

Multiple Disabilities

NICHCY Disability Fact Sheet #10 August 2013

Sharon's Story

Sharon is an active five year old who loves to spend time with her grandmother. She also loves to fingerpaint and play with the family dog. Sharon has multiple disabilities. When she was born, she didn't get enough oxygen. As a result, she has an intellectual disability, problems with mobility, and a speech impairment that makes it hard to understand what she's saying. That doesn't stop Sharon from chattering, though. She has a lot to say.

For Sharon's parents, it's been a long road from Sharon's birth to today. When she was just a baby, she began receiving special services called *early intervention*. These services help children with disabilities from birth to their third birthday. In early intervention, Sharon learned to crawl and to stand and—finally!—to walk with braces.

Now in preschool, Sharon receives special education services. Like early intervention, these services are meant to address her special learning needs. Her parents are very involved. They sit down often with the preschool staff and talk about Sharon's progress. The team also talks about Sharon's challenges and how to address them. Last week, for example, Sharon got a picture board to help her communicate. She's busy learning to use it.



is the

National Dissemination Center for Children with Disabilities.

NICHCY

1825 Connecticut Avenue N.W. Washington, DC 20009 1.800.695.0285 (Voice / TTY) 202.884.8200 (Voice / TTY) nichcy@fhi360.org http://nichcy.org Sharon's parents know that Sharon will always need some support because of her multiple disabilities. But her parents also know how determined Sharon can be when she's learning something new. She's going to learn it, by golly, there's no stopping her.

Causes of Multiple Disabilities

Having multiple disabilities means that a person has more than one disability. What caused the disabilities? Often, no one knows.

With some children, however, the cause *is* known. For example, Sharon's disabilities were caused by a lack of oxygen at birth. Other causes can include:

- Chromosomal abnormalities
- Premature birth
- Difficulties after birth

- Poor development of the brain or spinal cord
- Infections
- Genetic disorders
- Injuries from accidents¹

Whatever the cause, the result is that the child has multiple disabilities. Fortunately, there's help available. Keep reading to find out more.

Multiple Disabilities Aren't All the Same

The term *multiple disabilities* is general and broad. From the term, you can't tell:

- how many disabilities a child has;
- which disabilities are involved; or
- how severe each disability is.

Many combinations of disabilities are possible. For example, one child with multiple disabilities may have an intellectual disability and deafness. Another child may have cerebral palsy and autism. Sharon, above, had three different disabilities. All have multiple disabilities—but oh, such different ones!

To support, parent, or educate a child with multiple disabilities, it's important to know:

- which individual disabilities are involved;
- how severe (or moderate or mild) each disability is; and
- how each disability can affect learning and daily living.

The different disabilities will also have a *combined* impact. That's why it's also important to ask: How does the *combination* of these disabilities affect the child's learning, balance, use of the senses, thinking, and so on?

Have you recently learned that your child has multiple disabilities?

If so, you may find it helpful to read two articles on our website:

New to disability? http://nichcy.org/families-community/ new-to-disability

You are not alone http://nichcy.org/families-community/ notalone/

The answer will help parents and involved professionals decide what types of supports and services the child needs now and in the future.

Help for Children with Multiple Disabilities

When children have multiple disabilities, they are often eligible for the type of help that Sharon, our story girl, is receiving. In fact, more than 8,000 children in preschool (ages 3-5) received special education and related services in the U.S. in the Fall of 2011 because of their multiple disabilities.² More than 125,000 school-aged children did, too.³

For babies and toddlers | When a baby is born with multiple disabilities, his or her parents should know that there's a lot of help available—and immediately. Shortly after the diagnosis of multiple disabilities is made, parents will want to get in touch with the early intervention system in their community. We'll tell you how in a moment.

Early intervention is a system of services that helps infants and toddlers with disabilities (until their 3rd birthday) and their families. Early intervention services are available in every state and territory, as required by the Individuals with Disabilities Education Act (IDEA). These services may be provided on a sliding-fee basis. This means that the costs to the family will depend upon their income.

 To access early intervention services in your area, consult NICHCY's State Organizations page, online at: http://nichcy.org/stateorganization-search-by-state

There, select your state. Then use the drop-down menu to select "State Agencies." You'll get a list of State Agencies in your state. Look for the title "Early Intervention." The agency listed beneath will be able to put you in contact with the early intervention program in your community.

 To learn more about early intervention, visit NICHCY at: http://nichcy.org/babies/overview/

For children in school | IDEA also requires that special education and related services be made available to every eligible child with multiple disabilities. This includes preschoolers (ages 3-21). These services are specially designed to address the child's individual needs associated with the disabilities. The services are provided at no cost to families.

- To access special education services for a school-aged child with multiple disabilities, get in touch with your local school system.
 Calling the elementary school in your neighborhood is an excellent place to start.
- To learn more about special education (and there's a lot to know!), visit NICHCY. Find our special education information at: http://nichcy.org/schoolage/

IDEA's Definition

Speaking of IDEA, this very important federal law defines the term *multiple disabilities*.

Multiple disabilities...

...means concomitant [simultaneous] impairments (such as intellectual disability-blindness, intellectual disability-orthopedic impairment, etc.), the combination of which causes

such severe educational needs that they cannot be accommodated in a special education program solely for one of the impairments. The term does not include deaf-blindness. [§300.8(c)(7)]

As you can see, there's more to IDEA's definition of multiple disabilities than having more than one impairment or disability. A key

part of the definition is that the *combination of disabilities* causes the student to have severe educational needs. In fact, those educational needs must be severe enough that they cannot be addressed by providing special education services for only one of the impairments.

The federal definition of multiple disabilities gives two examples of possible combinations of disabilities:

- intellectual disability and blindness; and
- intellectual disability and orthopedic impairment.

But these are just examples. A child may have another combination of disabilities that causes severe educational needs—cerebral palsy and autism, for example, or blindness and an emotional disturbance. Whatever the combination is, a child served under IDEA's category of "multiple disabilities" will have a special education program that is designed to address the educational needs that arise from *all* of the child's disabilities, not just one.

Note that IDEA does not include deafblindness as an example of multiple disabilities. That's because deaf-blindness is defined separately and is a disability category of its own under IDEA.

Beyond the Federal Definition

So, what level of educational need is considered "severe enough" to make a student with multiple disabilities eligible for special education? Each state defines this for itself. So

it's important to know your state's definition of multiple disabilities. It's also important to know:

- how each disability affects the child's learning and functioning, and
- how the combination of disabilities does as well.

NICHCY offers many fact sheets on disabilities. To learn more about specific disabilities, visit our *Fact Sheets* page, at: http://nichcy.org/disability/ specific

Bear in mind that it's hard to say how a *combination* of specific disabilities will affect an individual child. That will depend on the disabilities involved and their severity.

The Evaluation Process

An in-depth evaluation of the child must be conducted (with parental consent) before any services or supports may be provided under IDEA. This evaluation is free of charge to families. Its purpose is to gather detailed information about:

- the nature and extent of the child's disabilities; and
- the educational or developmental needs resulting from those disabilities.

With information from the evaluation, parents and involved professionals can then work together to decide what services and supports the child will receive, given his or her individual needs.

This is a very brief overview of the evaluation process under IDEA. To learn more about this vital step, visit NICHCY's discussion at: http://nichcy.org/schoolage/evaluation

Supporting Children with Multiple Disabilities

Most children with multiple disabilities will need some level of help and support throughout their lives. How *much* support a child needs will depend on the disabilities involved. A child with mild multiple disabilities may only need intermittent support (mean-

ing, support is needed every now and again, or for particular tasks). Children with multiple, more severe disabilities are likely to need ongoing support.

Support in major life activities | When considering what supports a child needs, it's helpful to think about major life activities. "Major life activities" include activities such as:

- caring for oneself;
- performing manual tasks;
- seeing, hearing, eating, and sleeping;
- walking, standing, lifting, and bending;
- speaking and communicating;
- breathing;
- learning;
- reading;
- concentrating and thinking; and
- working.⁴

Are any of these major life activities a challenge for the child because of his or her disabilities? Five-year-old Sharon has difficulties with caring for herself, walking, standing, and communicating. Her intellectual disability makes learning, reading, concentrating, and thinking a challenge. Not surprisingly, these are the areas where Sharon needs extensive support. Only time will tell how much support she'll need as she grows older.

Tips for Parents

Learn about each of your child's disabilities. The more you know, the more you can help yourself and your child. To identify organizations that specialize in each of your child's disabilities, visit NICHCY's National Organizations Gateway, at: http://nichcy.org/org-gateway



Love and play with your child. Treat your son or daughter as you would a child without disabilities. Take your child places, read together, have fun.

Know your child's needs, play to his or her strengths. Each child with multiple disabilities has learning needs, yes, but each also has his or her own set of skills, strengths, interests, enthusiasms, and preferences. These can be used to motivate your child and enrich learning, growth, and individuality.

Don't let the labels get you down. What terms should you use to describe your child's disabilities? There may be many to choose from (e.g., delay, developmental disability, cerebral palsy, physical disability, speech or language disorder, multiple disabilities), and each one describes a different aspect of your child. Learn to understand and be comfortable with using each one. This will help you be an advocate for your child and his or her unique gifts and challenges.

Encourage your child to be independent. For example, help your son or daughter learn self-care skills such as getting dressed, grooming, and doing laundry.

Team with the professionals working with your child. As a parent, you have the right to participate in team meetings where your child's education or program is being planned. Be there. Share your unique knowledge of who your son or daughter is; advocate that the program address your child's needs.

Investigate assistive technology (AT). AT is appropriate, even essential, for many children

with multiple disabilities. Without AT, there may be many tasks they simply cannot do or will have difficulty doing. Computers, augmentative/alternative communication systems, communication boards, head sticks, and adaptive switches are just some examples of helpful AT. Visit the Family Center on Technology and Disability to

learn more about which AT devices may be useful to your child: http://www.fctd.info

Practice and reinforce. Do your child's disabilities affect his or her intellectual functioning? If so, he or she will be slower to learn new things and will have difficulty applying that learning in new situations. Be concrete. Give lots of hands-on opportunities for learning and practice. Give feedback immediately. Repeat the learning task in different settings.

Give your child chores. Keep in mind his or her age, mental capacity, attention span, and abilities. If necessary, divide tasks into small steps. Explain what your child is supposed to do, step by step, until the chore is done. Demonstrate. Offer help when it's needed and praise when things go well.

Find out what your child is learning at school. Look for ways to apply it at home. For example, if the teacher is reviewing concepts of money, take your child to the supermarket with you to help keep track of what money you're spending.

Look for social opportunities in the community (such as Scouts) or activities offered through the department of sports and leisure. Joining in and taking part will help your child develop social skills and have fun.

Talk with other parents whose children have disabilities—especially those who have one or more of the same disabilities as your child. Other parents can be a fountain of practical advice and emotional support. Visit the websites of the disability organizations you've identified to see if they have a parent group nearby.

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You can also identify parent groups in your area by consulting NICHCY's *State Organizations* page (see the box below). We also suggest reading *Parent Groups*, available online at: http://nichcy.org/families-community/help/parentgroups

Be patient, be hopeful. Your child, like every child, has a whole lifetime to learn and grow.

Tips for Teachers

Know the needs, play to the strengths. Each student with multiple disabilities will have his or her own set of skills, strengths, and learning needs. Learning more about each disability of the student will be helpful in addressing those learning needs. Also find out more about the student's strengths and interests, enthusiasms, and preferences. These can be used to motivate the student and enrich the education he or she receives. Parents are a great source of this information. So is the student!

Be familiar with the student's IEP. If you have a student with multiple disabilities in

your class, chances are that he or she has an individualized education program (IEP). The IEP will spell out the educational and functional goals to be worked on. You may have been part of the team that developed the IEP. If not, it's important to be familiar with what the student's IEP requires. Ask for a copy. Consult with administrators and other teachers, as needed, to make sure that the supports and services listed in the IEP are provided.

Make modifications. Students with multiple disabilities often need substantial modifications and accommodations in the classroom. This will help them access the general education curriculum at a grade-appropriate level. Find out about accommodations at: http://nichcy.org/schoolage/accommodations

Let the IEP team know what program supports or modifications *you* need. The student's IEP can include program modifications and supports for school personnel. Read more about this at: http://nichcy.org/schoolage/iep/iepcontents/modifications-personnel

Finding Organizations for Parents

There are many organizations in your state that can be especially helpful to parents of children with disabilities. Visit NICHCY's *State Organizations* page to identify what's available in your area. Go to: http://nichcy.org/state-organization-search-by-state

Select your state. From the drop-down menu, select "Organizations for Parents." Submit your search. Results will include several key parent organizations, including:

- The Parent Training and Information Center (PTI) for your state and possibly the Community Parent Resource Center (CPRC). PTIs and CPRCs know the relevant resources in your state and community. They can also give you information about disabilities, the educational rights of your child, or strategies for being an effective advocate for your child.
- The Parent to Parent program in your state. The P2P program matches parents in one-on-one relationships for sharing information, experiences, and emotional and practical support.

Our *State Lists* will give you the address and contact information for the main state office of these organizations. Often, they also have local offices. So, even if the main office isn't located nearby, check to see if there's a satellite office in your area. Very often, there is!

Allow partial participation, as necessary. Partial participation means that students with multiple disabilities aren't excluded from activities because they might not be able to complete a task fully or independently. Modifications can be made to the task itself or to how students participate.

Consider assistive technology (AT). AT is appropriate, even essential, for many students with multiple disabilities. Without AT, there may be many tasks they simply cannot perform or will have difficulty performing. Computers, augmentative/alternative communication systems, and communication boards are just some examples of helpful AT.

Visit the Family Center on Technology and Disability to learn more about which AT devices may be useful to a given student: http://www.fctd.info

Does the student need textbooks in another format?

IDEA requires that students with print disabilities be provided with accessible instructional materials. There are many disabilities that affect a student's ability to use print materials; does your student have one such disability? If so, visit the National AIM Center, to learn where and how to get textbooks and workbooks that your student will be able to use: http://aim.cast.org/

Practice and reinforce. Do your student's disabilities affect his or her intellectual functioning? If so, he or she will be slower to learn new things and will have difficulty applying that learning in new situations. Be concrete; give lots of hands-on opportunities for learning and practice. Give feedback immediately. Repeat the learning task in different settings.

Support related services in the classroom. Depending on the student's disabilities, he or she may need related services to benefit from special education. Related services may include speech-language therapy, occupational therapy,

physical therapy, or orientation and mobility services. It's best practice to provide these services in the classroom during the natural routine of the school, although some may be provided in other settings. Work with the related services personnel, as appropriate. Learn more about the related services your student receives or may need at: http://nichcy.org/schoolage/iep/iepcontents/relatedservices/

Address behavior issues. Behavior can be affected by having disabilities, especially a combination of disabilities. If a student's behavior is affecting his or her learning or the learning of others, IDEA requires that behavior

be addressed in the IEP. Is this a problem area for your student?

Learn what the law requires and effective strategies for addressing behavior issues in our *Behavior Suite*: http://nichcy.org/schoolage/behavior

A paraprofessional in your classroom? Some students with multiple disabilities will require the support of an aide or paraprofes-

sional. If this is so for your student, it helps to know about working with paraprofessionals. NICHCY offers a *Para* page, which paraprofessionals may also find useful, at: http://nichcy.org/schools-administrators/paras

Encourage the student's independence. It's natural to want to help a student who's struggling to do a task single-handedly, especially when you know there's a disability involved. But it's important for the child to develop the skills it takes to live as independently as possible, now and in the future.

When the time comes, support transition planning. IDEA requires that IEP teams and students plan ahead for the student's transition from school to the adult world. There's a lot to know about transition planning. When the time comes for the student to begin planning, have a look at our *Transition Suite*: http://nichcy.org/schoolage/transitionadult

Resources of More Information

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Hosken, C.K. (2008). *Severe and multiple disabilities* (Lecture #106). Retrieved December 19, 2012 from: http://www.agape-biblia.org/plugins/pract-ministries/Lect106.htm

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Organizations

National Center on Severe and Sensory Disabilities (NCSSD) | http://www.unco.edu/ncssd/

TASH | Advocates for inclusion for people with significant disabilities and support needs. http://tash.org/

Tots 'n Tech Research Institute | Find out more about assistive technology for young children. http://tnt.asu.edu/

National Lekotek Center | Find toys and play activities for children with special needs. http://www.lekotek.org/

March of Dimes | http://www.marchofdimes.com/

References

- ¹ Watson, S. (n.d.). *Tips for working with students with severe handicaps: Severe handicaps in the inclusional setting.* Retrieved January 4, 2013 from: http://specialed.about.com/od/physicaldisabilities/a/severe.htm
- ² Data Accountability Center. (2012, August). *Table B1-2. Number of children ages 3 through 5 served under IDEA, Part B, by disability and state: Fall 2011*. Rockville, MD: Author. Online at: https://www.ideadata.org/TABLES35TH/B1-2.pdf
- ³ Data Accountability Center. (2012, August). *Table B1-3. Number of students ages 6 through 21 served under IDEA, Part B, by disability and state: Fall 2011*. Rockville, MD: Author. Online at: https://www.ideadata.org/TABLES35TH/B1-3.pdf
- ⁴ Federal law at 42 USC §12102 defines "major life activities" as follows: "major life activities include, but are not limited to, caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working."



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