____
   _____

2. Explain how to calculate the **Adjustment** column when there are two IHSS recipients in the household both receiving PS. (proration)

3. Explain the reason for the method used to calculate the Adjustments.

4. Explain the resulting **Individual Need** – what does it represent?

5. When calculating the hours **Authorized to Purchase,** what numbers do you use and why?

6. Does a second consumer in the household receiving PS service from the same provider result in the consumers receiving fewer PS hours that they would if there was only one consumer? Explain your answer.

7. Fill in the WW line:

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use

PS CALCULATION ACTIVITY
EXAMPLE 8

1. Determine the factors that affect calculation of hours for this example:

   PCSP / IPW / Residual (circle one)

   NSI and SI (circle one)

   Number of recipients in the household: _____

   Number of recipients receiving Protective Supervision: _____

   Alternative Resources (voluntary and/or formal): _____
   _____
   _____

2. Explain why 45.03 is entered in the **Authorized to Purchase** column.

3. What are the actual **voluntary services** that the daughter would be available to provide PS? How did you come up with this number?

4. What would the **Alternative Resources** be as calculated? How did you come up with this number?

5. What number should be used in the **Alternative Resources** column and why?

6. What must happen to the **Authorized to Purchase** column and why?

7. Fill in the WW line:

Total Need	Adj.	Individual Need	Alt. Resources	Auth. Purchase	Unmet Need	County Use

USING THE EXCEL TOOL

Enter the number of hours to be purchased for each task. When entering numbers into the field, some require weekly and some monthly totals. When you plug in Monthly, the program will calculate the weekly number automatically.

	Auth to Purch
AA Domestic	**Monthly**
BB Meal Prep	Weekly
CC Meal Cleanup	Weekly
DD Laundry	Weekly
EE Food Shop	Weekly
FF Errands	Weekly
GG Heavy Clean	**Monthly**
HH Respiration	Weekly
II Bowel&Bladder	Weekly
JJ Feeding	Weekly
KK Bed Bath	Weekly
LL Dressing	Weekly
MM Menstrual	Weekly
NN Ambulation	Weekly
OO Transfer	Weekly
PP Bathing	Weekly
QQ Rubbing	Weekly
RR Prosthesis	Weekly
SS AccompMD	Weekly
TT AccompOther	Weekly
UU Grass	**Monthly**
VV Ice	**Monthly**
XX T&D	Weekly
YY Paramedical	Weekly

NOTES:

SI/NSI		Enter **S** for Severely impaired or **N** for Nonseverely impaired
PCSP Y/N		Enter **Y** if the consumer is PCSP eligible and **N** if consumer is Waiver or Residual
IHSS to Comp/Wk.		If the client lives with another IHSS recipient, enter the monthly hours authorized to that person, **UNLESS** that person is also authorized PS. Do not enter anything here for other clients who will also be authorized PS.
# PS Hsmates		Enter the number of other IHSS clients living with this recipient who are also authorized PS.

AltRes for PS		If the client has a formal or informal alternative resource that provides protective supervision time, enter the number of hours per week here. ***For example***; if the client attends Adult Day Health, enter the number of hours per week the client attends the center plus the weekly hours spent to and from the Center. If a daughter tells you she is willing to provide care for her mother without reimbursement, but wants time away for herself on a weekly basis, enter the number of weekly hours she intends to volunteer.

For ProtSup	On line WW, enter the following	***NOTES:***
Total Need		Total = 24h x 7days
Adjustment		IHSS services identified
IndNeed		Total need minus the adjustments (calculated by CMIPS)
AltResource		Need left to be provided by alternative resources to meet 24-hour need – IHSS will not pay
Purchase		IHSS services provided for PS (calculated by CMIPS)

Understanding SCI & Functional Goals

Spinal Cord Injury InfoSheet 4

Level - Consumer

Any damage to the spinal cord is a very complex injury. People who are injured are often confused when trying to understand what it means to be a person with a spinal cord injury (SCI). Will I be able to move my hands? Will I walk again? What can I do? Each injury is different and can affect the body in many different ways.

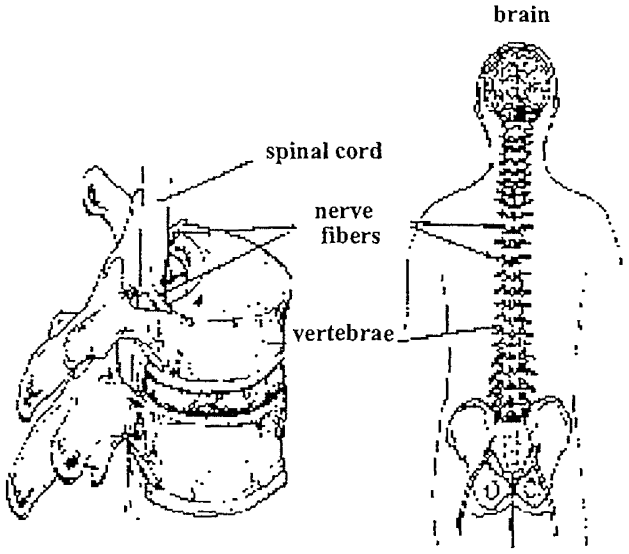
This is a brief summary of the changes that take place after a spinal cord injury. It tells how the spinal cord works and what some of the realistic expectations are for what a person should eventually be able to do following a spinal cord injury. Included is a chart of functional goals for specific levels of injury as well as additional information resources.

The Normal Spinal Cord

The spinal cord is a part of your nervous system. It is the largest nerve in the body. Nerves are cord-like structures made up of many nerve fibers. The spinal cord has many spinal nerve fibers that carry messages between the brain and different parts of the body. The messages may tell a body part to move. Other nerve fibers send and receive messages of feeling or sensation back to the brain from the body, such as heat, cold, or pain. The body also has an autonomic nervous system. It controls the involuntary activities of the body; such as, blood pressure, body temperature, and sweating.

The nerve fibers that make up the communication systems of the body can be compared to a telephone system. The telephone cable (spinal cord) sends messages between the main office (the brain) and individual offices (parts of the body) over the telephone lines (nerve fibers). The spinal cord is the pathway that messages use to travel between the brain and the other parts of the body.

Figure A

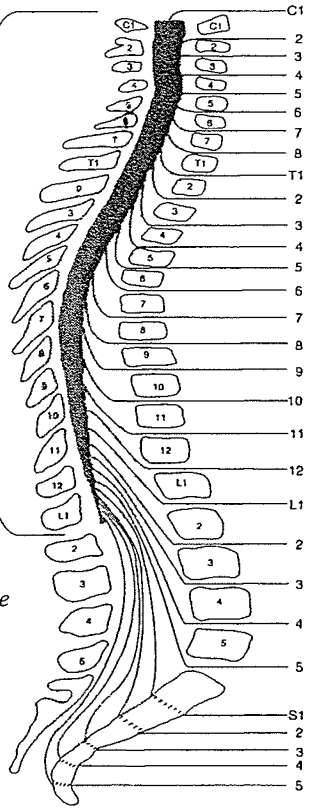


*The **spinal cord** goes through the center of the stacked **vertebrae.** These bones protect the spinal cord. The **nerve fibers** branch out from the spinal cord to other parts of the body.*

Because the spinal cord is such an important part of our nervous system, it is surrounded and protected by bones called vertebrae. The vertebrae, or backbones, are stacked on top of each other. This is called the vertebral column or the spinal column. The vertebral column is the number one support for the body. The spinal cord runs through the middle of the vertebrae [See Figure A].

The spinal cord is about 18 inches long. The cord extends from the base of the brain, down the middle of the back, to about the waist. The bundles of nerve fibers that make up the spinal cord itself are Upper Motor Neurons (UMNs). Spinal nerves that branch off the spinal cord up and down the neck and back are lower motor neurons (LMNs). These nerves exit between each vertebrae and go out to all parts of the body. At the end of the

Figure B



The **Spinal Cord** *ends in the back area near the waistline.*

The nerves within the spinal cord are **Upper Motor Neurons (UMNs).**

Spinal Nerves *branch out between each* **vertebrae.** *These are* **Lower Motor Neurons (LMNs).**

Nerves *descend from the end of the spinal cord down through the vertebral column, exiting at each level.*

spinal cord, the lower spinal nerve fibers continue down through the spinal canal to the sacrum, or tailbone. [See Figure B]

The spinal column is divided into four sections. The top portion is the cervical area. It has eight cervical nerves and seven cervical vertebrae. Moving down the back, the next section is the thoracic area. It includes the chest area and has twelve thoracic vertebrae. The lower back section is the lumbar area and has five lumbar vertebrae. The bottom section has five sacral vertebrae and is the sacral area. The bones in the sacral section are actually fused together into one bone.[See Figure C]

The Spinal Cord After an Injury

Damage to the spinal cord can occur from either a traumatic injury or from a disease to the vertebral column. In most spinal cord injuries, the backbone pinches the spinal cord, causing it to become bruised or swollen. Sometimes the injury may tear the spinal cord and/or its nerve fibers. An infection or a disease can result in similar damage.

After a spinal cord injury, all the nerves above the level of injury keep working like they always have. From the point of injury and below, the spinal cord nerves cannot send messages between the brain and parts of the body like they did before the injury.

The doctor examines the individual to understand what damage has been done to the spinal cord. An X-ray shows where the damage occurred to the vertebrae. The doctor does a "pin prick" test to see what feeling the person has all over his body (sensory level). The doctor also asks, "what parts of the body can you move?" and tests the strength of key muscle groups (motor level). These exams are important because they tell what nerves and muscles are working.

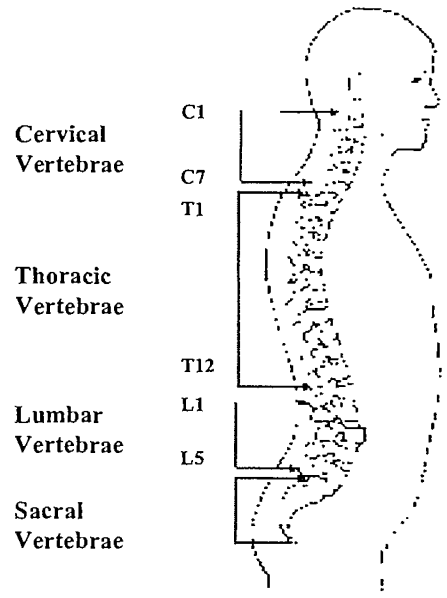
Each spinal cord injury is different. A person's injury is described by its **level** and **type**.

Level of Injury

The level of injury for a person with SCI is the lowest point on the spinal cord below which there is a decrease or absence of feeling (the sensory level) and/or movement (the motor level).

Tetraplegia [formerly called quadriplegia] generally describes the condition of a person with a

Figure C



The **vertebrae** *are numbered and named according to their location in the vertebral column.*

spinal cord injury that is at a level from C1 to T1. This individual can experience a loss of feeling and/or movement in their head, neck, shoulder, arms and/or upper chest.

Paraplegia is the general term describing the condition of a person who has lost feeling and/or is not able to move the lower parts of his/her body. The body parts that may be affected are the chest, stomach, hips, legs and feet. An individual with a level from T2 to S5 has paraplegia.

The higher the spinal cord injury is on the vertebral column, or the closer it is to the brain, the more effect it has on how the body moves and what one can feel. More movement, feeling and voluntary control of the body's systems are present with a lower level of injury. For example, a person with a C-5 level of injury has a decrease or loss of feeling and movement below the 5th cervical spinal cord segment. An injury at the T-8 level means the individual has a decrease or loss of feeling and movement below the eighth thoracic spinal cord segment. Someone with a T-8 level of injury would have more feeling and movement than someone with a C-5 level of injury.

Complete or Incomplete Injury

The amount of feeling and movement that an individual has also depends on whether the injury is complete or incomplete. A complete injury means there is no motor or sensory function in the S4 or S5 area, or anal area. If there is evidence of any motor or sensory function in this area, one of three incomplete injury classifications is given.

Some people with an incomplete injury may have feeling, but little or no movement. Others may have movement and little or no feeling. Incomplete spinal injuries differ from one person to another because the amount of damage to each person's nerve fibers is different. This fact makes it impossible to accurately predict how much of an individual's sensory and motor function will return. There is a greater chance of return of some or all of a person's motor and sensory function if an individual is incomplete at the time of injury.

Changes after the Initial Injury

Sometimes the spinal cord is only bruised or swollen after the initial injury. As the swelling goes down, the nerves may begin to work again. There are no tests at this time to tell how many nerves, if any, will begin to work again or when this will occur. This makes it impossible for medical staff to guarantee how much or when function may return.

Some individuals have involuntary movements, such as twitching or shaking. These movements are called spasms. Spasms are not a sign of recovery. A spasm occurs when a wrong message from the nerve causes the muscle to move. The individual often can not control this movement.

In addition to movement and feeling, a spinal cord injury affects how other systems of the body work. An individual with SCI learns new ways to manage his/her bladder and bowel. His/her skin and lungs often need special care and attention to stay healthy. There may also be changes in sexual function.

Functional Goals

Functional goals are a realistic expectation of activities that a person with spinal cord injury eventually should be able to do with a particular level of injury. These goals are set during rehabilitation with the medical team. They help the individual with SCI learn new ways to manage his/her daily activities and stay healthy.

Achievement of functional goals can also be affected by other factors, such as an individual's body type and health related issues. By striving to reach these functional goals, the hope is to give individuals with SCI the opportunity to achieve **Maximum Independence**.

The chart, "***Functional Goals for Specific Levels of Complete Injury***", shows the expected functional goals for a person with a complete injury at a particular level. Motor and sensory functions improve with lower levels of injury.

Resources

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Hammond M, Umlauf R, Matteson B, and Perduta-Fulginiti S. Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury. 2nd Ed. Washington, DC: Paralyzed Veterans of America, 1993. [Cost: $12 Order from PVA].

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Take Control: Multimedia Guide to Spinal Cord Injury-Vol.1. 1996. [CD-Rom programs Available from Arkansas Spinal Cord Commission, 1501 N University Ste 400, Little Rock, AR 72202, 501-296-1788, Email: arkscc@aol.com].

Organizations:

American Spinal Injury Association
345 East Superior Ave, Rm 1436
Chicago, IL 60611
312-238-1242
http://www.asia-spinalinjury.org

National Spinal Cord Injury Association (NSCIA)
6701 Democracy Blvd, Ste 300
Bethesda, MD 20817
800-962-9629
Email: resource@spinalcord.org
http://www.spinalcord.org

Paralyzed Veterans of America
801 18th St NW, Washington, DC 20006
800-424-8200
Email: info@pva.org
http://www.pva.org

RRTC on Aging with Spinal Cord Injury
Rancho Los Amigos Medical Center
7601 E Imperial Hwy, 800 West Annex
Downey, CA 90242-3456
562-401-7402
http://www.agingwithsci.org

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This publication is supported by grant #H133B980016 from the National Institute of Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, U.S. Department of Education, Washington, DC. Opinions expressed in this document are not necessarily those of the granting agency.

Spinal Cord Injury - Functional Goals for Specific Levels of Complete Injury

Functional goals are a realistic expectation of activities that a person with spinal cord injury eventually should be able to do with a particular level of injury. The current standard used to predict a person's outcome after injury is based on the International Standards for Neurological and Functional Classification of Spinal Cord Injury.

The level of injury is named for a region of the spine.

1. A "C" level of spinal cord injury occurs to one of the eight cervical nerves in the area of the seven cervical vertebrae.
2. A "T" level of injury occurs to one of the twelve thoracic nerves in the thoracic region of the vertebrae.
3. An "L" level of injury is to one of the five lumbar nerves in the lumbar area of the vertebrae. In actuality, the spinal cord ends around the L1 level.
4. An "S" level of injury occurs to one of the five nerves extending down from the spinal cord through the five sacral vertebrae, which are fused as one bone. Actually, an injury classified at these levels usually occurs higher in the spinal column than the sacrum because the cord ends well above the sacrum itself.

Level of Injury	Abilities	Functional Goals
C1-C3	C3 –Limited movement of head and neck	**Breathing**: Depends on a ventilator for breathing. **Communication**: Talking is sometimes difficult, very limited or impossible. If one's ability to talk is limited, communication can be accomplished independently with a mouth stick and assistive technologies like a computer for speech or typing. Effective verbal communication allows the individual with SCI to direct caregivers in the person's daily activities, like bathing, dressing, personal hygiene, transferring, as well as bladder and bowel management. **Daily Tasks**: Assistive technology allows for independence in tasks such as turning the pages of a book or magazine, using a telephone and operating lights and appliances. **Mobility:** Can operate an electric wheelchair by using a bead control, mouth stick, or chin control. A power tilt wheelchair allows for independent pressure relief.

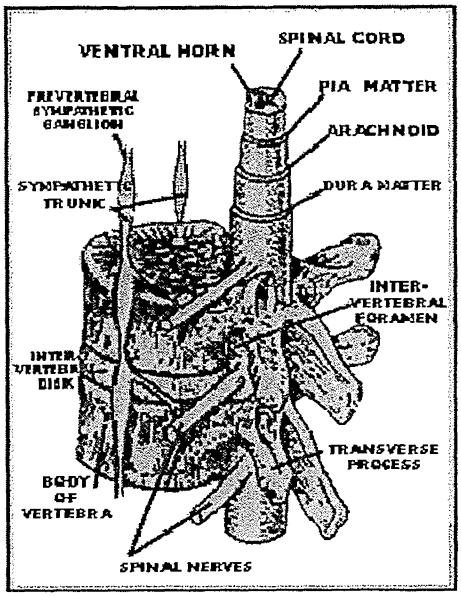
C3-C4	Usually has head and neck control. Individuals at C4 level may shrug their shoulders.	**Breathing**: May initially require a ventilator for breathing; usually adjust to breathing full-time without ventilatory assistance. **Communication:** Normal. **Daily Tasks:** With specialized equipment, some may have limited independence in feeding and independently operate an adjustable bed with an adapted controller.
C5	Typically has head and neck control, can shrug shoulder and has shoulder control. Can bend his/her elbows and turn palms face up.	**Daily Tasks**: Independence with eating, drinking, face washing, brushing of teeth, shaving and hair care after assistance in setting up specialized equipment. **Health Care:** Can manage their own health care by doing self-assist coughs and pressure reliefs by leaning forward or side-to-side. **Mobility:** May have strength to push a manual wheelchair for short distances over smooth surfaces. A power wheelchair with hand controls is typically used for daily activities. Driving may be possible after being evaluated by a qualified professional to determine special equipment needs.
C6	Has movement in head, neck, shoulders, arms and wrists. Can shrug shoulders, bend elbows, turn palms up and down and extend wrists.	**Daily Tasks:** With help of some specialized equipment, can perform with greater ease and independence, daily tasks of feeding, bathing, grooming, personal hygiene and dressing. May independently perform light housekeeping duties. Some individuals may also independently perform bladder and bowel management. **Health Care:** Can independently do pressure reliefs, shin checks, and turn in bed. **Mobility:** Some individuals can independently do transfers but often require a slide-board. Can use a manual wheelchair for greater ease of independence and drive with adaptive equipment.

C7	Has similar movement as an individual with C6, with added ability to straighten his/her elbows.	**Daily Tasks:** Able to perform household duties. Need fewer adaptive aides in independent living. Greater ease in performing household work and transferring. **Health Care:** Able to do wheelchair pushups for pressure reliefs. **Mobility:** Daily use of manual wheelchair. Can transfer with greater ease.
C8-T1	Has added strength and precision of fingers that result in limited or natural hand function.	**Daily Tasks:** Can live independently without assistive devices in feeding, bathing, grooming, oral and facial hygiene, dressing, bladder management and bowel management. **Mobility:** uses manual wheelchair. Can transfer independently.
T2 –T6	Has normal motor function in head, neck, shoulders, arms, hands and fingers. Has increased use of rib and chest muscles, or trunk control.	**Daily Tasks:** Should be totally independent with all activities. **Mobility:** A few individuals are capable of limited walking with extensive bracing which requires extremely high energy and puts stress on the upper body, offering no functional advantage. Can lead to damage of upper joints.
T7-T12	Has added motor function from increased abdominal control.	**Daily Tasks**: Able to perform unsupported seated activities. **Mobility:** Same as above. **Health Care:** Has improved cough effectiveness.
L1-L5	Has additional return of motor movement in the hips and knees.	**Mobility:** Walking can be a viable function, with the help of specialized leg and ankle braces. Lower levels walk with greater ease with the help of assistive devices.
S1-S5	Depending on level of injury, there are various degrees of return of voluntary bladder, bowel and sexual functions.	**Mobility:** Increased ability to walk with fewer or no supportive devices. **Daily Tasks:** Depending on the level of injury, there are also various degrees of return of voluntary bladder, bowel, and sexual functions. Greater improvements in function occur the lower the level of injury.

Spinal cord 101

http://www.spinalinjury.net/html/_spinal_cord_101.html

Some basic questions and answers...



What is Spinal Cord Injury? Spinal Cord Injury (SCI) is damage to the spinal cord that results in a loss of function such as mobility or feeling. Frequent causes of damage are trauma (car accident, gunshot, falls, etc.) or disease (polio, spina bifida, Friedreich's Ataxia, etc.). The spinal cord does not have to be severed in order for a loss of functioning to occur. In fact, in most people with SCI, the spinal cord is intact, but the damage to it results in loss of functioning. SCI is very different from back injuries such as ruptured disks, spinal stenosis or pinched nerves.

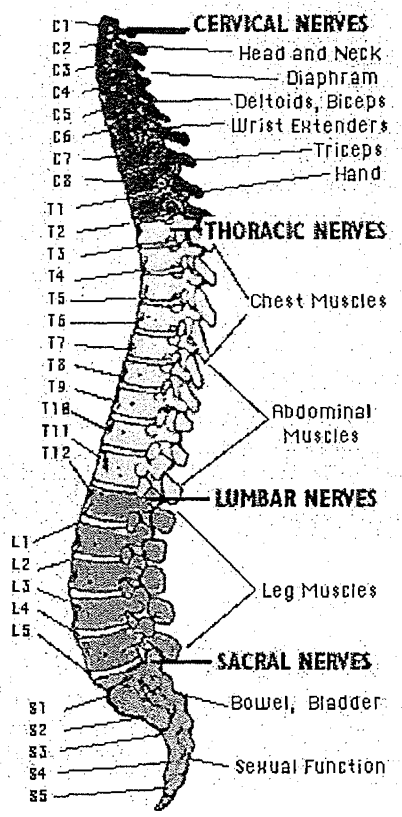
A person can "break their back or neck" yet not sustain a spinal cord injury if only the bones around the spinal cord (the vertebrae) are damaged, but the spinal cord is not affected. In these situations, the individual may not experience paralysis after the bones are stabilized.

What is the spinal cord and the vertebra? The spinal cord is about 18 inches long and extends from the base of the brain, down the middle of the back, to about the waist. The nerves that lie within the spinal cord are upper motor neurons (UMNs) and their function is to carry the messages back and forth from the brain to the spinal nerves along the spinal tract. The spinal nerves that branch out from the spinal cord to the other parts of the body are called lower motor neurons (LMNs). These spinal nerves exit and enter at each vertebral level and communicate with specific areas of the body. The sensory portions of the LMN carry messages about sensation from the skin and other body parts and organs to the brain. The motor portions of the LMN send messages from the brain to the various body parts to initiate actions such as muscle movement.

The spinal cord is the major bundle of nerves that carry nerve impulses to and from the brain to the rest of the body. The brain and the spinal cord constitute the Central Nervous System. Motor and sensory nerves outside the central nervous system constitute the Peripheral Nervous System, and another diffuse system of nerves that control involuntary functions such as blood pressure and temperature regulation are the Sympathetic and Parasympathetic Nervous Systems.

The spinal cord is surrounded by rings of bone called vertebra. These bones constitute the spinal column (back bones). In general, the higher in the spinal column the injury occurs, the more dysfunction a person will experience. The vertebra are named according to their location. The eight vertebra in the neck are called the Cervical Vertebra. The top vertebra is called C-1, the next is C-2, etc. Cervical SCI's usually cause loss of function in the arms and legs, resulting in quadriplegia. The twelve vertebra in the chest are called the Thoracic Vertebra. The first thoracic vertebra, T-1, is the vertebra where the top rib attaches.

Injuries in the thoracic region usually affect the chest and the legs and result in paraplegia. The vertebra in the lower back between the thoracic vertebra, where the ribs attach, and the



pelvis (hip bone), are the Lumbar Vertebra. The sacral vertebra run from the Pelvis to the end of the spinal column. Injuries to the five Lumbar vertebra (L-1 thru L-5) and similarly to the five Sacral Vertebra (S-1 thru S-5) generally result in some loss of functioning in the hips and legs.

What are the effects of SCI? The effects of SCI depend on the type of injury and the level of the injury. SCI can be divided into two types of injury - complete and incomplete. A complete injury means that there is no function below the level of the injury; no sensation and no voluntary movement. Both sides of the body are equally affected. An incomplete injury means that there is some functioning below the primary level of the injury. A person with an incomplete injury may be able to move one limb more than another, may be able to feel parts of the body that cannot be moved, or may have more functioning on one side of the body than the other. With the advances in acute treatment of SCI, incomplete injuries are becoming more common.

The level of injury is very helpful in predicting what parts of the body might be affected by paralysis and loss of function. Remember that in incomplete injuries there will be some variation in these prognoses.

Cervical (neck) injuries usually result in quadriplegia. Injuries above the C-4 level may require a ventilator for the person to breathe. C-5 injuries often result in shoulder and biceps control, but no control at the wrist or hand. C-6 injuries generally yield wrist control, but no hand function. Individuals with C-7 and T-1 injuries can straighten their arms but still may have dexterity problems with the hand and fingers. Injuries at the thoracic level and below result in paraplegia, with the hands not affected. At T-1 to T-8 there is most often control of the hands, but poor trunk control as the result of lack of abdominal muscle control. Lower T-injuries (T-9 to T-12) allow good truck control and good abdominal muscle control. Sitting balance is very good. Lumbar and Sacral injuries yield decreasing control of the hip flexors and legs.

Besides a loss of sensation or motor functioning, individuals with SCI also experience other changes. For example, they may experience dysfunction of the bowel and bladder,. Sexual functioning is frequently with SCI may have their fertility affected, while women's fertility is generally not affected. Very high injuries (C-1, C-2) can result in a loss of many involuntary functions including the ability to breathe, necessitating breathing aids such as mechanical ventilators or diaphragmatic pacemakers. Other effects of SCI may include low blood pressure, inability to regulate blood pressure effectively, reduced control of body temperature, inability to sweat below the level of injury, and chronic pain

How many people have SCI? Who are they? Approximately 450,000 people live with SCI in the US. There are about 10,000 new SCI's every year; the majority of them (82%) involve males between the ages of 16-30. These injuries result from motor vehicle accidents (36%), violence (28.9%), or falls (21.2%).Quadriplegia is slightly more common than paraplegia.

Is there a cure?

Currently there is no cure for SCI. There are researchers attacking this problem, and there have been many advances in the lab (see research updates). Many of the most exciting advances have resulted in a decrease in damage at the time of the injury. Steroid drugs such as methylprednisolone reduce swelling, which is a common cause of secondary damage at the time of injury. The experimental drug SygenÆappears to reduce loss of function, although the mechanism is not completely understood.

Do people with SCI ever get better?

When a SCI occurs, there is usually swelling of the spinal cord. This may cause changes in virtually every system in the body. After days or weeks, the swelling begins to go down and people may regain some functioning. With many injuries, especially incomplete injuries, the individual may recover some functioning as late as 18 months after the injury. In very rare cases, people with SCI will regain some functioning years after the injury. However, only a very small fraction of individuals sustaining SCIs recover all functioning.

Does everyone who sustains SCI use a wheelchair?

No. Wheelchairs are a tool for mobility. High C-level injuries usually require that the individual use a power wheelchair. Low C-level injuries and below usually allow the person to use a manual chair. Advantages of manual chairs are that they cost less, weigh less, disassemble into smaller pieces and are more agile. However, for the person who needs a powerchair, the independence afforded by them is worth the limitations. Some people are able to use braces and crutches for ambulation. These methods of mobility do not mean that the person will never use a wheelchair. Many people who use braces still find wheelchairs more useful for longer distances. However, the therapeutic and activity levels allowed by standing or walking briefly may make braces a reasonable alternative for some people.

Of course, people who use wheelchairs aren't always in them. They drive, swim, fly planes, ski, and do many activities out of their chair. If you hang around people who use wheelchairs long enough, you may see them sitting in the grass pulling weeds, sitting on your couch, or playing on the floor with children or pets. And of course, people who use wheelchairs don't sleep in them, they sleep in a bed. No one is "wheelchair bound."

Do people with SCI die sooner?

Yes. Before World War II, most people who sustained SCI died within weeks of their injury due to urinary dysfunction, respiratory infection or bedsores. With the advent of modern antibiotics, modern materials such as plastics and latex, and better procedures for dealing with the everyday issues of living with SCI, many people approach the lifespan of non-disabled individuals. Interestingly, other than level of injury, the type of rehab facility used is the greatest indicator of long-term survival. This illustrates the importance of and the difference made by going to a facility that specializes in SCI. People who use vents are at some increased danger of dying from pneumonia or respiratory infection, but modern technology is improving in that area as well. Pressure sores (learn more about pressure soars here) are another common cause of hospitalization, and if not treated - death.

Overall, 85% of SCI patients who survive the first 24 hours are still alive 10 years later. The most common cause of death is due to diseases of the respiratory system, with most of these being due to pneumonia. In fact, pneumonia is the single leading cause of death throughout the entire 15 year period immediately following SCI for all age groups, both males and females, whites and non-whites, and persons with quadriplegia.

The second leading cause of death is non-ischemic heart disease. These are almost always unexplained heart attacks often occurring among young persons who have no previous history of underlying heart disease.

Deaths due to external causes is the third leading cause of death for SCI patients. These include subsequent unintentional injuries, suicides and homicides, but do not include persons dying from multiple injuries sustained during the original accident. The majority of these deaths are the result of suicide.

Do people with SCI have jobs?

People with SCI have the same desires as other people. That includes a desire to work and be productive. The Americans with Disabilities Act (ADA) promotes the inclusion of people with SCI to mainstreamin day-to-day society. Of course, people with disabilities may need some changes to make their workplace more accessible, but surveys indicate that the cost of making accommodations to the workplace in 70% of cases is $500 or less.

Spinal cord 101

http://www.spinalinjury.net/html/complications_continued.html

Possible complications:

Skin Breakdown: Skin breakdowns (also termed "decubitus ulcers" or "pressure sores" are a major complication associated with spinal cord injury. They occur as a result of excessive pressure, primarily over the bones of the buttock (particularly the ischial tuberosities and the trochanters at the hip). Following a spinal cord injury, there are not only changes in muscle tone and sensation, but shifts in the supply of blood to the skin and subcutaneous tissues. Additionally, there is a loss of the normal elastic nature of the tissues underlying the skin. Increased stiffness, vascular alterations and alterations in muscle tone combine to significantly reduce the skin's ability to withstand pressure. It is estimated that the closing "pressure" for skin breakdown is between 40 and 50 millimeters of mercury (about the same amount of pressure as placing a stamp onto an envelope). This complication is combated fairly aggressively through the use of pressure-relieving cushions that are either gel based or consist of a number of air bladders to reduce risk of the person "bottoming out". The cost associated with medical and/or surgical care of a single decubitus ulcer can run anywhere from $10,000 to $50,000 per admission. This does not take into consideration the loss of productivity if the individual is in the work place

Osteoporosis and Fractures: The majority of people with SCI develop osteoporosis. In people without SCI, the bones are kept strong through regular muscle activity or by bearing weight. When muscle activity is decreased or eliminated and the legs no longer bear the body's weight, they begin to lose calcium and phosphorus and become weak and brittle. It generally takes some time for osteoporosis to occur. In people who use standing frames or braces, osteoporosis is less of a problem. Generally, though, 2-t years following SCI some degree of bone loss will occur.

Using the legs to provide support in transfering is helpful in increasing the load on the bones, which may reduce or slow down the osteoporotic process. Standing using a standing frame or a standing table also helps prevent weakening of the bones and so does using braces for functional or parallel bar walking. Newer techniques, such as electrical stimulation of the leg muscles, may decrease osteoporosis as wel.

Unfortunately, at the present time, there is no way to reverse osteoporosis once it has occurred. The main risk of osteoporosis is fracture. Once the bones become brittle, they fracture easily. An osteoporotic bone takes much longer to heal.

Pneumonia, Atelectasis, Aspiration: Patients with spinal cord injuries above the T4 level of injury are at risk to develop restriction in respiratory function, termed restrictive lung disease. This occurs five to 10 years following spinal cord injury and can be progressive in nature. The quadriplegic individual as part of a health care maintenance routine should have pulmonary function studies at yearly or every-other-year intervals between five and

10 years post injury. As the medical treatment of spinal cord-injured individuals continues to improve, respiratory complications of SCI are becoming more prominent. Adequate health maintenance and protection from this complication are appropriate and necessary as part of the long-term care of the spinal cord-injured individual.

Heterotopic Ossification: Heterotopic ossification is a condition not well understood that occurs in acute spinal cord injury and consists of the laying down of bone outside the normal skeleton, usually occurring at large joints such as the hips or knees. The primary problem with heterotopic ossification, or HO, is the risk for joint stiffening and fusion. Should the hip or knee become fused in a certain position, a surgical release is necessary to allow range of motion to occur. Unfortunately, it takes between 12 and 18 months for heterotopic bone to mature once it has developed. Activities that are used to prevent the development of HO include range of motion programs and other functional activities that move the joints within a functional range. Currently treatment is limited with the exception of preventing the joint fusion (termed ankylosis).

Spasticity: After spinal cord injury the nerve cells below the level of injury become disconnected from the brain. Following the period of spinal shock changes occur in the nerve cells that control muscle activity. Spasticity is an exaggeration of the normal reflexes that occur when the body is stimulated in certain ways. After spinal cord injury, when nerves below the injury become disconnected from those above, these responses become exaggerated.

Muscle spasms, or spasticity, can occur any time the body is stimulated below the injury. This is particularly noticeable when muscles are stretched or when there is something irritating the body below the injury. Pain, stretch, or other sensations from the body are transmitted to the spinal cord. Because of the disconnection, these sensations will cause the muscles to contract or spasm.

Almost anything can trigger spasticity. Some things, however, can make spasticity more of a problem. A bladder infection or kidney infection will often cause spasticity to increase a great deal. A skin breakdown will also increase spasms. In a person who does not perform regular range of motion exercises, muscles and joints become less flexible and almost any minor stimulation can cause severe spasticity.

Some spasticity may always be present. The best way to manage or reduce excessive spasms is to perform a daily range of motion exercise program. Avoiding situations such as bladder infections, skin breakdowns, or injuries to the feet and legs will also reduce spasticity. There are three primary medications used to treat spasticity, baclofen, Valium, and Dantrium. All have some side effects and do not completely eliminate spasticity.

There are some benefits to spasticity. It can serve as a warning mechanism to identify pain or problems in areas where there is no sensation. Many people know when a urinary tract infection is coming on by the increase in muscle spasms. Spasticity also helps to maintain muscle size and bone strength. It does not replace walking, but it does help to some degree in preventing osteoporosis. Spasticity helps maintain circulation in the legs and can be used to improve certain functional activities such as performing transfers or walking with braces. For these reasons, treatment is usually started only when spasticity interferes with sleep or

limits an individual's functional capacity

Autonomic dysreflexia: Autonomic dysreflexia (AD) is a condition that can occur in anyone who has a spinal cord injury at or above the T6 level. It is related to disconnections between the body below the injury and the control mechanisms for blood pressure and heart function. It causes the blood pressure to rise to potentially dangerous levels.

AD can be caused by a number of things. The most common causes are a full bladder, bladder infection, severe constipation, or pressure sores. Anything that would normally cause pain or discomfort below the level of the spinal cord injury can trigger dysreflexia. AD can occur during medical tests or procedures and need to be watched for.

The symptoms that occur with AD are directly related to the types of responses that happen in the sympathetic and parasympathetic nervous systems. Symptoms such as a pounding headache, spots before the eyes, or blurred vision are thee direct result of the high blood pressure that occurs when blood vessels below the injury constrict. The body responds by dilating blood vessels above the injury, causing flushing of the skin, sweating, and occasionally goosebumps. Some patients describe nasal stuffiness and will feel very anxious. Uncontrolled AD can cause a stroke if not treated.

The treatment for AD involves removing the reason for the stimulation. One of the first things a patient can do is to sit up. This naturally decreases blood prsessure. If there is a catheter in place, it should be checked to be certain that there is not a kink in the tubing. If there is not a catheter in place, the patient should be catheterized. The bowels should be checked to be ceratin there is no stool in the rectum. If the symptoms are caused by skin breakdown, the patient should get to an emergency department as soon as possible.

The primary risk of AD is stroke. It is a potentially life-threatening condition. If AD is left untreated, the body's attempt to control blood pressure will severely decrease the heart rate. This, combined with uncontrolled high blood pressure, can be fatal. For this reason, it is very important to treat this condition as soon as possible. The most important thing patients can do to prevent AD from occurring is to take good care of themselves. Patients should monitor bladder output and should maintain a regular bowel program which fully empties the bowels. They should also do regular skin checks to prevent pressure sores from occurring.

Deep vein thrombosis: (DVT) or pulmonary embolism is a potentially severe complication of spinal cord injury. As mentioned above, there are changes in the normal neurologic control of the blood vessels that can result in stasis or "sludging". Deep vein thrombosis in the lower leg is almost universal during the early phases of recovery and rehabilitation. Thromboses in the thigh, however, are a great concern, as they are at risk for becoming dislodged and passing through the vascular tree to the lungs. A major obstruction of the arteries leading to the lung can potentially be fatal. Therapeutic measures to reduce or eliminate the risk for deep vein thrombosis include Ace wrapping of the legs and the use of pneumatic compression stockings. Medications administered subcutaneously, such as heparin, are useful in reducing blood viscosity and improving flow. In the event that a thrombosis develops, treatment is begun with intravenous heparin. Once adequate anticoagulation is provided, the patient is switched to or medication, called Coumadin

Cardiovascular disease: Cardiovascular disease is a major long-term risk of spinal cord injury. SCI individuals live in general rather sedentary lives and are at higher risk for cardiovascular disease than the able-bodied population. Therefore, careful assessment of cardiovascular function and the encouragement

of exercise programs are appropriate and necessary long-term aspects of spinal cord injury management and care. The prescription of upper extremity exercise programs in spinal cord-injured individuals are similar to those used in other populations with the exception of the use of adaptive equipment such as racing wheelchairs or monoskis.

Syringomyelia- A post-traumatic enlargement of the central canal of the spinal cord is termed syringomyelia. It occurs in approximately 1-3% of all spinal cord-injured individuals. The primary risk of syringomyelia is a loss of function above the level of the original spinal cord injury. For example, in a patient with a thoracic-level spinal cord injury may complain to his or her physician of numbness and weakness involving the extremities. The condition will progress with time and needs to be treated aggressively through surgical drainage. Often patients with early evidence of a syrinx will be followed to evaluate the progression of the condition. Significant syringomyelia is treated with surgical decompression and the placement of a drainage tube into the spinal cord.

Neuropathic/Spinal Cord Pain- Neuropathic (nerve-generated) pain is a significant problem in some spinal cord-injured patients. Varying types of pain are described in spinal cord injury. Damage to the spine and soft tissues surrounding the spine can cause aching at the left of the injury. Nerve root pain is described as sharp or may be described as having an electric shock-type quality. Occasionally SCI patients will describe phantom limb pain or pain that radiates from the level of the lesion in a specific pattern that is related to injury or dysfunction at the nerve root or spinal cord level. Various medications and nerve block procedures have been described and are of some use in the treatment of neuropathic pain following spinal cord injury.

Respiratory Dysfunction- Respiratory complications and infection predominate as post-SCI complications. When the injury involves the upper thorax, the normal breathing pattern is permanently altered. The diaphragm does most of the work in quiet breathing. The chest wall muscles (intercostals) are used primarily for deep breathing or coughing. The abdominal muscles also participate in coughing. When the intercostal and abdominal muscles are paralyzed, the entire load is taken by the diaphragm. This results in poor coughing and a high risk of pneumonia. Pneumonia is one of the most common complications of acute spinal cord injury. Preventive measures are very important to reduce the risk of pneumonia. These include: percussion and drainage using gravity to assist; assisted coughing (also termed "quad" coughing); abdominal binders (to increase the resistance against which the diaphragm works); and early mobilization (i.e.; getting the patient out of bed as soon as possible)

What To Do If...

CONTINUED FROM OTHER SIDE

Rectal Bleeding.

Keep your stool soft. Be very careful to do digital stimulation gently and with sufficient lubrication, and keep your fingernails short. If you have hemorrhoids, you may treat them with an over-the counter hemorrhoidal preparation such as Anusol or Anusol HC. If bleeding persists or is more than a few drops, consult your health care provider.

Excessive Gas.

Avoid constipation. Increase the frequency of your bowel programs. Avoid gas-forming foods, such as beans, corn, onions, peppers, radishes, cauliflower, sauerkraut, turnips, cucumbers, apples, melons and others that you may have noticed seem to increase your own gas. Try simethicone tablets to help relieve discomfort from gas in your stomach.

Bowel program takes a long time to complete.

Try switching from a suppository to mini-enemas. Increase your intake of dietary fiber and add or increase the dose of psyllium hydromucilloid. Try switching your program to a different time, and be sure you schedule it after a meal to help increase intestinal peristalsis.

Autonomic dysreflexia during bowel program.

Use xylocaine jelly (available by prescription from your health care provider) for digital stimulation. You may also need to insert some of the jelly into your rectum before beginning the program. Keep your stool as soft as possible. If dysreflexia persists, consult your health care provider. You may need medication to treat or prevent this condition.

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Revised 1998, 2006

Staying Healthy After a Spinal Cord Injury

Taking Care of Your Bowels: Ensuring Success

Northwest Regional SCI System

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What To Avoid

Regular use of stimulant laxatives.

Stimulant laxatives such as bisacodyl (Dulcolax) tablets, phenolphthalein (Ex-Lax), cascara, senna and magnesium citrate are not recommended for use as a regular part of a bowel program. An occasional small dose of a mild laxative, such as Milk of Magnesia or an herbal laxative, can be used to treat constipation if other measures have not worked. If you need to use laxatives frequently, discuss the problem with your health care provider.

Enemas.

Any full-size enema (such as Fleet's, soap suds or tap water) is too irritating to the bowel and can cause autonomic dysreflexia. A "mini-enema", which has only a few drops of liquid stool softener, does not fall into this category and can be used regularly. Occasionally, your health care provider may prescribe a full-size enema as preparation for a medical procedure or for treatment of severe constipation.

Skipping or changing the time of your program.

Your bowels will move more predictably if your bowel care program is carried out on a regular, predictable schedule. Skipping your program can also result in constipation or accidents.

Rushing.

The more tense you are, the more difficult it will be for you to empty your bowels. A hurried program will increase the likelihood of an unplanned bowel movement later in the day.

More than four digital stimulations at a time.

This can cause trauma to the rectum, resulting in hemorrhoids or fissures (cracks or breaks in the skin).

Long fingernails.

They can damage the rectal tissue and cause bleeding, even through a glove.

What To Do If...

Stool is too hard (constipation).

Do your bowel program on a daily basis until constipation resolves. Add or increase the dose of a stool softener (such as ducosate or colace). Add or increase the dose of psyllium hydro-mucilloid (such as Metamucil or Citrucel). Increase your fluid intake (this is essential if you are increasing psyllium). Increase your activity level and your intake of dietary fiber. Avoid foods that can harden your stool, such as bananas and cheese.*

Stool is liquid or runny (diarrhea).

Temporarily discontinue the use of any stool softeners. Continue your bowel program at the regular time and frequency. (If you are having accidents, increase the frequency of your program.) Try adding or increasing the dose of psyllium hydro-mucilloid (Metamucil, Citrucel), which adds bulk to liquid stool. If the diarrhea seems to be related to an acute viral or bacterial illness, change to a liquids only or very bland diet for 24 hours (avoid milk, however). If diarrhea persists for more than 24 hours or if you have a fever or blood in your stool, consult your health care provider.

A frequent cause of diarrhea is a blockage or impaction of stool (liquid stool leaks out around the blockage). Evaluate whether you may have this problem. Have you had small hard stools recently? Or have you had no results from the past several programs? If you suspect impaction, consult your health care provider.

Frequent bowel accidents.

Be sure your rectum is completely empty at the end of your program. Increase the frequency of your program (some people with a flaccid bowel may need to empty their bowels twice daily). Try using only half of a suppository. Evaluate stool consistency — if it's too hard or too soft, see above. Monitor your diet for any foods that may over stimulate your bowel, such as spicy foods.*

Mucous accidents.

If you notice a clear, sticky, sometimes odorous drainage from the rectum, try switching from a suppository to a mini-enema or using only half of a suppository. Avoid hard stools.

No results for 3-4 days.

Treat constipation as recommended above. If there are no results in three days, take 30 cc. of Milk of Magnesia or a single dose of an herbal laxative at bedtime. Do your bowel program in the morning. If there are still no results, repeat the dose of Milk of Magnesia or herbal laxative the next evening. If there are no results in the morning, consult your health care provider.

CONTINUED OTHER SIDE

Spinal Cord Injury - InfoSheet #9

"Bowel Management"

How the Body Works

The food you eat and drink provides your body with many nutrients. These nutrients give you energy and help you stay healthy. As food moves through your body it breaks down so the nutrients can enter your blood stream. This process is called digestion. After the food is digested, the left-over waste products move into the large intestine. Here water is removed, leaving stool or fecal matter. The stool moves into the last part of the large intestine, called the colon or bowel.

As the bowel fills with stool it stretches. This triggers messages to the body. One message starts muscles to move the stool down through the bowel. Another message lets you know it is time to go to the bathroom and controls the muscle at the opening of the rectum (anus). This muscle allows you to control when the waste (stool) leaves the body. This is often called a bowel movement or BM.

After a spinal cord injury, the message sent by the nerves located in your bowel are not able to reach your brain like before your injury. This means you will not get the message that tells you the bowel is full and it is time to go to the bathroom. Another change is you may not be able to move the muscle at the opening from the rectum (anus) that controls when you have a bowel movement.

How will you have a bowel movement after SCI?

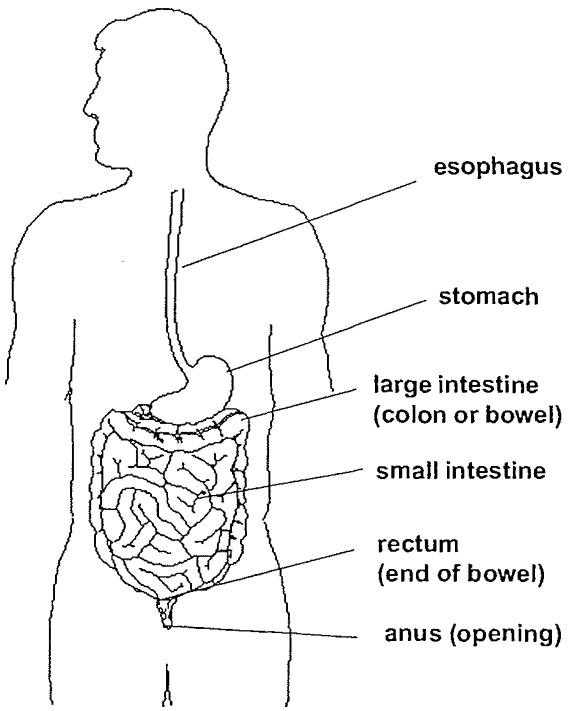
You will need to train your bowels to have a bowel movement at the time you want. Your bowel program outlines the steps you need to take in order to have a BM. You and your doctor will decide which bowel program is best for you, based on the kind of spinal cord injury that you have.

How does your level of SCI affect your bowel program?

If you have an SCI above the T12 level, your program will differ from someone who has an injury below T12.

An injury above T12 is usually called an upper motor neuron injury. UMN are nerves located within the spinal cord. With this type of injury you do not receive the message telling you the bowel is full. The muscle that controls the opening and closing of the anus stays tight. When the bowel gets full it will empty by reflex (or automatically). Your doctor and nurse call this problem an upper motor neuron or reflex bowel.

The Digestive System



An injury below T12 is usually called a lower motor neuron (LMN) injury. The LMN are nerves that branch out from the spinal cord and go to other body parts and organs. With a LMN injury the messages do not get to the spinal cord. That means your reflexes do not work normally and the anal muscles stay relaxed. Your nurse and doctor call this lower motor neuron or flaccid bowel.

What are the different types of bowel programs?

Individuals with a spinal cord injury above T-12, or with an upper motor neuron (UMN) injury, follow a bowel program that usually includes taking daily stool softeners or using a laxative along with digital stimulation.

Stool softeners are medicines like (pericolace or senokot). You want the stool to remain soft so it is easier to empty the bowel.

A suppository is medicine shaped like a bullet that you put in your rectum. The ingredients in the suppository help trigger the muscles and nerves in the bowel so you have a BM. It helps you have a bowel movement at the right time and avoid accidents. At first, it is likely that you will use Dulcolax suppositories. Later you may want to try glycerine suppositories. They are gentler and cheaper. Dulcolax also is available in pill form that can be taken by mouth.

You will learn, by trial and error, what medicines you need to make your bowel program work for you. Some people do not need to use both suppositories and stool softeners. Your body will let you know what you need.

The bowel program for an individual with an injury below T-12 is manual removal (disimpaction) of the stool. At first you will do this program every other day. Later, you may need to do this more frequently to avoid unplanned bowel movements or accidents. Your bowel program may need adjusting, depending on what and how much you eat. You may need to do your bowel program both after breakfast and dinner to avoid accidents (unplanned BM's).

What you need to do to help make your bowel program work for YOU?

For best results with your bowel program try to:

1. Do your bowel program at the same time every day. You want to teach your bowels when to have a BM. You can train your bowels by following a regular schedule.

2. Transfer to a toilet or bedside commode. It helps to sit up during your bowel program. Remember, gravity helps move the stool down into the rectum.

   Do not use a bed pan. A bedpan may damage your skin.

   If you can not sit up on a toilet or commode, lay on your left side. The bowel ends on the left side of your body. This makes it easier to complete the BM.

3. Do your bowel program about 30 minutes after a meal or a high fiber snack. If you are not able to do your bowel program right after your meal, do it as close to your regular time as possible. Eating some high fiber food (such as fruits, popcorn, cereal, bran muffins) and drinking a warm liquid (such as hot tea, warm prune juice, hot lemonade, hot apple cider) before using a suppository, will help you have a BM. The new food going into your digestive system starts the intestines to move the stool out of your body.

4. Take time to complete your program in private. If you share a bathroom, find a time when you can relax and not be rushed.

5. Keep the stool well formed. If your stool is either too hard or too soft, it will be difficult to empty your bowel. You may need to adjust your stool softeners or diet. Some medicines, like antibiotics, may cause you to have softer or loose stools.

6. There are assistive devices available that can help individuals with limited hand function do their own bowel program. Ask your nurse about a suppository inserter, a finger extension, or a digital stimulator if you have problems doing your own bowel program.

Steps to follow in your bowel program

REMEMBER:The lining of the rectum is delicate. Be gentle when placing the suppository, removing stool, or doing digital stimulation during your bowel program.

How to do digital stimulation.

1. Wash your hands.
2. Put on exam gloves.
3. Insert a lubricated gloved finger into the rectum (Coat the gloved finger with a lubricant such as, K-Y jelly).
4. Move the finger gently in a circular motion for several minutes.
5. If you have little or no results after 10-15 minutes, try again. If that fails, you may use a suppository.

How to give yourself a suppository

1. Wash your hands.
2. Put on exam gloves.
3. Insert lubricated gloved finger into the rectum. (Coat the gloved finger with K-Y jelly to lubricate.)
4. Remove any stool that is in the rectum. (If you put the suppository into stool it will not work.)
5. Take off the wrapper and coat the suppository with a lubricant (KY jelly).
6. Insert suppository into the rectum as high as you can and place it against the wall of the intestine (bowel).
7. If after waiting 30 - 45 minutes you have had little or no results, you may need to do digital stimulation. Do this until the rectum is empty.
   Note * If you have a bowel accident during the day, still use the suppository after your meal in the evening. This will help keep your body on schedule for regular bowel movements.

How to do manual disimpaction. (remove by hand)

1. Wash your hands.
2. Put on exam gloves.
3. Inset lubricated gloved finger into the rectum.
4. Remove stool that is in the rectum with your finger.
5. Continue to remove the stool until you cannot feel or reach any stool in the bowel.
6. Wait a few minutes and check your rectum again to make sure you emptied your rectum of stool.

How to handle problems with your bowel program

Constipation

Signs:
* Hard, stone-like stools
* Irregular bowel movements
* No bowel movement in several days
* Swollen or hard stomach
* Lack of appetite

Causes:
- Not drinking enough fluids
- Not following a scheduled bowel program
- Not eating a diet with plenty of fiber
- Not getting enough activity
- Not taking stool softener
- Some medications: pain medications, iron, and certain anti-acids

Solutions:
* Eat a balanced diet that includes plenty of foods high in fiber.
* Drink at least 8-9 (8 oz) glasses of water/liquid a day.
* Stay on a scheduled bowel program.
* Keep active.
* Use a stool softener (Surfak, Colace, Castor Oil).
* Add a dose of fiber for bulk (Metamucil Fibercon, Senokot, or Citrucel).

Impaction

Signs: Same as for constipation
Causes: Same as for constipation
Solutions: Gently remove stool from rectum with a lubricated, gloved finger. If this does not help, use an enema.
If you become more uncomfortable, call your doctor.

Diarrhea

Signs: Many, loose and watery stools
Causes:
- Eating foods that are spicy, high in fat, or contain caffeine (coffee, tea, chocolate, or cola drinks)
- Over use of stool softeners/laxatives
- Medications that irritate the stomach or intestines
- Antibiotics may cause you to have soft or loose stools
- Medical problems, like the flu
- Emotional problems, stress
- Poor diet

Solutions:

* Check your diet for foods that disagree with you.
* Stop taking any laxatives until the diarrhea stops.
* Stop using stool softeners. After diarrhea is over, adjust your dose until your stool is of proper hardness.
* Drink plenty of liquids to prevent dehydration.

*** **If the diarrhea lasts longer than 24 hours or there is blood in the stool, call your doctor.**

Autonomic Dysreflexia

Autonomic Dysreflexia is a response to a painful stimulant. This pain can be caused by hemorrhoids, rough digital stimulation, or a full bowel.

If you have an AD attack during your bowel program, try the following.

* Keep on a regularly scheduled bowel program with adequate emptying. You may have to increase the frequency of your bowel program.
* Get in a comfortable position during bowel program.
* Use anesthetic ointment on the anal area 5-10 minutes before digital stimulation.

How to Prevent Bowel Accidents

The best way to prevent bowel accidents from happening is to follow a schedule for your program. You want to teach your bowels when to have a BM. You can train your bowels by following a regular schedule.

If you are on a regular schedule and know you are emptying well, but still have accidents, keep track of what you eat and drink. Foods are often the cause of the problem.

Antibiotics may cause you to have softer or loose stools. Taking less of your stool softener medication may help.

How to have a successful bowel program

To avoid problems with your bowel program, remember what you can do to help your **S-E-L-F!****

Schedule:

Plan a time every day or every other day to do your bowel program. It works best if it is after eating a meal. Keep the same schedule every day. Plan ahead for special occasions that may interrupt your normal schedule to avoid problems.

Exercise:

The more active you are, the easier it is for the food you eat to travel through your digestive system. Get out of bed and exercise some every day.

Liquids:

An important part of your diet is liquids. Drink at least 8 - 9 (8oz) glasses of liquid each day. This will keep your BM from getting too hard and prevent constipation or impaction.

Food:

Eat a variety of foods every day, especially foods with fiber. Fiber (roughage) is found in fresh fruits and vegetables and whole grain breads and cereals. Roughage helps control your bowels and prevents constipation. Try to limit spicy foods, greasy foods, and "junk" foods. Eat foods like fruits and vegetables, such as apples, beans, carrots, okra, potatoes, greens, and green salads.

Remember! If a specific food gave you diahrrea or constipation before your injury, it still can - and probably still will.

** This idea was adapted from the (SILS [Spinal Injury Learning Series]Norris, Noble, and Strickland: Learning Systems, Jackson, Mississippi, 1978.)

Published by:
Medical RRTC on Secondary Conditions of SCI
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619 19th St. S, Birmingham, AL 35249-7330
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This publication is supported in part by a grant (#H133B980016) from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitation Services, Dept. of Education, Washington, D.C. 20202. Opinions expressed in this document are not necessarily those of the granting agency. **The University of Alabama at Birmingham provides equal opportunity in education and employment.**

CONTINUED FROM OTHER SIDE

Spontaneous Voiding

The bladder muscles contract to start the bladder-emptying process. This may be under your control (voluntary) or not (involuntary):

A. **Normal Voiding.** This is done under your control. When the bladder gets full, messages are sent to the sacral level of the spinal cord and carried to the brain. The brain sends messages back to the bladder to contract, and to the sphincter muscle to open, so you can void.

B. **Sphincterotomy.** This surgical process weakens the bladder neck and sphincter muscle to allow urine to flow out more easily. After this surgery, you will urinate involuntarily, and must wear a collection device.

C. **Condom Catheter.** These collection devices are worn by men for incontinence problems or after sphincterotomy (see above). They are made of latex rubber or silicone that covers the penis and attaches to a tube that drains into a collection bag.

Stimulated Voiding

Voiding is encouraged in one of several ways, such as:

A. **Anal or Rectal Stretch.** This method for relaxing the urinary sphincter is usually used along with an abdominal corset and valsalva (see below).

B. **Credé.** This method involves manually pressing down on the bladder.

C. **Tapping.** The area over the bladder is tapped with the fingertips or the side of the hand, lightly and repeatedly, to stimulate detrusor muscle contractions and voiding.

D. **Valsalva.** This method involves increasing pressure inside the abdomen by bearing down as if you were going to have a bowel movement.

Surgical Alternatives

A. **Mitrofanoff.** A passageway is constructed using the appendix so that catheterization can be done through the abdomen to the bladder.

B. **Bladder Augmentation.** Surgical enlargement of the bladder.

C. **Sphincterotomy.** See the description of this procedure in the "Spontaneous Voiding" section.

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Staying Healthy After a Spinal Cord Injury

BLADDER MANAGEMENT

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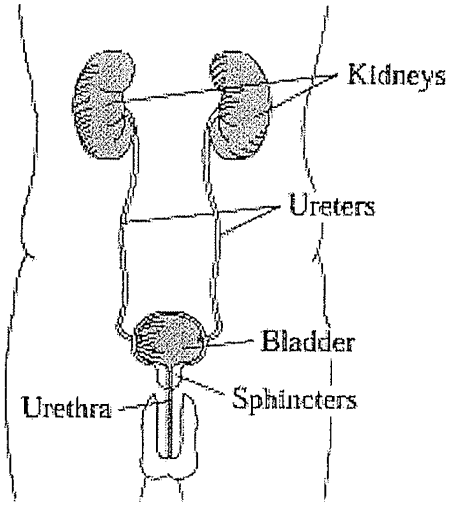
The Urinary System

The Urinary System is made up of five major parts:



The Kidneys

The two kidneys filter waste and excess water from the blood and produce urine. Urine is being produced every minute of the day.

The Ureters

Each kidney has a thin, hollow tube that connects to the bladder. Urine flows down the ureters from the kidneys and empties into the bladder. The ureters have one-way valves in them, so even if you were to stand on your head urine could not flow back to the kidneys from the bladder.

The Bladder

The bladder is a collapsible sac lying in the pelvis. It is able to stretch to hold urine until you are ready to urinate. The bladder walls are made up of a series of muscles known collectively as the *detrusor muscles*. When you are ready to urinate, the detrusor muscles contract (squeeze) to help push the urine from the bladder. The lower portion of the bladder, which funnels urine into the urethra, is called the *bladder neck* or *bladder outlet*.

The Sphincter Muscles

The internal and external sphincter muscles form a ring around the urethra to keep urine in the bladder. When you are ready to urinate, these muscles relax to allow urine to flow out of the bladder.

The Urethra

The urethra is a small tube that allows urine to flow from the bladder to outside the body. The male urethra is 8-10 inches long and the female urethra is 1-2 inches long. The external urethral opening from the body is called the *meatus* for both men and women.

Voiding (Urination)

Normally, when the bladder becomes full (about 1-2 cups for most people), nerve endings in the bladder wall send a message to the brain via the spinal cord. The brain sends a message back to the bladder to *contract the detrusor muscles* and *relax the sphincter muscles* so you can void. If you can't get to a toilet, the brain delays the messages until you are ready to void.

After spinal cord injury

The bladder, along with the rest of the body, undergoes dramatic changes. Since messages between the bladder and the brain cannot travel up and down the spinal cord, the voiding pattern described above is not possible.

Depending on your type of spinal cord injury, your bladder may become either "floppy" *(flaccid)* or "hyperactive" *(spastic* or *reflex)*.

The Flaccid Bladder

A floppy bladder loses detrusor muscle tone (strength) and does not contract for emptying. This type of bladder can be easily overstretched with too much urine, which can damage the bladder wall and increase the risk of infection.

Emptying the flaccid bladder can be done with techniques such as Credé, Valsalva, or intermittent catheterization. It is very important that you do not let your bladder get overfull, even if it means waking up at night to catheterize yourself more frequently.

The Reflex Bladder

The detrusor muscles in a hyperactive bladder may have increased tone, and may contract automatically, causing incontinence (accidental voiding). Sometimes the bladder sphincters do not coordinate properly with the detrusor muscles, and medication or surgery may be helpful.

Bladder Management

Foley or Suprapubic Catheter

A tube is inserted through the urethra or abdomen and into the bladder, where a balloon on the end holds it in place. It remains in the bladder and drains constantly, so the bladder is never full.

Intermittent Catheterization

You drain your bladder several times a day by inserting a small rubber or plastic tube. The tube does not stay in the bladder between catheterizations.

CONTINUED OTHER SIDE

Living with spinal cord injury

http://www.spinalinjury.net/html/_bladder_care_and_management.html

"Bladder Care and Management"

By: RRTC in Secondary Complications in SCI at the University of Alabama at Birmingham, Dept. of P M & R

The body's urinary system has three major functions. It makes urine in the kidneys; stores urine in the bladder; and removes urine from the body through the urethra. The kidneys filter waste products and water from the blood to form urine. The urine moves from the kidneys to the bladder through tubes, called ureters. The bladder temporarily stores the urine. The bladder is made of muscle and can stretch to hold about 2 cups of urine. The muscles (sphincters) at the neck of the urethra control the flow of urine from the bladder. When the sphincter muscles relax, the urine flows out through the urethra. The urethra is a slender tube that runs from the bladder to the outside of the body. Once the bladder startsto empty, it normally empties all of the urine.

How the Urinary System Works After a Spinal Cord Injury: Nerves near the end of the spinal cord (the sacral level of the spine) control how the urinary system works. The spinal cord injury usually does not affect how the kidneys work or how the urine collects in the bladder. The changes that usually take place after an SCI are how the bladder and sphincter muscles work. After a spinal cord injury, messages can no longer travel normally between the bladder or sphincter muscles and the brain. Individuals usually can not feel when the bladder is full or they do not have the "urge" to urinate. The bladder muscles and sphincter muscles must work together so you have control of when you urinate (empty your bladder). These muscles also cause the bladder to empty completely.

What is a Bladder Management Program? A bladder management program allows you to plan for bladder emptying in an acceptable manner when it is convenient for you. This helps you avoid accidents and prevent infections. Your level and type of injury affect the choice you and your doctor make for your bladder program. Because each person's injury is different, your doctor will probably conduct some tests to see how your bladder functions. You also need to consider your hand function. How easy is it for you to do your own bladder program? Can you manage alone or will you need help? During your rehabilitation you learn different ways to empty your bladder. The methods most frequently used are intermittent catheterization (ICP); indwelling catheter (Foley); and the condom external catheter for males. You may use just one program or a combination of methods. You will need to decide the method that works best for you.

How does level of injury affect your Bladder Management Program? Generally there are 2 ways the bladder works after a spinal cord injury. Spastic or Reflex Bladder means that when your bladder fills with urine, a reflex automatically triggers he bladder to

empty. The problem with a spastic bladder is you do not know when the bladder will empty. You are also at greater risk for sphincter dyssynergia [see explanation under problems]. Spastic or Reflex bladder usually occurs when the injury is above the T12 level. The choices in bladder management methods for an individual with a spastic/reflex bladder include ICP, indwelling catheter (Foley), and condom catheter(males). Flaccid or non-reflex bladder means one's reflexes may be sluggish or absent. You may not feel when the bladder is full. It then becomes over-distended or stretched. This can cause the urine to back up through the ureters to the kidneys. Stretching also affects the muscle tone of the bladder. Individuals with injuries below T12/L1 usually have a flaccid bladder. The bladder management program most commonly used with flaccid bladder is ICP To avoid problems, do not allow too much urine (over 400cc) to collect in your bladder if it is flaccid.

Urinary Tract Problems: Kidney (renal) failure used to be the leading cause of death for individuals with a spinal cord injury. Today with the improved methods of bladder management, there are fewer and less severe complications with the kidneys. The more common cause of death related to the urinary tract is now sepsis (a blood stream infection resulting from a symptomatic infection in the urinary tract) rather than kidney failure. The loss of normal bladder function after spinal cord injury places one at increased risk for urinary tract infection (UTI), regardless of the type of bladder management used. A urinary tract infection can occur in the bladder, the kidney, or other parts of the urinary tract. Urinary tract infection remains the most common secondary medical complication following a spinal cord injury and it is certainly one of the most costly.

Urinary Tract Infection: Most persons with a spinal cord injury (80%) have bacteria in the urine that are identified by a urine culture. This is not considered serious unless it leads to signs or symptoms. Your doctor may be able to identify a serious UTI by its symptoms and a physical exam. Bladder infection (cystitis) is the most common. Symptoms of a bladder infection may include going to the bathroom frequently, passing blood in the urine, cloudy and odorous urine, increased spasticity in the lower extremities, fever and chills. Depending on your level of injury, you may feel a burning with urination, or discomfort in the lower pelvic area, abdomen, or lower back. Infection of the testicles (epidymitis) can have any of the symptoms of a bladder infection plus the scrotum is swollen, hot and red. An individual with an incomplete injury may feel pain in the testicles.

Treatment of UTI: Because symptoms are similar for any UTI, you must see your doctor for lab tests to determine the need for treatment. Research shows that UTIs that do not have symptoms usually do not need treatment with antibiotics. Use an antibioticonly when symptoms (fever, chills and pain) are present. Excessive treatment with antibiotics may lead to resistant strains of bacteria, which become more difficult to treat

Medical Problems in the Urinary Tract: Other medical problems can develop in the bladder, kidneys, and ureters. Dyssynergia occurs when the bladder contracts but the sphincter does not open. The urine can"back up" in the kidneys. This is called "reflux" action. Treatment includes medications or surgery to open the sphincter. Kidney and

bladder stones can form. They interfere with the function of the kidney/bladder and cause infection. Incontinence or urine leakage may be a problem for some individuals. Treatment can include both drugs and surgery. Medications are often used to control bladder spasms and tighten the sphincter muscles. Several surgical options are available for treating incontinence, including various forms of urinary diversion. A new urinary reservoir ("pouch") is made from bowel tissue. The ureters are implanted into the new bladder "pouch". The urine is drained through an opening (stoma) in either the navel or stomach wall. A new surgical method is bladder augmentation cystoplasty. Here the bladder is enlarged using bowel tissue. Since surgery involves both the urinary and gastrointestinal systems, recovery time is longer.

Bladder Cancer: Research in aging with SCI shows a small increase in the risk of bladder cancer among individuals with spinal cord injury who have been using indwelling catheters for a long period of time. In a study at Craig Hospital the rate of bladder cancer was only .2% in those seen over the first 10 years post-injury. But by 30 years post injury the risk was at 9%. If you've used an indwelling catheter for more than 10 years, have regular cystoscopic evaluations. Smoking also increases the risk for developing bladder cancer

Treating Medical Problems in the Urinary Tract: Often problems in the urinary tract do not have any symptoms. This means they can go undetected until they become serious. Your routine physical exam and laboratory studies are the best ways to find problems early and treat them before they become serious. Your doctor can then treat problems before there are serious complications.

Keeping your Urinary System Healthy: Individuals with SCI are more likely to have UTIs or problems with the urinary system. To avoid problems and keep your urinary system healthy, Empty your bladder completely After your SCI, you may not have the "urge" to urinate. Your bladder often does not empty completely. When the bladder does not empty completely, germs or bacteria are likely to grow in the urine left in the bladder. These bacteria can cause an infection in the bladder. Use a "clean technique" catheterization. Always wash your hands before and after doing the catheterization. Be sure your catheter and equipment are clean. Keep Skin Clean and Dry Research studies show that harmful bacteria usually remains on the skin in the genital area of individuals with SCI. This may be related to skin moisture, urine leakage, pH, local skin temperature, personal hygiene, and/or neurogenic bowel management. If you have urine leakage or a bowel accident, change your wet, soiled clothes immediately. Clean the area around the genitals with soap and water everyday. Drink plenty of liquids A steady intake of fluids helps "wash out" bacteria and waste materials. Drinking the recommended amount of liquids helps avoid problems and lessens the chance of stones forming. How much fluid you need to drink each day depends on your bladder management program. With an indwelling catheter, you need to keep your fluid intake high. This means drinking 15 - 8 oz. glasses or 3 quarts of liquids each day. If you do intermittent catheterization, you need to drink 8 to 10 - 8 oz. glasses or 2 quarts between breakfast and dinner. The recommendation is to make water your "beverage of choice". Make it your #1 beverage and drink all other beverages in moderation. Limit carbonated beverages to 1 per day.

Keep Bladder Pressures Low: While you need to drink the recommended amount of fluids, you also need to empty your bladder on a regular schedule. With ICP, your goal is to limit the amount of fluid that collects in the bladder to 8 ounces or less (400cc). This means you can intake about 4 oz each hour while awake. Drinking more than this causes the bladder to overstretch, making you more susceptible to infection or reflux. You need to catheterize more frequently if you drink more.

Take Medications As Prescribed: There are different times that your doctor may prescribe medication to treat problems related to your bladder management program. It is very important to take only the medication that is prescibed and to finish taking all the medicine as directed.

Have a Regular Urologic Check-up: If you have infections and get ill more than once or twice a year, this alerts you that something may not be right with your bladder management program. Check with a urologist to see how your bladder is working. A regular urologic exam that includes renal scan and KUB is recommended. The renal scan checks to see how your kidneys are functioning. The KUB is simply an X-ray of the abdomen that can detect kidney or bladder stones. These tests may be done once every 6 months, annually, or every 2 years, depending on your medical history.

Case Scenario – Cody
Assessing Children

You have recently been contacted by the Regional Center requesting an IHSS evaluation. You are completing the initial assessment.

Cody is an eight-year-old child who was diagnosed with Cerebral Palsy at birth. Cody's mother states that she recently moved here from another state because she had heard through an online support group that she would be able to get more help for Cody in California and get paid for taking care of him. She states that the only help she received in the prior state was with doctor visits and physical and occupational therapy. She states that she stopped working when Cody was born, and that in her former state, she received SSI for Cody and subsidized housing vouchers.

When you arrive for the assessment, you find Cody seated in his wheelchair in the living room with his mother. His wheelchair appears to be standard but much too large for him. His mother states that she has learned through her online support group that there are many services that Cody can get through IHSS. She states that she would like help with housework because she does not have time to do this while taking care of Cody and maintaining her new website for single parents who provide care to children with Cerebral Palsy. She would also like help with preparing meals for him, doing the laundry for both her and her son, and shopping and errands since she does not have time to do these tasks. She also would like help with all of Cody's personal care. She states that Cody will begin his new school in the next week. The bus will pick him up at 8:30 a.m. and return him home at 3:30 p.m. each day. His mother states that she is looking forward to him going to school again so she can have more time for herself and her online support group activities. Cody's mother also states that she would like to have respite care authorized for Cody so that she can attend support groups and get away.

Group Tasks:

Based on the information above and using the Annotated Assessment Criteria, Age Appropriate Guidelines, and other resources, answer the following questions:

1. Using the Age Appropriate Guidelines, identify those categories that you would assess as a "1" because children of Cody's age would not be expected to complete those tasks.
2. Identify how you would address the need for help with Domestic and Related Services with Cody's mother.
3. Identify contacts you would make to obtain additional information.
4. Identify any referrals that you would make.
5. Identify how you would address the request for respite.
6. Identify alternative resources that may reduce the assessed need for services.

Case Scenario – James
Assessing Children

James is a 12-year-old male with muscular dystrophy who lives in a two-bedroom apartment with his mother. He is incontinent and has issues with skin breakdown. He wears braces on his legs and uses a wheelchair to move from room to room. He attends school five days per week from 8:00 a.m. to 3:30 p.m.

At the last assessment, the county assessed his FI rankings as follows:

Housework 5
Laundry 5
Shopping 5
Meal Prep/Cleanup 5
Bathing and Grooming..... 4
Dressing 4
Bowel and Bladder..... 4
Transfer 4
Eating 1
Respiration 1
Memory 1
Orientation 2
Judgment 2

James' mother is his provider and indicates that she must do all Domestic and Related Services for him. She states that she must assist him in and out of the shower, help him wash his body and shampoo his hair, and assist with his oral hygiene and grooming. James is able to transfer independently from his wheelchair to his bed or to a couch or chair, and eat independently, although his mother must cut his food for him. At the interview, James is alert and friendly. He states that he likes school and is interested in computers.

In completing the SOC 293, the social worker indicated a need for Domestic and Related Services which were prorated to reflect two persons in the household and then shown as met by an alternative resource, his mother, with no hours authorized for purchase. A need for personal care was assessed for Bathing and Grooming, Dressing, Bowel and Bladder Care, and Moving In and Out of Bed. The SOC 293 indicates that no alternative resources are available for personal care services.

Group Tasks:

Based on the information above and using the Annotated Assessment Criteria, Age Appropriate Guidelines, and other resources, answer the following questions:

1. Using the Age Appropriate Guidelines, identify how you would assess the FI rankings for Domestic and Related Services.
2. Discuss whether there are any other FI scores that do not seem to be consistent with the available information.
3. Discuss whether the information provided indicates that there are alternative resources available, and if so, who would the potential provider(s) of these resources be and what services may be available?

Case Scenario – Joe

Joe is a 19-year-old male, living in a house with his parents, Nola and Jim, and his siblings, Kathy (age 11) and Billy (age 10). The following is a summary of the documentation in the case file from the last assessment:

- Joe was diagnosed with schizophrenia at age 16. Joe stated that he is afraid of strangers, believes people are following him, and that he is afraid to go anywhere without at least one of his parents. Joe's mother stated that Joe will not take his medications – he believes that someone is trying to kill him through the medications – without direct and persistent encouragement. She expressed frustration that it seems to take her longer and longer to get him to take his medication.

- Nola states that Joe would not eat if she did not make him eat three meals a day. She also states that Joe does not go near the stove because he believes there are transmitters hidden in the stove which are trying to take over his mind. Joe requires other family members eat a few bites of their food before he eats. When asked during the home visit about his ability to assist his family when they are cleaning up after meals, Joe stated "that is woman's work." His mother states that Joe refuses to help clean up after meals for this reason. Joe does, however, enjoy doing laundry, and he is always willing to assist his mother with the family's laundry. His mother complained that she has a difficult time getting Joe to clean his room and sometimes it takes her several days to get him to make his bed.

- Joe's mother states great frustration with Joe's ongoing refusal to bathe or to change his clothing. She further states that she must be in the room with him when he bathes and dresses, because without constant reminding and supervision, he would just get in the shower, barely wet his hair, put the same clothing back on, and be done. She also says Joe has obsessive thoughts about his teeth (brushing them 4-6 times during the day), and that she does not trust him to shave without close supervision.

- According to Joe's father, Jim, on at least two separate occasions Joe tried to harm his brother when the two were home without parental supervision, because the brother took one of Joe's Pokémon cards. The father further stated that Joe recently killed the family cat. His mother finally had to leave her job to provide 24-hour care to Joe because of his behavior.

- Joe's parents request Domestic and Related Services and Personal Care as well as Protective Supervision because they are afraid that leaving him alone his siblings will result in physical harm to them.

You have recently conducted a reassessment and find that there are several changes that have occurred since the last assessment.

- Joe is withdrawn during the assessment and refuses to answer any of your questions. His mother states that he has been detained on a 5150 hold twice in the last year for aggressive behavior toward his brother. His bedroom is very disorganized and dirty. He refuses to do any housework and does not allow his mother in his room to clean it.

- Nola states that for about the past six months Joe has been hearing voices that compel him to kill himself. He will no longer leave the home and refuses to bathe or change his clothes. You note that he appears very disheveled and has a strong body odor. He no longer helps with the laundry and still will only eat food after another family member has eaten several bites.

- Nola insists that Joe needs Protective Supervision without which he would be at risk for seriously injuring or killing himself or others. Jim's father stated he is considering placing Joe in a locked facility.

- A new medical evaluation received from Joe's primary care physician states that Joe is at risk of placement and needs assistance with personal care and domestic and related services. The SOC 821 completed by Joe's psychiatrist states: "Patient's schizophrenia compromises his ability to perform complex tasks, or to plan. When properly supervised, he can sometimes perform simple tasks and follow sequential instructions; however, he sometimes experiences episodes of extreme delusions and hallucinations which can lead to violent behavior. Patient requires 24-hour Protective Supervision because he refuses to take medications, and could become violent towards others."

Mental Illness 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 characteristics of Gary's obsessive-compulsive disorder.
2. Gary's IHSS functional limitations.
3. Techniques 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.

Characteristics	Functional Limitations
Techniques for Interaction	

Svetlana – Depression

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.

Group Tasks:

Based on the information provided, list your answers on the flipchart using the format illustrated below:

1. The characteristics of Svetlana's depressive disorder.
2. Svetlana's IHSS functional limitations.
3. Techniques that would help in working with Svetlana.

Characteristics	Functional Limitations
Techniques for Interaction	

Joan – Hoarding

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 characteristics of Robert's schizophrenia.
2. Robert's IHSS functional limitations.
3. Techniques that would help in working with Robert.

Characteristics	Functional Limitations
Techniques for Interaction	

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 who various family members were. 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 which resulted in the fire alarms going off. 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.

Case Scenario – Rochelle
Assessing Complex Medical Conditions

Rochelle is a 32-year-old female who resides in a three-room trailer with her provider, a male adult friend. Her provider does not have another job and states that he is with her 24-hours per day, 7 days per week. Her diagnoses include Multiple Sclerosis, depression, and migraines. During the current assessment, Rochelle states that in the last year, she has begun having seizures. You find that the assessment is more complex because her condition can vary from one day to the next. She can be independent in a particular activity on one day and totally dependent in that activity on the following day.

At the reassessment, Rochelle meets you at the door and walks the few steps to the chair where she remains seated during the interview. She states that her method of ambulation changes from day to day. The trailer has a very narrow hallway so she sometimes uses the walls to brace herself when she ambulates from room to room. She states that at times she crawls from room to room. She states that she uses a wheelchair when outside of the home, but you note that there does not appear to be room for a wheelchair in the narrow hallway. Rochelle indicates that on some days, she does not get out of bed.

She also tells you during the interview that she has problems with her memory. She seems unclear about many of her responses to your questions. She states that she does not know how many hours or what services are approved for her.

Rochelle indicates that she is intermittently incontinent of bowel and bladder, but that on good days, she is independent in this area. She states that she has become increasingly depressed over her deteriorating condition. She indicates that when she discussed this with her regular physician, he indicated that the depression was normal.

As you leave the interview, the provider accompanies you to your car and states that he is becoming depressed as well about the continuing amount of care he must provide and the fact that he is not able to get away at all because of Rochelle's needs.

Group Tasks:

Based on the information above and using your resources, answer the following questions:

1. How would you assess the need for Ambulation, Bowel and Bladder Care, Menstrual Care, and Bathing and Grooming?
2. Indicate the questions that you would ask and how you would assess the need, taking into consideration good days versus bad days.
3. Indicate any other actions/referrals that you would initiate based on what you learned during the home visit.

Case Scenario – Michael
Assessing Complex Medical Conditions

Michael is a 28-year-old male who became a C-5 quadriplegic as a result of an automobile accident approximately 10 years earlier. He resides with his 59-year-old mother. He has been receiving IHSS since he was discharged from the hospital following the accident.

You have recently been assigned to Michael's case and are in the process of conducting a reassessment. In reviewing the case prior to the home visit, you note that the original paramedical form (SOC 321) obtained following discharge from the hospital is being used to assess the need for paramedical services. In reviewing the provider's information and timesheets, you also note that the file indicates that Michael has frequently changed providers. Although his mother has medical problems of her own, she provides care for Michael when he does not have any provider or when the provider is not there. During the prior assessments, 283 hours were assessed. The notes indicate that Michael is "total care." Although the face sheet has been updated during prior home visits, the narrative notes primarily indicate that there have been no changes in his condition.

When you conduct the home visit, Michael is in his hospital bed in the bedroom. He appears to be very angry and non-communicative. You have difficulty obtaining information from him and end up getting much of the information from his mother. She verifies that Michael is very difficult to communicate with, has frequent outbursts, and is verbally abusive to her and his providers at times. She states that the current provider has only been working for about one week and that if Michael doesn't start treating the new provider better, she will probably end up quitting too. She indicates that the Public Authority has been helpful in making referrals. However, they recently stated that they would not be able to continue doing so because they were running out of people who could provide the care he requires. She states that sometimes she feels that Michael would be better off in a nursing home, but then states that she would never consider this because she feels he would deteriorate and she would be abandoning him. She states that Michael has two brothers and a sister in the area, but they refuse to visit or help with his care because Michael is also verbally abusive with them.

In discussing with her the need for Bowel and Bladder Care and Transfers, she states that she must do all bowel care for Michael and that he uses a condom catheter. You observe that there is a Hoyer lift in the bedroom. She states that all transfers are done using the lift. Michael's mother states that she believes he could do some things such as feeding himself, shaving, and brushing his teeth, but he refuses to do anything. She states that the current hours do not reflect all of the time that is spent caring for him.

Group Tasks:

Based on the information above and using your resources, answer the following questions:

1. What specific questions should be asked in order to correctly assess the need for Bowel and Bladder Care and assistance with Transfers?
2. Determine steps to follow to appropriately assess Paramedical services.
3. Discuss the situation regarding Michael's anger and treatment of his mother and providers.
4. Discuss any referrals that you would make. What suggestions would the group have for obtaining additional providers?
5. How would you evaluate his mother's statement about him being able to do more for himself and would this affect your assessment of the need for services?
6. How would you address his mother's statement regarding placing him in a SNF?
7. Discuss whether the statement that all quadriplegics are total care and should receive the maximum number of hours of service is correct.