



## SOUTH CENTRAL PENNSYLVANIA HEALTH CARE QUALITY UNIT

# IT'S YOUR HEALTH SPRING 2011



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[www.theadvocacyalliance.org](http://www.theadvocacyalliance.org)

## MARCH IS DEVELOPMENTAL DISABILITIES AWARENESS MONTH

### Definition of Intellectual Disability

Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.

**Intellectual functioning** – also called intelligence – refers to general mental capacity, such as learning, reasoning, problem solving, and so on.

One criterion to measure intellectual functioning is an IQ test. Generally, an IQ test score of around 70 or as high as 75 indicates a limitation in intellectual functioning.

Standardized tests can also determine limitations in adaptive behavior, which comprises three skill types:

**Conceptual skills** – language and literacy; money, time, and number concepts; and self-direction.

**Social skills** – interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules/obey laws and to avoid being victimized.

**Practical skills** – activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone.

On the basis of such many-sided evaluations, professionals can determine whether an individual has an intellectual disability and can tailor a support plan for each individual.

But in defining and assessing intellectual disability, the American Association on Intellectual and Developmental Disabilities (AAIDD) stresses that professionals must take additional factors into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave.

Finally, assessments must also assume that limitations in individuals often coexist with strengths, and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period.



## AUTISM AWARENESS MONTH

We look forward to celebrating the wonderful people in our lives affected by autism on April 2 and throughout April, which is Autism Awareness Month.

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders.

Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. An estimated 1.5 million individuals in the U.S. and tens of millions worldwide are affected by autism. Government statistics suggest the prevalence rate of autism is increasing 10-17 percent annually. There is not established explanation for this increase, although improved diagnosis and environmental influences are two reasons often considered. Studies suggest boys are more likely than girls to develop autism and receive the diagnosis three to four times more frequently. Current estimates are that in the United States alone, one out of 70 boys are diagnosed with autism.

There is a growing interest among researchers about the role of the functions and regulation of the immune system in autism – both within the body and the brain. Piecemeal evidence over the past 30 years suggests that autism may involve inflammation in the central nervous system. There is also emerging evidence from animal studies that illustrates how the immune system can influence behaviors related to autism.

While the definitive cause (or causes) of autism is not yet clear, it is clear that it is not caused by bad parenting. Dr. Leo Kanner, the psychiatrist who first described autism as a unique condition in 1943, believed that it was caused by cold, unloving mothers. Bruno Bettelheim, a renowned professor of child development perpetuated this misinterpretation of autism. In the 1960s and 70s, Dr. Bernard Rimland, the father of a son with autism, who later founded the Autism Society of America and the Autism Research Institute, helped the medical community understand that autism is not caused by cold parents but is in fact a biological disorder.

### Key Traits of Autism

Each person affected by Autism portrays different characteristics, at varying degrees. They may display some of the following symptoms:

- Limited verbal and non verbal communication
- May communicate with gestures
- Short attention span
- May experience sensory impairment
- Little interest in interaction with others
- Less responsive to non verbal communication and eye contact
- May be overactive/passive
- Lack of spontaneous or imaginative play
- Does not imitate others actions
- Does not initiate play
- Resistance to changes in routine
- May show aggression to self/others

# DisAbility & Sexuality

People with physical or intellectual disabilities in our society are often regarded as non-sexual adults. Sex is very much associated with youth and physical attractiveness, and when it is not, is often seen as "unseemly". If sex and disability are discussed, it is very much in terms of capacity, technique, and fertility – in particular, male capacity and technique and female fertility – with no reference to sexual feelings (Zola, 1988). This approach ignores other aspects of sexuality, such as touching, affection, and emotions.

*To be human is  
to be sexual"*  
(Winder, 1983)

If we accept that sexual expression is a natural and important part of human life, then perceptions that deny sexuality for disabled people deny a basic right of expression.. The perception of people with disabilities as non-sexual can present a barrier to safe sex education, both for workers who may be influenced by these views, and for disabled people themselves in terms of gaining access to information and acceptance as sexual beings.

In relation to intellectual disability, society frequently takes the view that intellectually disabled people have no rights at all to pursue social and sexual relationships. They have often been completely denied sex education. Intellectually disabled people are sometimes regarded as sexually deviant because they may exhibit socially inappropriate sexual behavior. Just as can happen in the rest of the community, some intellectually disabled people grow up in situations (e.g. institutions) which differ from the norm in many ways. This can cause difficulties in social and personal development, and can contribute to the development of socially inappropriate behavior. It can also be more difficult for intellectually disabled people to distinguish between public and private behaviors.

In addition, opportunities for sexual exploration among disabled people, particularly the young, are very limited. There is often a lack of privacy and they are much more likely than other young people to receive a negative reaction from an adult if discovered. The general reduction in life choices also has an impact on self-esteem which in turn affects sexuality (Smith, 1987).

It is important for educators – particularly those involved in education programs with disability workers or disabled people – to understand community attitudes towards disability and sexuality, and the impact of these views upon disabled people themselves.

Source: Royal Adelaide Hospital, Australia



## Links to Check Out

**Dawn Ontario Disabled Women's Network:** [http://dawn.thot.net/disability\\_sexuality.html](http://dawn.thot.net/disability_sexuality.html)

**SexualityandU.CA:** [http://sexualityandu.ca/en/teachers/teaching\\_sex\\_ed\\_for\\_youth\\_with\\_intellectual\\_disabilities?/teachers/tools-10-1.aspx](http://sexualityandu.ca/en/teachers/teaching_sex_ed_for_youth_with_intellectual_disabilities?/teachers/tools-10-1.aspx)

**Autism Speaks:** [http://www.autismspeaks.org/inthenews/world\\_autism\\_awareness\\_day\\_2010.php](http://www.autismspeaks.org/inthenews/world_autism_awareness_day_2010.php)

**Autism Awareness:** <http://autismawareness.net/>

**Mental Health America:** <http://www.mentalhealthamerica.net/>

**NAMI:** <http://www.nami.org/>

**The ARC:** <http://www.thearc.org/page.aspx?pid=2530>

**American Association of Intellectual and Developmental Disabilities:**

<http://www.aaid.org/index.cfm>

[http://www.aaid.org/content\\_198.cfm](http://www.aaid.org/content_198.cfm)



# May is Mental Health Month

## What is Mental Illness?

Mental illnesses are medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life.

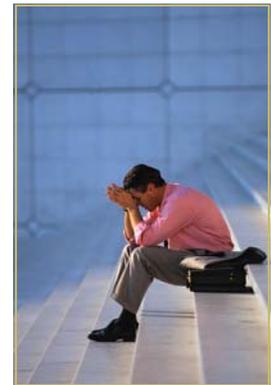
Serious mental illnesses include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post traumatic stress disorder (PTSD) and borderline personality disorder. The good news about mental illness is that recovery is possible.

Mental illnesses can affect persons of any age, race, religion, or income. Mental illnesses are not the result of personal weakness, lack of character or poor upbringing. Mental illnesses are treatable. Most people diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in an individual treatment plan.

In addition to medication treatment, psychosocial treatment such as cognitive behavioral therapy, interpersonal therapy, peer support groups and other community services can also be components of a treatment plan and that assist with recovery. The availability of transportation, diet, exercise, sleep, friends and meaningful paid or volunteer activities contribute to overall health and wellness, including mental illness recovery.

## Here are some important facts about mental illness and recovery:

- Mental illnesses are serious medical illnesses. They cannot be overcome through "will power" and are not related to a person's "character" or intelligence. Mental illness falls along a continuum of severity. Even though mental illness is widespread in the population, the main burden of illness is concentrated in a much smaller proportion-about 6 percent, or 1 in 17 Americans-who live with a serious mental illness. The National Institute of Mental Health reports that One in four adults-approximately 57.7 million Americans-experience a mental health disorder in a given year
- The U.S. Surgeon General reports that 10 percent of children and adolescents in the United States suffer from serious emotional and mental disorders that cause significant functional impairment in their day-to-day lives at home, in school and with peers.
- The World Health Organization has reported that four of the 10 leading causes of disability in the US and other developed countries are mental disorders. By 2020, Major Depressive illness will be the leading cause of disability in the world for women and children.



- Mental illness usually strike individuals in the prime of their lives, often during adolescence and young adulthood. All ages are susceptible, but the young and the old are especially vulnerable.
- Without treatment the consequences of mental illness for the individual and society are staggering: unnecessary disability, unemployment, substance abuse, homelessness, inappropriate incarceration, suicide and wasted lives; The economic cost of untreated mental illness is more than 100 billion dollars each year in the United States.
- The best treatments for serious mental illnesses today are highly effective; between 70 and 90 percent of individuals have significant reduction of symptoms and improved quality of life with a combination of pharmacological and psychosocial treatments and supports.
- With appropriate effective medication and a wide range of services tailored to their needs, most people who live with serious mental illnesses can significantly reduce the impact of their illness and find a satisfying measure of achievement and independence. A key concept is to develop expertise in developing strategies to manage the illness process.
- Early identification and treatment is of vital importance; By ensuring access to the treatment and recovery supports that are proven effective, recovery is accelerated and the further harm related to the course of illness is minimized.
- Stigma erodes confidence that mental disorders are real, treatable health conditions. We have allowed stigma and a now unwarranted sense of hopelessness to erect attitudinal, structural and financial barriers to effective treatment and recovery. It is time to take these barriers down.

## Every journey begins with that first step.

In 2011, thousands of concerned citizens in nearly 80 communities across the nation will walk together to raise money and awareness about our country's need for a world-class treatment and recovery system for people with mental illness.

**The NAMI Walk will take place May 7, 2011  
at 10:30 AM at Nay Aug Park in Scranton.**

**For more information please contact Marie  
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# FAQs on Intellectual Disability

**What is an intellectual disability?** Intellectual disability is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

**Is intellectual disability the same as developmental disability?** Not exactly. Developmental disability is an umbrella term that includes intellectual disability but also includes physical disabilities. Some developmental disabilities can be strictly physical, such as blindness from birth. Some individuals have both physical and intellectual disabilities stemming from genetic or other physical causes (e.g., Down Syndrome, fetal alcohol syndrome). Sometimes intellectual disabilities can stem from nonphysical causes, such as the level of child stimulation and adult responsiveness.

**Is intellectual disability just determined by an IQ test?** No, but the IQ test is a major tool in measuring intellectual functioning, that is, mental capacity for learning, reasoning, problem solving, and so on. A test score of around 70—or as high as 75—indicates a limitation in intellectual functioning.

Other tests determine limitations in adaptive behavior, which covers three types of skills:

- **Conceptual skills**—language and literacy; money, time, and number concepts; and self-direction
- **Social skills**—interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, and the ability to follow rules, obey laws, and avoid being victimized
- **Practical skills**—activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, use of the telephone

But evaluation and classification of individuals with intellectual disabilities is a much more complex issue. The major function of the American Association on Intellectual and Developmental Disabilities (AAIDD) is to publish the most advanced thinking in its manual, *Mental Retardation: Definition, Classification and Systems of Supports*. The most recent edition was published in 2002; the next is due in 2010.

In defining and assessing intellectual disability, AAIDD stresses that professionals must consider such factors as

- Community environment typical of the individual's peers and culture
- Linguistic diversity
- Cultural differences in the way people communicate, move, and behavior

**What causes intellectual disability?** Some disabling conditions classified as developmental disabilities—such as autism or cerebral palsy—might include intellectual disabilities. Other developmental disabilities, such as Down Syndrome, fetal alcohol syndrome, and fragile X syndrome, could well include intellectual disabilities. Intellectual disabilities could also be caused by social factors, such as the level of child stimulation and adult responsiveness, and educational factors, such as the availability of family and educational supports that can promote mental development and greater adaptive skills.

Nevertheless, according to the AAIDD manual, *Mental Retardation: Definition, Classification and Systems of Supports*, approximately 40 to 50 percent of the causes of intellectual disabilities currently have no identifiable origin.

**What's the most modern thinking about how to help people with intellectual disabilities?** AAIDD stresses that the overarching reason for evaluating and classifying individuals with intellectual disabilities is to tailor supports for each individual, in the form of a set of strategies and services provided over a sustained period.

The goal is to enhance people's functioning within their own culture and environment in order to lead a more successful and satisfying life. Some of this enhancement is thought of in terms of self-worth, subjective well being, pride, engagement in political action, and other principals of "disability identity."

**Is intellectual disability the same as mental retardation? Why do programs still say mental retardation?** Mental retardation and intellectual disability are two names for the same thing. But intellectual disability is gaining currency as the preferred term. In fact, the American Association on Mental Retardation changed its name in 2007 to the American Association on Intellectual and Developmental Disabilities. It is crucial that 'mental retardation' and 'intellectual disability' should be precisely synonymous in definition and in all related

classification because current federal and state laws contain the term 'mental retardation'. That is the term used in law and public policy to determine eligibility for state and federal programs, including the Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver. Also, the term 'mental retardation' is used for citizenship and legal status, civil and criminal justice, early care and education, training and employment, income support, health care, and housing and zoning.

**How are intellectual disability and developmental disability different?** **Intellectual disability** forms a subset within the larger universe of developmental disability, but the boundaries often blur as many individuals fall into both categories to differing degrees and for different reasons. **Developmental disabilities** are defined as severe chronic disabilities that can be cognitive or physical or both. The disabilities appear before the age of 22 and are likely to be lifelong.

Intellectual disabilities encompass the “cognitive” part of this definition, that is, those disabilities that are broadly related to thought processes. Because intellectual and other developmental disabilities often co-occur, intellectual disability professionals often work with people who have both types of disabilities.

Some developmental disabilities are purely physical, such as congenital deafness or visual impairment resulting from the individual's mother contracting rubella while pregnant. These are not intellectual disabilities. Other developmental disabilities can be caused by cerebral palsy, epilepsy, autism, or other disabling conditions. These conditions might or might not include intellectual disabilities.

Still other developmental disabilities can result from chromosomal disorders, such as Down Syndrome, fetal alcohol syndrome, and fragile X syndrome. These instances could well include intellectual disabilities—but not always. For example, according to the Centers for Disease Control, males with fragile X syndrome generally have mild to severe intellectual disabilities, whereas females can have average intelligence.

On the other hand, some causes of intellectual disabilities are not physical. These include social factors, such as the level of child stimulation and adult responsiveness, and educational factors, such as the availability of family and educational supports that can promote mental development and greater adaptive skills.

**Why did AAIDD change the term from 'mental retardation' to 'intellectual disability'?** AAIDD's move to replace 'mental retardation' with 'intellectual disability' does not change the basic definition of the term, but it does reflect a change of vision.

AAIDD stresses that the term 'intellectual disability' has exactly the same definition as the association's most recent (2002) definition of mental retardation. It covers the same population of individuals who were previously diagnosed with mental retardation or who were eligible for that diagnosis. This exact fit is crucial because the term 'mental retardation' is used in law and public policy to determine eligibility for state and federal programs, including the Individuals With Disabilities Education Act—IDEA (2004), Social Security Disability Insurance, and Medicaid Home and Community Based Waiver.

Also, the term 'mental retardation' is used for citizenship and legal status, civil and criminal justices, early care and education, training and employment, income support, health care, and housing and zoning. But the word change from 'mental retardation' to 'intellectual disability' does reflect a revised focus.

- It is less offensive to persons with disabilities.
- It is more consistent with internationally used technology.
- It emphasizes the sense that intellectual disability is no longer considered an absolute, invariable trait of a person.
- It aligns with current professional practices that focus on providing supports tailored to individuals to enhance their functioning within particular environments.
- It opens the way to understanding and pursuing “disability identity,” including such principles as self-worth, subjective well being, pride, engagement in political action, and more.

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## IDEAS FOR OUR NEWSLETTER?

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