



Realizing the Bright Future of Your Child with an Intellectual Disability

A Guide for New Parents



Special Olympics
Young Athletes



“

Through my sons...

I have learned what is important in life.

Through my sons...

I have made wonderful friends who see me for what I am.

Through my sons...

I feel that I am making a contribution to society.

Through my sons... I have been blessed.

”

Patricia Hickey

Special Olympics Family Leader,
Special Olympics Ireland

Your child has an intellectual disability.

This is a moment you will likely never forget.
The words are shocking.
Everything after that may seem like it comes in a fog.

In the two seconds it takes to say those 5 words,
the whole world has changed for your family forever.

Going through your head may be;

**“I don’t believe this.
How can this be?”**

“How do we know that this is true?”

**“Why didn’t anyone
tell me before?”**

“Did I do something to cause this?”

“What do we do now?”

“What will the future hold?”



This guide was written to help you step into the new world you will be experiencing.

This takes time and hopefully this guide will be useful to you today and all along your new path. In the next few pages, you will receive information about:

- how your child got the diagnosis,
- how to cope with the feelings you might be experiencing,
- steps to finding out possible causes for your child’s intellectual disability,
- finding the right therapies and supports for your child,
- resources that you may want to use, and
- a glimpse of the future.

Although it may not seem like it right now, the future for your child is a bright one—brighter now than ever before for children with intellectual disabilities.

What is Intellectual Disability?

Some families are told about their child's diagnosis before or right after birth. This usually occurs if it is part of a genetic syndrome, like Down syndrome. For other families, the diagnosis may come in the toddler or early school years.

When receiving a diagnosis, your child may be diagnosed with an intellectual disability or with global developmental delays.

In general, global developmental delay is used for children under 5 years old, before they can participate well in psychology testing. After about 5 years old, children are diagnosed with intellectual disabilities.

What you should know is that intellectual disability is not a disease. It is not static or unchanging. It is a condition and its expression can change with therapies and supports.

Intellectual disability begins in childhood and includes deficits in:

- **Intellectual functions**, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience.
- **Adaptive functioning** in activities of daily life, such as communication, social participation and independent living.

Often, the time immediately after the diagnosis is a tumultuous one for families. There are many feelings, including fear, disappointment, confusion and anger mixed with protectiveness, hope, pride and love. These are typical feelings. You may be experiencing multiple feelings at once. Some parents take a while coming to terms with the diagnosis. Others feel relief that they finally have an answer. Because many children with intellectual disabilities physically appear no different than anyone else, it can sometimes be hard at first to believe the diagnosis.

“Disability isn't another country; it's another world.”

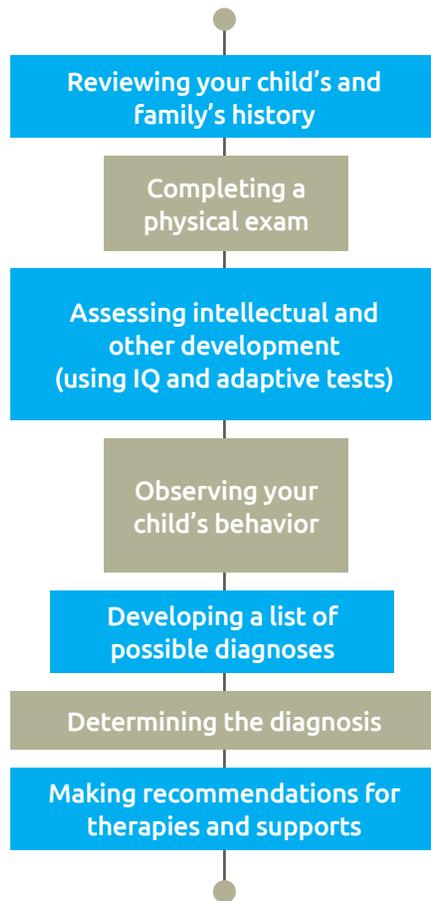


Psychologists used to think that parents' first reactions were "grieving" for their lost "normal" child. More recent studies talking directly with parents find a different picture. Parents have a range of reactions. The fact is that much of the family's first impressions are based on how the diagnosis is given and the supports available. If the diagnosis is given in an accurate and compassionate manner and you understand the future picture accurately, you will be better able to understand and cope with the challenges and the joys you will experience.

Even if that wasn't the case for your family, you can still now develop an understanding of the future and the transformation that will occur for your family. When you are ready, you may wish to better understand how the diagnosis was made and what the causes are.

My Child's Diagnosis

A psychologist or physician should go through the following steps to diagnose your child:



In practice, the diagnosis of an intellectual disability is based on the following:

- Whether your child scored below about 70-75 on an IQ (intellectual quotient) test.
- Whether your child scored in the low range on an adaptive functioning test (everyday social and practice skills).
- Whether the condition is present from childhood.

Important Definitions to Remember

Global Developmental Delay (GDD)

GDD is an intellectual and adaptive impairment in children under 5 years old. The diagnosis is based on the child not meeting developmental milestones in several areas of intellectual functioning. Young children with GDD do need further intellectual testing to make a definite diagnosis and to understand the severity of the condition.

Many children who have global developmental delay at a very young age do not go on to have intellectual disability in later testing.

IQ

An IQ test is a major tool in measuring intellectual functioning, which is the mental capacity for learning, reasoning, problem solving, etc. A test score below or around 70-75—indicates a limitation in intellectual functioning. Many more factors affect the future than just IQ. Effort, motivation, self-discipline and personality may affect success just as much or more than IQ.

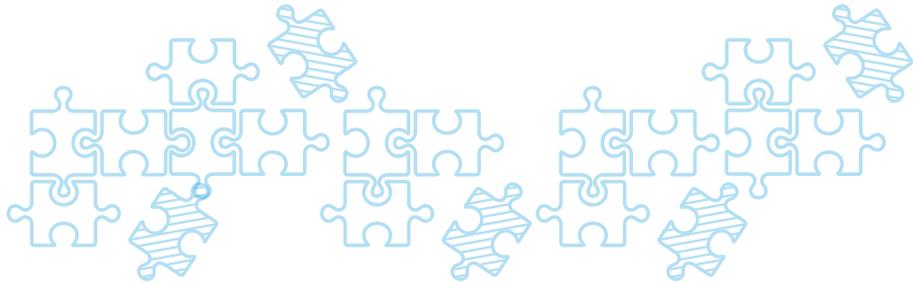
Levels of Intellectual Disability

For years, psychologists used mild, moderate, severe and profound to indicated IQ points. The levels of severity in the new definition of intellectual disability are based on how much support your child needs to function, with intermittent, limited, extensive, & pervasive supports.

“ Too often, students with intellectual disabilities are given low expectations because it makes it easier... to deal with them. What people believe about intelligence is more important than the actual intelligence. ”

—Daniel Paris

Understanding Intellectual Disabilities



Many children have other conditions that can occur together with intellectual disability, like autism spectrum disorders, epilepsy or cerebral palsy.

There is much confusion about the difference between autism (autism spectrum disorders) and intellectual disability. Many children have both. But, in autism, there are deficits in social communication (such as having conversation and making friends). There are also repetitive or restricted behaviors and interests (such as repetitive hand flapping). In intellectual disability, the deficits are in intellectual functioning (learning/problem solving).

If you suspect any of these other conditions, you should see your doctor to discuss further testing.

“ I began to scrutinize our pasts for anything we might have done that could have caused harm to our son. ”



Dispelling Myths about Intellectual Disability



Myth

Children with intellectual disabilities won't ever walk or talk.



Fact

Most children with intellectual disability DO learn to walk, talk, make friends and ALL children can interact in some way with your community.

- About 85% of children have MILD and about 10% have MODERATE intellectual disability.
- Children with SEVERE or PROFOUND intellectual disability DO communicate too—they may communicate through gestures, signs and expressions if not using words.



Myth

Children with intellectual disabilities cannot learn.



Fact

All children learn. They learn at their own pace and in their own time. Parents—you are your child's first teachers.

- Providing a positive environment which supports learning will help your child learn more and faster.
- Children do better if their parents have higher expectations of them and put emphasis on effort not ability.



Myth

Children with intellectual disabilities will never get a job or live independently. They will be dependent for their whole futures.



Fact

Children with intellectual disabilities should be included in classroom settings with children of all abilities.

- More people with intellectual disabilities are employed than ever before. Many are athletes, including millions worldwide participating in Special Olympics.
- According to studies, about half of people with intellectual disabilities do get married and possibly up to a quarter have children.



Myth

Families of children with intellectual disabilities do not do well. The child puts tremendous burden on the family.



Fact

All parents feel some increased demands to give their child the best. Some families report decreased well-being but most families adapt well. Most actually find benefits to having a child with intellectual disability.



A Word about Words...

WORDS DO MATTER!

Use the term “intellectual disability” when referring to the conditions including impairments in intellectual and adaptive functioning.

The old term of “mental retardation” has such negative connotations that it is no longer used. The slang term “retard” is often used to put people down and it is simply insensitive. “The R Word” campaign seeks to remove the use of the word “retarded” from our vocabulary. Additionally, Rosa’s Law now replaces “mental retardation” with “intellectual disability” in federal law.

For more information and to take the R word pledge, please visit www.r-word.org



Advice from Other Parents...

There are a lot of areas of life that are going to be different with your child. It will take extra attention and effort. At the same time, so much of your life with your child will be the same as life with any child. You are still going to wake up to breakfast and sit down to dinner. You are still going to feel the sunshine and the rain together. And you are going to love. A lot. Many families say that having their child with intellectual disability was the best thing that ever happened to them.

You already have the skills you need to raise your child. Your baby requires the same care as all babies do—feedings, diaper changes, rocking to sleep, tickling, cuddling, going to the park. As you get to know your child, you will understand your child's individual needs. Sometimes you'll make a mistake, but for the most part, you're going to do fine. In fact, you may be enriched by your child having an intellectual disability.

Now, take a deep breath.

You can do this.

Therapies and Support

There are treatments, therapies, supports and services that can help your child reach their potential throughout their life.

Here is a brief look at some of the therapies and services that can help promote the development, education, health and personal well-being of your child. This is not an exhaustive list. Most of all, they are not all needed at the same time.

 **Speech therapy** to help with any speech or language problems.

 **Occupational therapy** to develop fine motor skills and focus on activities such as feeding and dressing.

 **Physical therapy** to improve balance, hand-eye coordination and motor skills.

 **Infant development or play therapy** to promote overall developmental and play skills.

 **Cognitive therapies** to improve memory, logic and reasoning skills.

 **Mental health therapy** to help with emotional development and regulating feelings, such as anger, so as to avoid aggression.

 **Family therapy** to help family members understand the nature of intellectual disability, address their feelings and develop coping skills.

“ **It feels like you’re all of a sudden spinning on a wheel going faster and faster—you have to do this and do that and if you don’t get this therapy right now, your child will never do well. How do you know what is helpful and what’s a waste of time and money, or even worse, what’s harmful to your child?** ”

Before you explore the various therapies and supports, here are some suggestions to help you evaluate your options.

 **Seek out other families who are dealing with the same issues.** Finding out your child’s diagnosis can be lonely and scary. The best cure for fear and isolation is to arm yourself with information and surround yourself with a strong support group. Most communities have local support groups and there are many online.

 **Find a team of trusted professionals.** Find a team of teachers, doctors, therapists and advocates that you trust. You have valuable information to share with them—you are the best expert on your child. In turn, these professionals can help evaluate the resources in your area. They can help maximize your child’s potential. Children do better when parents and professionals are able to work together.

 **Determine whether a particular therapy or support is right for your child.** No child is the same. Children have a wide range of functioning and developmental differences. Plan therapies specifically for your child. You should ask yourself, “Is this right for my child? Which issues do I specifically want to address? How will I know if it is working?” There are many therapies out there that do not have sufficient evidence to show that they work; even if they do improve some children, those children may not be similar to yours. Be informed before you spend time, stress and resources.

 **Be there at the start and throughout the therapy or support.** How do you know if the therapy you are using is a good one and working as well as it should? You should decide on therapy goals that are important to your child and family; participate in the therapies as you can; and revisit your goals to make sure they still fit. This allows you to monitor the progress of your child. You can decide whether to continue or if you need to change course. Changing therapies and therapists is to be expected. No therapy or support plan will be appropriate for a lifetime. Most are designed and tested for short periods, like three to six months, though may be used in practice for longer.

Supporting Your Child for the Future

EARLY INTERVENTION PROGRAM

In the first 3 years of life, children in the United States may get services from the Early Intervention Program in each state. These services are required by U.S. law under the Individuals with Disabilities Education Act (IDEA) Part C. These services are directed by your family and are designed to meet your needs and priorities.

The goals and plans for your child will be put together after you meet with your Early Intervention team in an Individual Family Service Plan (IFSP). Those services may include: medical, nursing, or nutrition services, physical therapy, occupational therapy, speech therapy, psychological therapy, counseling, family training and others.

THE SCHOOL YEARS AND IEPs

If your child is in public schools in the United States, your child will likely have an assessment by the school district and you will attend an “IEP” meeting. IEP stands for Individualized Educational Plan. This is the blueprint of the services and supports the school district will provide based on the goals you mutually set for your child for the year or until their next IEP.

The goals that are set are critical. They should be specific, meaningful to you and your family and achievable. When teachers have high, appropriate expectations, students with intellectual disabilities achieve more. Their behavior may improve dramatically. All children learn when given a chance to be independent and make their own choices. The IEP process can be challenging. Many families find it useful to attend educational workshops. Some bring advocates along to assist with the process. Once an IEP is in place, parents should closely monitor progress to best support their child.

Services like the ones mentioned above are offered in many countries.

“ Recognize the importance and challenge of providing a strongly stimulating environment and an active schedule for your child. ”



BASIC HEALTHCARE

Your child may qualify for government health benefits. You should contact your local department of health to determine if your child qualifies.



All children have the same basic healthcare needs, including vaccines and annual checkups. Your child’s primary doctor should continue to provide your child with all the regularly-scheduled medical care and preventive health screenings.



In addition to general health concerns, children with intellectual disabilities may be at a higher risk for other health challenges, such as oral/dental issues. Dental visits may need special preparation to ensure the best comfort and care of your child.



Weight issues are also common in children with intellectual disabilities. It is important that your child’s weight and height are measured at every doctor’s visit. Your child should eat a healthy diet and get lots of exercise to maintain a healthy weight and develop to his or her fullest potential.



Later on, the same screenings we all need for high blood pressure, heart disease, cancer and dental disease will also be needed. People with intellectual disabilities typically do not get as much preventive care as people without intellectual disabilities. This is something to watch carefully.

You may find you are unhappy with the health care your child is receiving. If so, seek information, referrals and support from advocacy groups like the *American Academy of Developmental Medicine and Dentistry* (www.aadm.org).

Supporting Your Child for the Future

STAYING HEALTHY AND ACTIVE THROUGH SPECIAL OLYMPICS



Special Olympics provides many opportunities for people with intellectual disabilities to build confidence and learn new skills. Along the way, they become welcomed and valued members of their communities. See below some of the ways Special Olympics helps support and engage your child throughout their lifetime.

Early Childhood

Along with your child's physical and occupational therapies, you may also consider Special Olympics Young Athletes™. It is a sport and play program for children with and without intellectual disabilities, ages 2 to 7 years old. Young Athletes introduces basic sport skills, like running, kicking and throwing. It offers families, teachers, caregivers and people from the community the chance to share the joy of sports with all children.

Childhood, Adolescence and into Adulthood

Children 8 and older can take part in Special Olympics. That's one way to help ensure your child stays healthy and active throughout their life. Special Olympics provides over 30 individual and team sports for people with intellectual disabilities. Some teams join people with and without intellectual disabilities. Special Olympics sports provide a chance to stay active and healthy, and also allow participants to discover new strengths and abilities. Special Olympics changes the perception of people with intellectual disabilities around the world.

GENERAL HEALTH AND WELL-BEING

Special Olympics also offers a range of programs to promote health, fitness and wellness. Fun and welcoming health screenings for our athletes check eyes, ears, feet, teeth, general fitness and more. Other programs bring community health care to our athletes worldwide, all the time. To learn more, visit www.specialolympics.org/health.



A letter of hope from a Special Olympics Athlete...

I am a high school graduate and I am employed at my local grocery store. I love my job! I have a lot of friends at work and in my community. I have a girlfriend and I love her very much. Lizzy and I both have Down syndrome.

I have been a Special Olympic athlete since I was 8 years old. Now, I'm 24 and am a year-round athlete! I also serve on Missouri's Special Olympics Board of Directors as the athlete representative.

Special Olympics has made me a better person and given me amazing opportunities! I was honored to speak at the United Nations at the Conference for the Rights of People with Disabilities. I met President and First Lady Obama. I was a member of our State and National Youth Activation Committee – a youth group that promotes inclusive education, competitive employment and community living. I became an advocate because of the things I've learned! I want to make a difference in the world we live in.

I have worked hard to do my best in everything.

I wear hearing aids and sometimes people don't always understand me, so I have learned to work hard to talk clearly – sometimes I'm better than others! I have learned to do new things from so many people.

I have been challenged to do and be better. I have learned to do things that are really hard by just trying and trying again! I have learned to be a better me because of all of those opportunities!

I work hard to do all I can to make a difference every day!

My hope is that every single person learns to believe they can do ANYTHING! I hope each child learns to believe in themselves and that they have family that love them, provide opportunities for them and support them in doing things that are challenging! Because together you can accomplish anything! It takes all of us doing our best to make our world a great place!

I hope you and your family explore the world together – because it's a GREAT place to grow!

Jared, 24, Missouri



A letter of encouragement from a Parent...

Fellow parents,

My husband and I understand the sense of loss you may feel when you learn your child has an intellectual or developmental disability. You may be experiencing or have experienced grief for the dreams for your child you feel are lost; dreams filled with hopes for all they will encounter and cherish in their lifetime, dreams of growing into individuals of excellent character, living meaningful and fulfilling lives. Dreams of all they can be and will become!

A disability means those dreams may alter; the new reality is that you do not really know what life may offer your child. For example, we were encouraged by our pediatrician to institutionalize our newborn son; but we could imagine doing nothing more than taking him home within the embrace of our loving family. As difficult as this moment may feel for you, I can assure you that love does indeed conquer all! I can encourage you, in the most difficult moments, to simply focus on loving your child. Reveling in the day-to-day accomplishments – happy smiles, rolling over, splashing in their bathwater, learning to crawl and walk and making tiny sounds or signs - because life experiences develop one's sense of who they are. Therefore, I ask you to encourage and celebrate the many accomplishments your child achieves! Small achievements become large accomplishments as our children grow into understanding who they are.

In time, you will understand your child's disability is not a detriment; it does not define who your child is or what your child can achieve! Your child's personality is uniquely theirs – they may have a sense of humor, may be adventurous, eager to learn, love profoundly, hate foods with textures or even loud noises, love butterflies and raindrops, like to be brave but perhaps doesn't always feel that way! Your child's life is not devalued or devastated by a diagnosis! Your child's life may be different; different does not mean less meaningful.

You and your child will learn to deal with those differences; providing opportunity or experience in striving to overcome barriers are valuable life lessons. As a small child we are frequently influenced by the perceptions of those who love us. I encourage you to provide every opportunity for growth for your child. Please have high expectations of your child; in a positive, encouraging and accountable manner. We should not expect less from our child because of their disability – it's important to recognize that they may not accomplish growth or success in the same manner as many do, but our differently abled child will still accomplish remarkable milestones and pursue life goals! In fact, our child may often work harder and more intently to accomplish milestones taken for granted by their peers.

My husband and I can say, our son has brought profound meaning to our lives. We have become advocates! We value small and great accomplishments, his courage and enthusiasm for life beautifully color every moment and his love for others is genuinely selfless! Jared has made us better individuals by simply being who he is! He faces life with humor and enthusiasm – nothing is impossible! Jared possesses a remarkably genuine regard for others, works diligently and demonstrates a thoughtful kindness to every individual he encounters! He colors our life in the most beautifully profound way; making us better by simply sharing his thoughts, his laughter and experiences!

Our dreams for our children may alter, but I can assure you they can and will achieve more than we may have hoped possible! It begins with love, growing into experiences and accountability. Know that you give them wings in each experience and opportunity! I encourage you to savor the moments as your child's life unfolds before you! I wish you success throughout this parenting journey as it holds more gifts than you can possibly imagine!

Brenda, Jared's mom

Selected Books & Articles

Parent to Parent USA—Provides emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained “Support Parent”.

www.p2pusa.org

Family Voices—A national network of state based organizations focusing on family-centered care for children with disabilities and special needs. Also includes the family to family portal.

www.familyvoices.org

My Child without Limits—Part of United Cerebral Palsy, provides information, resources, supports and a community for children with developmental delays and disabilities. Includes the Inspire Community, an online discussion and support group.

www.mychildwithoutlimits.org

Technical Assistance Alliance for Parents—Includes a nationwide Parent Center Directory which serves families of children of children of all ages (birth through 26 years) with all disabilities.

www.taalliance.org

Special Olympics—The world’s largest sports organization for children and adults with intellectual disabilities, providing year-round training and competitions to more than 4.5 million athletes in 170 countries.

www.specialolympics.org

Best Buddies—Organization for friendships, employment and leadership for people with intellectual and other developmental disabilities with chapters throughout the US and internationally.

www.bestbuddies.com

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A special thank you to the following individuals for their support in creating this resource.

Alicia Bazzano, MD, PhD (author)

Bergen Nelson, MD, MPH
(Mattel Children's Hospital, UCLA navigator)

Mattel Inc.

Mattel Children's Hospital UCLA

Funding provided by Mattel



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