

Understanding Intellectual Disability: A Parent's Guide

Introduction

As a parent, you may have many questions regarding your child's intellectual disability diagnosis. As you look for answers, you may encounter information about intellectual disability, its causes, and possible treatments. All of these different opinions can make it challenging for a family to organize options and begin to choose a treatment plan that best fits the family.

We hope that this packet will help better prepare you to understand the information you receive about treatments for intellectual disability, as well as give you the chance to look over the most recent professional opinions about intellectual disability.

Westside Regional Center anticipates supporting your family as you proceed from your child's initial diagnosis to ongoing support throughout his or her lifetime.

What is Intellectual Disability?

Intellectual disability (formerly known as mental retardation) affects peoples' capacity to develop cognitive (reasoning) and adaptive skills (social and daily living practices). It includes mild, moderate, severe and profound disability levels, depending on cognitive and adaptive skills. It is usually characterized by:

- problems with learning, thinking, attention, language, perception and memory;
- problems with daily living and self-care skills (such as bathing and dressing);
- delays in language and/or delays in motor skills.

Intellectual disability is *not* a disease in itself – it occurs when a condition impairs the development of the brain. There are many factors that can cause this, but the most common causes are:

- *Genetic conditions*- Many genetic diseases have been found to be related to intellectual disability. For example, some examples of these conditions can be abnormal genes inherited from parents or errors that occur when genes combine. Common genetic disorders include Down syndrome, fragile X syndrome and phenylketonuria (PKU).
- *Complications during pregnancy* -The use of alcohol or other drugs during pregnancy can cause intellectual disability. In the case of fetal alcohol system, the brain does not develop properly before birth.
- *Environmental factors*. Other risks factors that can harm brain development include malnutrition, environmental contaminants, and illnesses. One example of an environmental factor is lead poisoning. Young children sometimes eat paint that has flaked off the walls of their home and this paint may contain the element lead. Lead has many harmful effects on growing children, one of which is damage to the brain.

- *Problems at birth* -Premature infants and/or those with low birth weights are most often at great risk of intellectual disability. Unusual stress on the head during birth, lack of oxygen or other problems during birth can also cause the condition.
- *Childhood illnesses* -The absence of adequate nutrition or diseases such as whooping cough, chicken pox, and measles can lead to meningitis and encephalitis, which can damage the brain of a growing child. Childhood injuries can also lead to intellectual disability. A blow to the head or a violent shaking by an adult may cause brain damage and intellectual disability.

How did my child receive this diagnosis?

An individual is considered to have intellectual disability based on the following three criteria:

- Whether the ability of your child’s brain to learn, think, solve problems, and make sense of the world (called IQ or intellectual quotient) is below 70-75;
- Whether your child has the skills he or she needs to live independently (called adaptive behavior, or adaptive functioning); and
- Whether the condition is present from childhood.

A doctor or psychologist determines a diagnosis of intellectual disability through a series of steps:

- **Carefully looking over the parents’ and child’s medical history.** This is an important first step – it allows the doctor to understand your own parental concerns, as well as review the results of your child’s previous tests and medical history. Some forms of intellectual disability are caused by treatable illnesses. Hyperthyroidism is an example. Hyperthyroidism is a condition in which the thyroid gland produces too much thyroid hormone. A child's mental disorder may be treated, then, by first treating the medical problem that caused it.
- **Assessing your child’s development.** The doctor will usually ask about the age of your child when he/she first started to talk, walk, crawl, or roll over, as well as signs of any behavioral issues. This will allow you doctor to see if there was any indication of developmental delay in your child’s history.
- **Administering specialized exams.** To determine if intellectual disability is caused by a genetic syndrome, your child may need an MRI of the brain (brain scan) and blood tests for specific genetic disorders. Professionals will also use standardized tests to measure your child’s IQ and his/her adaptive behavior capabilities. Significant problems in adaptive behavior impact your child’s daily life and affect his/her ability to respond to a particular situation or to the

Adaptive Functioning can include:

Conceptual Skills

- Language
- Reading and writing

Social Skills

- Interpersonal relationships
- Responsibility
- Self-esteem
- Interaction with the community; learning non-aggressive behavior

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.

environment. Testing your child's capabilities is especially important because it allows you to choose treatments and therapies that better fit your child's situation.

Evaluating Treatments

Before you explore the various treatments for intellectual disability, here are some suggestions to help you evaluate your options for your child's therapy.

Find a team of trusted professionals. You will need to make important decisions about your child's education and treatment. Find a team of doctors, psychologists, teachers and therapists that you trust. These professionals can help evaluate the resources in your area and help maximize your child's potential.

Seek out other families who are dealing with the same issues. Most communities have support groups for parents of children with intellectual disability, as well as the option for online forums on the Internet. This can be a great outlet for emotional support, as well as a place to discuss treatment experiences with other parents.

Determine whether this treatment is right for your child. No child with intellectual disability is the same –children with intellectual disability often display a wide range of functioning and developmental differences. For example, intelligence for children with intellectual disability can range from mildly to severely impaired. For these reasons, one of the most important things to remember when thinking about treatments is to plan them specifically for your child. You must ask yourself, "Is the treatment right for my child? Which issues do I specifically want to address?" The best place to start is to have a complete assessment of your child's strengths, challenges, and needs by a team of medical professionals, including a physician, psychologist, physical therapist, occupational therapist, and a speech therapist (this could be done, in part, by the medical professionals working within WRC or medical professionals that you already have). The exam would allow you to research treatments that specifically focus on the issues that are most important for your child.

Understand how much time and commitment the treatment will require. It is important to know that your family will play an important role in supporting and helping to carry out treatments. Therefore, many treatments may be stressful, not only for your child, but for your entire family. Some treatments may not have great benefit for your child in his or her situation. When considering possible treatments, you should consider both the financial and emotional costs. *Does the benefit outweigh the costs for your child and family?* Also, if you decide to pursue a specific treatment, it is important that you know how to decide if the treatment is working. This allows you to monitor the progress of your child, so that you can decide whether or not you should continue or stop the treatment after a period of time.

Management and Treatment of Intellectual Disability

While there is no cure for intellectual disability, treatments and services can help your child attain his or her potential – physically, mentally, and emotionally. Children with Intellectual disability now have the opportunity to attend special preschool programs and

day schools. These programs and schools teach children basic skills, such as bathing and feeding themselves. They also provide educational programs, extracurricular activities, and social events developed especially for children with intellectual disability.

WRC has included a brief look at some of the therapies that can help promote the development, education, interests, and personal well being of your child:

- **Speech therapy** to help with any speech or language problems
- **Occupational therapy** to develop strategies for everyday living, with a focus on activities such as dressing, bathing, and using the bathroom.
- **Physical therapy** to improve balance, hand-eye coordination, motor skills, walking, and muscle stretching
- **Behavior therapy** to help with social and emotional development, such as controlling anger/aggression, appropriate public behavior, socialization, and peer relationships.

Treatment may also include family therapy. The purpose of family therapy is to help family members understand the nature of intellectual disability. It also helps them develop skills for dealing with the special needs of their child. Parents may also receive counseling to help them deal with feelings of anger or guilt.

As your child approaches adulthood, his or her situation will depend on the severity of their disability. People who have mild intellectual disability are generally able to care for themselves with special training and, as adults, can often enjoy some independence in their daily living skills and even work with supervision. People who have severe intellectual disability may have much greater challenges with speech, coordination, and the ability to learn; they also frequently have physical disabilities and can need constant care and supervision.

What to expect medically

Individuals with intellectual disability have the same basic healthcare needs as typically developed people, including vaccine schedules, as well as screenings for high blood pressure, heart disease, cancer and dental disease. Your child's primary doctor should continue to provide your child with regularly-scheduled medical care and preventive health screenings.

Resources at WRC

- Health and Medical Department (310-258-4254)
- Equipment Clinic
- Family Resource Center (310-258-4063)
- Service Coordination
- Support Groups – Birth to Five Parent, Teen Social Group, Networking and Social Group
- Trainings & Events – self advocacy, consumer discussion, and behavior management

References

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

http://www.aamr.org/Policies/faq_intellectual_disability.shtml

<http://www.cdc.gov/ncbddd/dd/ddmr.htm>

<http://www.faqs.org/health/Sick-V3/Mental-Retardation.html>

[Diagnostic and Statistical Manual of Mental Disorders](#) (DSM-IV)