

# TIPS FOR PARENTS WHO LEARN THEIR NEWBORN HAS A DEVELOPMENTAL DISABILITY



NATIONAL RESOURCE CENTER *for*  
HEALTHY MARRIAGE *and* FAMILIES

## TIPS FOR PARENTS

Lauren Clark, R.N., Ph.D., FAAN; Professor and Shapiro Family Endowed Chair in Developmental Disability Studies, School of Nursing, University of California Los Angeles, and Erin Johnson, Ph.D.; Research Associate, Department of Obstetrics and Gynecology, University of Utah School of Medicine

This research-based tip sheet is to provide tips for parents who receive news about their expected child or their newborn's developmental disability. Among the most common disorders identified through prenatal screening and testing are Down syndrome, fragile X syndrome, spinal muscular atrophy, cystic fibrosis, Edwards' syndrome, spina bifida, and neural tube defects like anencephaly. Topics covered in this tip sheet include realizing that parents are not alone if they experience a child's diagnosis with a developmental disorder and tips for what they can do to create a hopeful future for themselves as a couple and for their child. This information will be useful for both parents and service providers who work directly with parents.

With scientific advances, expectant couples often know quite a bit about the genetic makeup of their unborn child. There are [different ways to test for developmental differences](#). Down syndrome is one of the most common chromosomal disorders [screened for prenatally using blood tests and ultrasound](#). Routine screening or genetic testing, such as non-invasive prenatal testing using cell-free DNA, gives couples early and specific fetal DNA diagnostic information. This tip sheet is intended to provide guidance and suggestions to two groups of parents: expectant parents who plan to continue a pregnancy after they learn that their child may have a developmental disability (prenatally) and parents who first learn of their newborn's developmental disability shortly after birth (neonatally).

## HEARING THE DIAGNOSIS

Whether they hear news delivered prenatally or neonatally, parents describe the moment of the developmental disability diagnosis as unexpected and momentous. They explain that they embark on an emotional roller coaster and feel as if their plans for the future are torn apart (Clark et al., in review; Nelson Goff et al., 2013; Staats, Nelson Goff, Springer, & Monk, 2015). The diagnosis changes parents' views of the future for their child. They think about their responsibility as parents differently and the kind of family they will have in a new way. Sometimes changes in expectations feel heavy, and the future feels hopeless. If hearing the diagnosis is difficult for parents, they are certainly not alone in their feelings of anger, sadness, or hopelessness.



Children with developmental disabilities and their parents remind us that difficult news is not bad news. In a 2005 study, mothers of children with Down syndrome were more optimistic when their providers talked about the

positive aspects of Down syndrome and offered current printed materials (Skotko, 2005). About half of families in one study were satisfied with the overall interaction of their health care provider at the time of their child's Down syndrome diagnosis. The rest of the families were either neutral or dissatisfied (Kelly, Johnson, Shaul, Beall, & Carey, 1998). Providers can learn how to improve their part of the diagnostic conversation. Practice guidelines offer advice about what essential information to offer parents and how to deliver the news face-to-face in a sensitive, private, and supportive way (Sheets, Crissman, Feist, et al., 2011).

Now more than ever, the conversation about a newborn's developmental disability diagnosis is more than a single event. It may start prenatally or at birth. Over time, each child's unique abilities and personality become more pronounced, and parents grow to love their child and build on their child's strengths. Providers often address the positive aspects of the condition and the ways that the baby is like other babies (Dent & Carey, 2006). Parents also learn about how other parents advocate for educational, social, and technologic opportunities to benefit their child. By joining communities of families in similar situations, parents may find friendship and advice through online and in-person networks (see Text Box 1).

## TIP 1: REMEMBER: YOU ARE NOT ALONE

Developmental disabilities are common. About [one in every six children in the U.S. has a developmental disability](#), with an increasing number of children diagnosed with autism, attention deficit hyperactivity disorder, and

hearing loss. Developmental disabilities [occur among all racial, ethnic, and socioeconomic groups](#). Disability—whether physical or intellectual—is part of the fabric of the human experience. Andrew Solomon, a thought leader about disability, wrote in an impassioned [New York Times opinion piece](#), "The Dignity of Disable Lives." He wrote, "Disabled lives are lives, and are charged with inherent dignity. Most people with disabilities don't wish they had never been born; most people with disabilities contribute to the world they inhabit; most people with disabilities both give more to and get more from life than their nondisabled peers may be inclined to guess. Some have rich lives despite their disability, but others would say they have rich lives at least in part because of their disability."

Knowing they have much to learn, many parents wonder how they will face the unexpected experience of parenting a child who is different from typical children. These are some of the common questions parents ask.

## Will my child face a life of suffering?

Because Down syndrome is the most common developmental disability (Constestabile, Benfenati, & Gasparini, 2010; Grieco, Pulsifer, Seligsohn, Skotko, & Schwartz, 2015), we know quite a bit about these parents' experiences. They wonder if their child will face a life of suffering and ask themselves if their child's life will have meaning. Fifteen people with Down syndrome answered this question for future moms in a [short video](#) produced in honor of World Down syndrome Day in 2014. Researchers, too, have asked these questions. In one study, they found that 99 percent of people with Down syndrome were happy with their life. Furthermore, 97 percent of people with Down syndrome liked who they were (Skotko, Levine, & Goldstein, 2011a). Parents, too, report a fulfilling life. The vast majority of parents contacted by researchers through Down syndrome organizations expressed love for their son or daughter, pride in him or her, and a positive outlook on life (Skotko, Levine, & Goldstein, 2011b). Based on this research, you may find that whether you ask a person with a developmental disability or their parents, you'll often hear the same thing: they are happy with their life and happy with who they are.



## Will more information help me feel better about the situation?

Parents typically grieve the loss of the child they expected. And then they begin to love the child they have. Along the way, they begin to deal with the practicalities: health care, preschool, and social issues. So much information is available to parents that it can be overwhelming to sort through what applies to their child. Technical or unduly negative information is least helpful (Clark et al., in review). What parents are seeking, without knowing it, is a community that shares their experience and can help them find hope and meaning in parenting a child with a developmental disability. Sharing the journey of parenthood with other parents offers practical advice as well. As one mother explained, her social media contacts had expertise to share: "My daughter with Down syndrome needed glasses. It is hard to find glasses for a 2-year old, and with her slightly different facial features and the flattened bridge of her nose, no glasses in our town fit her face. I finally connected with parents who told me about a company in Korea that made eyeglass frames for children, and my daughter's face measurements worked with those styles. We placed an order for some pink Hello Kitty glasses—adorable!—on the internet. It was a gift to have parents on the Facebook page send us suggestions!" Similarly, parents found support and encouragement through local children's playgroups and parent-to-parent disability support groups. Family members, friends, and health care professionals can listen and offer support as well.



Numerous national groups connect parents of children with developmental disabilities and often have local chapters (See Text Box 1).

**Text Box 1.** National resources offering information and support for parents of children with developmental disabilities

### Down syndrome-specific information

- Global Down Syndrome Foundation. <https://www.globaldownsyndrome.org/about-down-syndrome/resources/national-down-syndrome-organizations-2/>
- National Down Syndrome Society. <https://www.ndss.org/about-down-syndrome/down-syndrome/>
- National Association for Down Syndrome. <https://www.nads.org/>
- Centers for Disease Control and Prevention. Facts about Down Syndrome. <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome.html>
- U.S. National Library of Medicine, MedlinePlus. <https://medlineplus.gov/downsyndrome.html>
- National Institute of Child Health and Human Development. Down Syndrome: Condition Information.
- U.S. National Library of Medicine. Primary Prevention of Down Syndrome. <https://www.nichd.nih.gov/health/topics/down/conditioninfo>

### Social media connections

- Meriah Nichols Down syndrome Groups on Facebook. <https://www.meriahnichols.com/down-syndrome-groups-on-facebook/>

### Information and Support Networks for Families

- The Arc. [www.thearc.org](http://www.thearc.org)
- Family Network on Disabilities. [www.fndusa.org](http://www.fndusa.org)
- Center for Parent Information & Resources. [www.parentcenterhub.org](http://www.parentcenterhub.org)
- Family Voices. [www.familyvoices.org](http://www.familyvoices.org)



## TIP 2: IMAGINE: WHAT'S AHEAD FOR OUR CHILD? FOR US AS A FAMILY?

The shock of the unexpected diagnosis begins to recede as parents revisit what they already know. In many ways, the news of the diagnosis hasn't changed the basic job of being a parent. The baby is just a baby. Babies need to be cared for and loved. As the child grows, parents help each child, whatever their abilities, to achieve their potential. As parents told us during our research interviews, they begin to realize it's the same job, whether you are a parent of a child with Down syndrome or a typically developing child.

As couples make sense of the news that their child has a developmental disability, they need information about what [day-to-day life](#) may be like given their child's unique situation and abilities. Six families shared their day-to-day life with a child with Down syndrome in Pittsburgh. These families shared how they reached out to other families and connected with the medical care and education experts they needed. Part of reaching out is letting your family and friends know about the baby and the diagnosis. Rick Smith wrote a popular blog in 2016 called [Noah's Dad](#) about their son's birth and how they announced his birth and Down syndrome diagnosis to friends and family. Other families post on social media or make phone calls or call a family meeting. There are different ways to enlist family support, and you can choose whatever works for your family.

Often, the language and terms professionals use are new to parents (see Text Box 2 for terms associated with developmental disability). As families learn the vocabulary about disability and the official labels or terms for their child's diagnosis, they also begin to educate other people. The baby's grandparents, family friends, and neighbors may be at a loss as to how to talk with parents. In general, parents would prefer "congratulations on your new baby!" to expressions of sympathy. These same people may not know the family's preferred way of referring to the child's diagnosis and disability. Parents can model how to use these terms in matter-of-fact, accurate ways. Using up-to-date terms helps friends and family who may be



less familiar with current disability language to learn the language of disability as well.

As parents gain skill and confidence learning how to talk about their child's diagnosis and developmental disability, they may begin to think about the future. These are some of the questions parents ask as they imagine the future.

How can we promote our child's well-being? Children with developmental disability thrive when their needs are met at home, at school, and in medical settings. At home, talking, reading, cuddling, and offering a safe and loving environment can help every child. By acting early, you can smooth your child's pathway into the services available—often free of charge—to children with disabilities or developmental delays. Services may start as soon as the baby is transitioned from the hospital to the home, or as soon as the child enrolls in an early intervention program. For more information, see Part C of the Individuals with Disabilities Education Act (IDEA) legislation that covers early intervention, explained clearly at the [Medical Home Portal](#).

Developmental monitoring, developmental screening, and a comprehensive developmental evaluation are different. [The Centers for Disease Control and Prevention website](#) explains how and when each of these may

**Text Box 2.** Questions parents may ask about unfamiliar disability terms Adapted from [the American Association on Intellectual and Developmental Disabilities FAQs on intellectual disability](#) and [Intellectual Disabilities by the American Academy of Child & Adolescent Psychiatry](#)

### **What's the preferred way to talk about a child's disability?**

The people-first language movement was developed in the disability community as a way of referring to the individual first and the disability second. People with disabilities are people, first and foremost. By saying “a child with autism” (not an autistic child) or “a child with Down Syndrome” (rather than a Downs child) we communicate the uniqueness of the person and reduce generalizations and stereotypes about a group of people. Much has changed since people with disabilities were pitied or ignored or portrayed as helpless. [The Texas Council for Developmental Disabilities](#) has more information about people-first language.

### **What are developmental disabilities?**

Developmental disability is an umbrella term. It includes severe chronic disabilities that may be physical or cognitive or both. Developmental disabilities appear before age 22 and are likely to be lifelong. Cerebral palsy and epilepsy are examples of developmental disabilities that affect physical development. Down Syndrome and Fetal Alcohol Syndrome are examples of developmental disabilities that affect cognitive or thought processes with some physical impairment as well.

### **What is 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. Intellectual disability isn't diagnosed just by an IQ test, even though an IQ around 70—or as high as 75—indicates a limitation in intellectual functioning. Limitations in adaptive behavior is part of intellectual disability, too, and may be seen in conceptual skills, social skills, and practical skills. Individuals with intellectual disability may have problems with speaking, reading, eating, using a telephone, taking care of themselves, or interacting appropriately with others. This [video from Special Olympics](#) explains more about intellectual disability.

### **Is intellectual disability the same as developmental disability?**

Intellectual disability is one kind of developmental disability.

### **Is intellectual disability the same as mental retardation?**

In the past, people used to use the term “mental retardation,” but we no longer use that term. The newer term, intellectual disability, covers the same group of people who were diagnosed with mental retardation in past years. Because it takes time for language to change in legislation, regulation, and even for the names of organizations, you may still see or hear the words “mental retardation.” Parents and people with intellectual disability are clear that the “R word” for mental retardation is no longer acceptable and have a campaign to end the “R word.” A [30-second public service announcement video](#) explains why.

be suited to your needs. Parents and grandparents can monitor and screen to celebrate their child's accomplishments and identify any concerns early. A comprehensive developmental evaluation is done by a

specialist (often a pediatrician or child psychologist). The evaluation can set the stage for understanding how to arrange the best educational and health care services for the child's specific needs. To find out the cause of the

developmental disability and the child's specific strengths and needs for support, check with your child's doctor or a children's hospital to arrange for a comprehensive evaluation. Many professionals are involved in the evaluation. General medical tests as well as neurological, psychological, learning, and education tests will be part of the evaluation. Hearing, speech, vision, and physical therapy assessments also help identify strengths and limitations. Often, a developmental pediatrician or a child psychologist or psychiatrist coordinates these tests. When the evaluation is done, the evaluation team sets up a time to meet with the family and the school to develop a comprehensive treatment and education plan. When a child has disabilities, the goal is to help the child meet his or her potential to learn and grow as part of a family and community. Each state offers a variety of educational and support services.

## What can we do to prepare for success as a family?

Parents explain that it's important to find meaning, purpose, and hope for the future after you find out your child has a developmental disability. A baby, with or without a disability, has an uncharted future. Only time will tell what he or she will do. Brains and bodies adapt over time. The American Academy of Child and Adolescent Psychiatry tells parents: "There is hope; each child is different and may reach goals not felt possible when the diagnosis of intellectual disability was made." ([https://www.aacap.org/AACAP/Families\\_and\\_Youth/Facts\\_for\\_Families/FFF-Guide/Children-with-an-Intellectual-Disability-023.aspx](https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Children-with-an-Intellectual-Disability-023.aspx)).



Part of making sense of the diagnosis is sharing the news with others and figuring out what it means for everyone. Parents first consider how to best explain the diagnosis. Then they decide when to tell their own parents, other children in the family, and their friends and relatives. Through discussion, their experiences and core beliefs bring perspective to the new diagnosis.

Parents look for hope and find it in memorable messages so momentous they can quote them word-for-word months or years later. They often open themselves to memorable messages by purging negative ones. They replace negativity with positive, inspirational ways of viewing their life with a child with Down syndrome. Memorable messages give parents a touchstone as they work to rewrite their expectations for the future. One parent kept singing the refrain of a popular song, "everything's gonna be okay." Another parent found purpose and meaning in his situation by reminding himself, "raising her is more alike than different." A mother said she thought of parenting a child with a developmental disability as seeing a new color for the first time. According to the many parents we interviewed (Clark et al., in review), they hadn't expected to raise a child with a developmental disability, and wouldn't have chosen this path, but they could find joyful meaning in their experience and their child's life.

Andrew Solomon, who has talked with hundreds of families of children with disabilities, told of a mother of a child with a very serious disability. For the first year of his life, every doctor she saw "rattled off a catalogue of what was likely to go wrong and asked her if she was prepared to deal with it all. When her son was a year old, a doctor who specialized in his condition lifted the baby up, held him aloft in the light, and said, 'Let me tell you, that's going to be a handsome young man one day.' The rewarding life she was to have with her son began that very day." She told this story on the day of her son's joyful wedding, a reminder that an unexpectedly positive future is possible. (Solomon, 2019, p. xii).



## What is the prognosis of a child with Down syndrome and their outlook on life?

Most children with Down syndrome have mild to moderate intellectual disability. That means they reach developmental milestones later than other children. One mother said her pediatrician explained it this way: "Your daughter will ride a bike. She may do it at 8 or 9, but she will ride a bike." She also expects her daughter will learn to read, make her own breakfast, and go to college one day (Clark et al., in review).

There are many resources to help children with developmental disabilities achieve their goals. [Early intervention](#) may begin right away. After that, preschool and K-12 education can offer inclusive and individualized education. [Colleges and universities also offer admission](#) and programs to support students with intellectual and developmental disabilities to have a college experience and earn a degree.

Throughout childhood, physical therapy, occupational therapy, and speech therapy can help children progress in meeting developmental milestones. These services may be included as part of their Individual Education Plan ([IEP](#)) in public schools as part of the Individuals with Disabilities Education Act ([IDEA](#)). By [law](#), free appropriate public education is available to eligible children with disabilities throughout the nation from birth through age 21. As they grow up, people with Down syndrome and other developmental disabilities—like all people—may find fulfilling jobs and romantic relationships, and lead happy, productive lives until their 60s or beyond (<https://medlineplus.gov/downsyndrome.html>; <https://my.clevelandclinic.org/health/diseases/17818-down-syndrome/outlook--prognosis>).



### TIP 3: HOPE: CREATING A HOPEFUL FUTURE

Parents rely on meaning-making messages to reinvent their sense of parenting purpose and maintain a positive frame of mind. They look for hope by replacing negative messages with positive, inspirational ways of viewing their life with a child who has a developmental disability such as Down syndrome.

Families have a variety of interpretations to choose from as they make sense of disability, ability, potential, limitations, expectations, and relationships. Parents find hope by sharing the diagnosis with friends and family, connecting with other parents with children who have developmental disabilities, embracing meaningful messages about their role as parents, and adjusting to their child's unique pace and personality. Clinicians can offer hope-affirming messages more deliberately to parents and at earlier points in the parenting experience.



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