

5) Bill experiences seizures on a regular basis. His IQ is 125 (100 is average). He also has cerebral palsy, which makes it difficult for him to speak clearly or walk more than a few steps. Based on this information, which of the following labels might accurately apply to Bill?

- a. epilepsy
- b. intellectual disability
- c. developmental disability
- d. cognitive disability
- e. country music fan



6) Susie has an IQ score of 69. She has been married for 22 years and is a full-time homemaker. Her husband is an electrician. Susie is not a good money manager, so her husband pays the bills and manages the accounts. Based on this information, which of the following labels might accurately apply to Susie?

- a. epilepsy
- b. intellectual disability
- c. developmental disability
- d. cognitive disability
- e. bad housekeeper

7) Match the characteristic with the disability (some may match more than one):

- A. Down syndrome
- B. Prader-Willi syndrome
- C. Fragile X syndrome

_____ The risk of having a child with this syndrome increases with parental age.

_____ Involuntary focus on food, never feels full

_____ 50% of people with this syndrome have congenital heart defects

_____ Girls with this generally are less disabled and perform better than boys

_____ Picking at skin irritations and other compulsive behavior

_____ Whole images, such as pictures, logos, or words can often be recognized well.

What is a Developmental Disability?

Developmental Disabilities Act of 1970: PL 91-517

The Developmental Disabilities Act of 1970 was instituted in order to address the needs of individuals with mental retardation, cerebral palsy, and epilepsy. The reasons these conditions were combined were:

- < They are all major causes of substantial limitations to adults disabled in childhood. In fact, these three disorders account for 80% of adults disabled in childhood.
- < They all tend to cause multiple challenges requiring special and similar services throughout childhood and adult life.
- < There is a significant overlap of the three conditions; for example, half of all people with cerebral palsy are also mentally retarded, as are 20-30% of people with epilepsy.

PL 91-517 also established Developmental Disabilities Councils, state planning bodies made up of consumers/family members, state agencies, and providers, in order to give people more involvement and control in planning DD services.



Following a strong lobbying effort, autism was added to the developmental disability categories in 1975.

How many of the people you support have some type of developmental disability? What is the most common diagnosis? How common is it for people to have more than one disabling condition?

The Categorical Approach

Before 1990, people with mental retardation (now called intellectual disabilities), cerebral palsy, epilepsy and/or autism, were categorically considered to be developmentally disabled -- in other words, the *diagnosis* of one of those disabilities automatically categorized the individual as being developmentally disabled. The categorical definition of developmental disability has three components:

- 1) The disability is manifested prior to the age of 18
- 2) The disability will continue indefinitely
- 3) The disability presents a significant limitation for the individual

Functional Approach

In 1990 a new law, the “Developmental Disabilities Assistance and Bill of Right Act” (PL 101-496) threw out the categorical approach and used a functional approach to re-define development disability in this way:

“The term *developmental disability* means a severe, chronic disability of a person 5 years of age or older that:

- A. Is attributable to a mental or physical impairment, or a combination.
- B. Is manifested before the age of 22
- C. Is likely to continue indefinitely
- D. Results in substantial functional limitation in three or more of the following areas of major life activity:
 1. Self care
 2. Receptive and expressive language
 3. Learning
 4. Mobility
 5. Self-direction
 6. Capacity for independent living
 7. Economic self-sufficiency
- E. Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services that are of lifelong or extended duration and are individually planned and coordinated.”

How does your state establish eligibility for DD services? Is it done by IQ score, and if so, what is the cut off? Is it done by diagnosis alone? Are functional limitations considered? Are there different levels of eligibility?

Cognitive or Intellectual Disability

Here's how the American Association on Intellectual and Developmental Disabilities (AAIDD) defines intellectual disability: (<http://www.aaid.org>). It is a disability that:

- < Occurs before age 18
- < Is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills

[Note: The phrase "significant limitations in intellectual functioning" is defined in terms of an IQ score of 70 to 75 or below. It must be coupled with limitations in adaptive skills.]

"Mental retardation is not something you have, like blue eyes, or a bad heart. Nor is it something you are, like short, or thin.

It is not a medical disorder, nor a mental disorder.

Mental retardation is a particular state of functioning that begins in childhood and is characterized by limitation in both intelligence and adaptive skills.

Mental retardation reflects the "fit" between the capabilities of individuals and the structure and expectations of their environment." (from AAMR website)

Why do you think the AAMR website states that mental retardation is not a medical disorder or a mental disorder? What does that mean?

What are adaptive skills?

Adaptive skills are those learned by people in order to function in their everyday lives.

Significant limitations in adaptive skills affect a person's ability to respond to a particular situation or to the environment. Assessment of adaptive skills looks at areas like these:

Conceptual skills: receptive and expressive language, reading and writing, money concepts, self-direction.

Social skills: interpersonal, responsibility, self-esteem, is not gullible or naïve, follows rules, obeys laws, avoids victimization.

Practical skills: personal activities of daily living such as eating, dressing, mobility and toileting; instrumental activities of daily living such as preparing meals taking medication, using the telephone, managing money, using transportation and doing housekeeping activities;

occupational skills; maintaining a safe environment.¹



¹ www.thearc.org/NetCommunity/Document.Doc?&id=143

How do intellectual disabilities affect individuals?

About 87% of people with intellectual disabilities will only be a little slower than average in learning new information and skills. They may not even be diagnosed as having intellectual disabilities until they get to school. As they become adults, many people with mild ID can live independently. Other people may not even consider them as having a disability.²

***Does this information surprise anybody?
Are these the folks you're working with?***

The remaining 13% of people with intellectual disabilities score below 50 on IQ tests. These people will have more difficulty in school, at home, and in the community. A person with more severe intellectual disabilities will need more intensive support his or her entire life. However, with early intervention, an appropriate education and supports as an adult, all can lead satisfying lives in the community. ³ .

How many people are affected by intellectual disabilities?

Studies have shown that somewhere between 1% and 3% of Americans have intellectual disabilities, depending on how they are counted. Based on IQ score alone, the percentages would be closer to 3% - that's about 8,860,000 in the US.

Causes

It is not possible to identify the exact cause for most people who have cognitive or intellectual disabilities. About half the time, a person's cognitive disability is caused by more than one factor. There are four general causes that are often involved:

* Genetic conditions. Sometimes intellectual disability is caused by abnormal genes inherited from parents, errors when genes combine, or other reasons. Examples of genetic conditions are Down syndrome, fragile X syndrome, and Prader-Willi syndrome.

* Problems during pregnancy. For example, there may be a problem with the way the baby's cells divide as it grows. A woman who drinks alcohol or gets an infection like rubella during pregnancy may also have a baby with intellectual disability .

* Problems at birth. If a baby has problems during labor and birth, such as not getting enough oxygen, he or she may have intellectual disability .

* Health problems. Diseases like whooping cough, the measles, or meningitis can cause intellectual disability . ID can also be caused by extreme malnutrition (not eating right), not getting enough medical care, or by being exposed to poisons like lead or mercury. ⁴



² <http://www.nichcy.org/pubs/factshe/fs8txt.htm> DD and ID Handout Page 6

³ *Ibid* for continuing education in rehabilitation

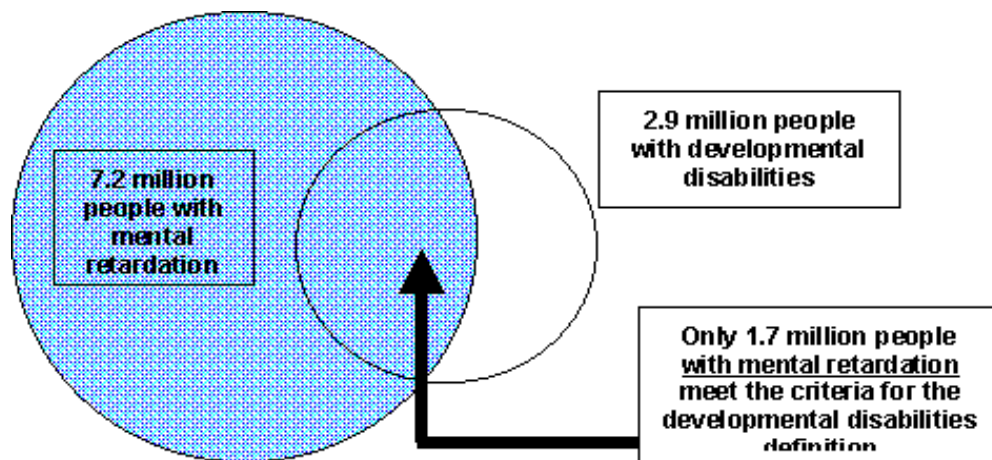
⁴ *Ibid*

Is Intellectual Disability the Same as Developmental Disability?

The definitions of these two conditions overlap, but are not equivalent. Adding to the confusion is that many people think "developmental disabilities" is simply a nicer term for "mental retardation" and do not realize the terms actually refer to two different groups of people.

The major differences are in the age of onset (ID before 18 vs. DD before 22), the number of functional areas impacted (three or more for DD, one for ID), and the fact that the developmental disability definition does not refer to an IQ requirement.

Estimated Number of People with Mental Retardation Who Do Not Meet the Federal Criteria for Developmental Disabilities [\(<http://www.thearc.org/ga/mrdd.html>\)](http://www.thearc.org/ga/mrdd.html)



7.2 million (people with mental retardation in the U.S.)

-1.7 million (people with developmental disabilities who have mental retardation)

5.5 million (people with mental retardation not considered developmentally disabled)

76% of people with mental retardation do not meet the criteria for having developmental disabilities (generally because they don't meet the functional limitation requirement)

42% of people with developmental disabilities do not have mental retardation.

Does it surprise you that a person could have a cognitive disability and not meet the criteria for developmental disabilities? What do you think about that?

What's in a Name?

In American society, being labeled with “mental retardation” can be stigmatizing - and the term is offensive to many people. In reflection of these facts, The Arc recently changed its mission statement to say “we work to include children and adults with cognitive, intellectual and developmental disabilities in every community;” and they discourage states, officials, families or individuals from using the term “mental retardation.” However, they “recognize that the general public, including families, individuals, funders, administrators, and public policymakers at local, state and federal levels, are not necessarily aware that the term ‘mental retardation’ is offensive and outdated.”

What labels are used to describe the people you serve:

How are they labeled by the agencies that pay for services?

What labels do they use to describe themselves?

What labels do you use when you talk about your job (to your neighbor, perhaps)? How about when you talk to potential employers? To other professionals?

A few years ago, a private family foundation offered a \$50,000 prize to the person who could come up with a descriptor for people with disabilities that would be less stigmatizing than “disabled” or “handicapped.” The winner? *“Differently Abled.”*

What do you think about that? In your conversations with others, do you think “differently abled” would be a good substitute for the labels you use now?

Genetic Causes of Cognitive Disability

This exercise offers an opportunity to learn more about three of the genetic causes of cognitive disability. Work alone or with a partner to review ONE of the syndromes and answer the questions below, then report back to your group.

Review the information about the syndrome you're reporting on – Down Syndrome, Fragile X Syndrome, or Prader-Willi Syndrome – and answer the following questions:

1. Is this syndrome inherited, caused by genetic mutation, or both?
2. How common is it?
3. How does it generally impact people?
4. Have you ever worked with a person who had this label? If so, how well did he/she match the written profile you've been provided with today?
- 5a. For Down syndrome: People with Down syndrome are increasingly living through their fifties and beyond. They also tend to have older parents. What implications do these two facts have for agencies like yours?
- 5b. For Fragile X: We know that many men with fragile X have a better receptive (listening) than expressive (speaking) vocabulary. How should you use this information in building job support for an individual?
We also know that for many women with fragile X, "poor auditory memory for sequences may also cause difficulties in mathematics." How might this information be important on the job?
- 5c. For Prader-Willi: People with PWS tend to have obsessive-compulsive behaviors as well as an involuntary focus on food. What kind of support might help these folks be successful on the job?

Down Syndrome

National Down Syndrome Society: <http://www.ndss.org/>

What is Down syndrome?

Down syndrome is the most common genetic condition caused by chromosomal abnormalities. One in every 800 to 1,000 children is born with Down syndrome (about 5,000 per year in the US, affecting approximately 350,000 families).

The most common form of Down syndrome is called Trisomy 21, because it involves an extra copy of the 21st chromosome.

The additional genetic material that causes Down syndrome can originate from either the father or the mother. Approximately five percent of the cases have been traced to the father.

Down syndrome affects people of all races and economic levels.

Women age 35 and older have a significantly increased risk of having a child with Down syndrome - a one in 400 chance at age 35 and a one in 110 chance by age 40. At age 45 the incidence becomes approximately one in 35. Since many couples are postponing parenting until later in life, the incidence of Down syndrome conceptions is expected to increase.



What impact does Down syndrome have on society?

Individuals with Down syndrome are becoming increasingly integrated into society and community organizations, such as school, health care systems, work forces and social and recreational activities. Individuals with Down syndrome possess varying degrees of intellectual disability, from very mild to severe. Most people with Down syndrome have IQs in the mild to moderate range of intellectual disability (35-70).

Due to advances in medical technology, individuals with Down syndrome are living longer than ever before. In 1910, children with Down syndrome were expected to survive to age nine. With the discovery of antibiotics, the average survival age increased to 19 or 20. Now, with recent advancements in clinical treatment, as many as 80 percent of adults with Down syndrome reach age 55, and many live even longer.

Do people with Down syndrome have other health issues?

Individuals with Down syndrome have a higher incidence of certain medical problems than people without this syndrome.

Heart disease: Up to 50 percent of individuals with Down syndrome are born with congenital heart defects. The majority of these can now be surgically corrected

Alzheimer's disease: Estimates vary, but about 25 percent or more of individuals with Down syndrome over the age of 35 will develop the clinical signs and symptoms of Alzheimer's-type dementia.

Leukemia: Individuals with Down syndrome have a 15 to 20 times greater risk of developing leukemia. Most of these are categorized as acute megakaryoblastic leukemia, which tends to occur in the first three years of life and for which there is a high cure rate.

Here are some myths about Down syndrome:

Myth: Down syndrome is a rare genetic disorder.

Myth: People with Down syndrome are severely retarded.

Myth: Most people with Down syndrome are institutionalized.

Myth: Children with Down syndrome must be placed in segregated special education programs.

Myth: People with Down syndrome are always happy.

Myth: Adults with Down syndrome are unable to form close interpersonal relationships leading to marriage.

Fragile X Syndrome

<http://www.fragilex.org/html/summary.htm>

What is Fragile X Syndrome?



Fragile X syndrome is the most common inherited cause of cognitive disabilities. It is caused by a change or mutation in a gene on the X chromosome, and occurs in about 1 in 3600 males and 1 in 4000 to 6000 females.

The physical, cognitive, behavioral, sensory, speech and language impacts of fragile X differ in males and females. In general, females with fragile X either do not have the characteristics seen in males, or the characteristics show up in a milder form.

The difference is probably due to the fact that females have two X chromosomes and males have one X and one Y. As a result, females who have fragile X potentially have two sets of instructions for making FMRP (fragile X mental retardation protein), one of which may be functioning. Males with fragile X have only one X chromosome with its nonfunctioning gene.

It appears that females are able to produce enough of the FMRP to fill most of the body's needs, but not all.

How does Fragile X Syndrome impact people?

Some individuals experience significant challenges because of the effects of fragile X, while the impact on others is so minor that they will never be diagnosed.

Up to 80% of males with fragile X syndrome are described as cognitively delayed.

The affects of fragile X may be complicated by additional issues as attention deficit hyperactivity disorder (ADHD), seizure disorders, anxiety, speech and language disorders, sensory motor problems, and other issues that may impact both test taking and learning.

Many people with fragile X achieve more than would be expected based upon an IQ score.

Males

Cognitive strengths among boys and men with fragile X include verbal labeling and single word vocabulary. Receptive (listening) vocabulary may be higher than expressive (speaking). Vocabulary for subjects of personal interest may also be higher than you would expect based upon overall scores.

Memory for situations and for favorite TV shows, videos, and songs is often excellent. Boys and men with fragile X are often wonderful mimics.

Weaknesses are usually seen in higher-level thinking and reasoning skills – things like complex problem solving, cause and effect questions, and other abstract tasks.

Visual matching and visual perception tasks with meaningful information (e.g. puzzles with a known picture, as opposed to abstract block designs) are often strengths.

Visual cueing is often a powerful learning strategy for males with fragile X, and whole images, such as pictures, logos, or words can often be recognized well.

Quantitative (math) skills are often a weakness for both males and females with fragile X.

(ALSO FOR MANY HUMAN SERVICE PROVIDERS!)

On adaptive functioning scales, many males score well on adaptive living items, indicating good abilities to learn self-care and household management skills, while scoring more poorly on socialization and communication items.

Females

Girls and women with the full fragile X mutation (that is, a mutation on both X chromosomes) may have the same patterns of strength and weakness as do males, but their overall levels of performance are usually higher.

About thirty percent of women with the full mutation have IQ scores of 85 or above; some of these women have specific learning disabilities. Many women with IQs below 85 have scores in the low average range (70 to 85).

Strengths in females are generally found in vocabulary and comprehension items on IQ tests. Strengths are also seen in short-term memory for visual, meaningful material. These strengths are the basis for good achievement in reading, spelling, and writing for many girls and women with fragile X.

Weaknesses are seen in "executive functioning", which refers to abilities in planning, attending, sustaining effort, generating problem solving strategies, using feedback, self-monitoring, and shifting responses. Many of these are higher-level abilities that allow a person to reason and think abstractly. They may also affect conversational processing (understanding the give and take of conversation).

Other weak areas tend to be in nonverbal areas of learning. Spatial relations for abstract information (e.g. block designs) and quantitative processing (e.g. numerical reasoning) are often areas of difficulty, affecting the learning of mathematics. Poor auditory memory for sequences may also cause difficulties in mathematics.

Prader-Willi Syndrome

<http://www.pwsausa.org/>

What is Prader-Willi syndrome (PWS)?

PWS is a complex genetic disorder that typically causes low muscle tone, short stature, incomplete sexual development, cognitive disabilities, problem behaviors, and a chronic feeling of hunger that can lead to excessive eating and life-threatening obesity.



What causes it?

Most cases of PWS are attributed to a spontaneous genetic error that occurs at or near the time of conception for unknown reasons. In a very small percentage of cases (2 percent or less), a genetic mutation that does not affect the parent is passed on to the child, and in these families more than one child may be affected. A PWS-like disorder can also be acquired after birth if the hypothalamus portion of the brain is damaged through injury or surgery.

How common is it?

It is estimated that one in 12,000 to 15,000 people has PWS. Although considered a "rare" disorder, Prader-Willi syndrome is one of the most common conditions seen in genetics clinics and is the most common genetic cause of obesity that has been identified. PWS is found in people of both sexes and all races. It is diagnosed by special genetic testing on a blood sample.

What causes the appetite and obesity problems in PWS?

People with PWS have a flaw in the hypothalamus part of their brain, which normally registers feelings of hunger and satiety. While the problem is not yet fully understood, it is apparent that people with this flaw never feel full; they have a continuous urge to eat that they cannot learn to control. To compound this problem, people with PWS need less food than their peers without the syndrome because their bodies have less muscle and tend to burn fewer calories.

Does the overeating associated with PWS begin at birth?

No. In fact, newborns with PWS often cannot get enough nourishment because low muscle tone impairs their sucking ability. Many require special feeding techniques or tube feeding for several months after birth, until muscle control improves. Sometime in the following years, usually before school age, children with PWS develop an intense interest in food and can quickly gain excess weight if calories are not restricted.

Do diet medications work for the appetite problem in PWS?

Unfortunately, no appetite suppressant has worked consistently for people with PWS. Most require an extremely low-calorie diet all their lives and must have their environment designed so that they have very limited access to food. For example, many families have to lock the kitchen or the cabinets and refrigerator. As adults, most affected individuals can control their weight best in a group home designed specifically for people with PWS, where food access can be restricted without interfering with the rights of those who don't need such restriction.

What kinds of behavior problems do people with PWS have?

In addition to their involuntary focus on food, people with PWS tend to have obsessive or compulsive behaviors that are not related to food, such as repetitive thoughts and verbalizations, collecting and hoarding of possessions, picking at skin irritations, and a strong need for routine and predictability. Frustration or changes in plans can easily set off a loss of emotional control in someone with PWS, ranging from tears to temper tantrums to physical aggression. While psychotropic medications can help some individuals, the essential strategies for minimizing difficult behaviors in PWS are careful structuring of the person's environment and consistent use of positive behavior management and supports.

What does the future hold for people with PWS?

With help, people with PWS can expect to accomplish many of the things their "normal" peers do - complete school, achieve in their outside areas of interest, be successfully employed, even move away from their family home. They do, however, need a significant amount of support from their families and from school, work, and residential service providers to both achieve these goals and avoid obesity and the serious health consequences that accompany it. Even those with IQs in the normal range need lifelong diet supervision and protection from food availability.

Although in the past many people with PWS died in adolescence or young adulthood, prevention of obesity can enable those with the syndrome to live a normal lifespan. New medications, including psychotropic drugs and synthetic growth hormone, are already improving the quality of life for some people with PWS. Ongoing research offers the hope of new discoveries that will enable people affected by this unusual condition to live more independent lives.

Quiz Answers

What is a developmental disability?

A severe, chronic disability of a person 5 years of age or older that:

- *Is attributable to a mental or physical impairment or both*
- *Is manifested before age 22*
- *Is likely to continue indefinitely*
- *Results in substantial functional limitation in three or more areas of major life activity*
- *Reflects the person's need for care, treatment, or other services.*

What is the difference between the categorical approach and the functional approach to diagnosis of people with developmental disabilities?

Categorical: the diagnosis of mental retardation, cerebral palsy, epilepsy, or autism automatically categorized the individual as being developmental disabled.

Functional: the individual needs to show substantial functional limitation in three or more areas of major life activity and need care, treatment, or other services as well as having a documented mental or physical impairment.

What percentage of people with intellectual disability score at 50 or below on IQ tests?

13%.

Which number comes closest to describing the number of people with cognitive disabilities (mental retardation) in the US (based on IQ scores)?

c. 9,000,000 - 3% of 295 million people

Bill experiences seizures on a regular basis. His IQ is 125 (100 is average). He also has cerebral palsy, which makes it difficult for him to speak clearly or walk more than a few steps. Based on this information, which of the following labels might accurately apply to Bill?

- epilepsy – **Yep**
- intellectual disability – **Nope**
- developmental disability - **Yep**
- cognitive disability - **Nope**
- country music fan - **Don't know!**

Susie has an IQ score of 69. She has been married for 22 years and is a full-time homemaker. Her husband is an electrician. Susie is not a good money manager, so her husband pays the bills and manages the accounts. Based on this information, which of the following labels might accurately apply to Susie?

- a. epilepsy – **Nope**
- b. intellectual disability – **Yep**
- c. developmental disability - **Nope**
- d. cognitive disability – **Yep**
- e. bad housekeeper – **Don't know!**

Match the characteristic with the disability (some may match more than one):

A. Down syndrome B. Prader-Willi syndrome C. Fragile X syndrome

 A The risk of having a child with this syndrome increases with parental age.

 B Involuntary focus on food, never feels full

 A 50% of people with this syndrome have congenital heart defects

 C Girls with this generally are less disabled and perform better than boys

 B Picking at skin irritations and other compulsive behavior

 C Whole images, such as pictures, logos, or words can often be recognized

well.

30 Minute Lesson: Feedback Form

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Topic of Lesson _____

- Facilitator Version
- Participant Version
- Non-Facilitated Group Version
- Self-Study Version

1. On a scale of 1 to 5, please rate the relevancy of these materials to your job _____
(1 is worst, 5 is best)
2. On a scale of 1 to 5, please rate the positive impact of these materials on your professional skills, knowledge, and abilities (1 is worst, 5 is best) _____
3. On a scale of 1 to 5, please rate the positive impact of these materials on your organization (1 is worst, 5 is best) _____
4. What was the most useful part of the lesson?
5. What was the least useful part of the lesson?
6. How could this lesson be improved?
7. What additional topics would you like to see in a 30 Minute Lesson?