



## Talking to Your Child About His or Her Disability

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Self advocacy is an important skill for people with a disability. The first step toward building and developing that capacity is for parents to talk openly and honestly with their child about his/her disability and its impact. This will give a child the necessary information to advocate for himself/herself and lead a quality life. In order to self advocate a child needs to have:

1. Awareness of self
2. Acknowledgement of personal strengths and challenges
3. Acceptance of who they are

### **Parents should talk to their child about his/her disability, because:**

- Even if the child doesn't ask, he may still have questions or want information.
- If parents don't talk to their child about the disability someone else will.
- The child may not have an awareness of her disability.
- Keeping secrets is not good for the child or family and may actually be harmful.
- Students who have a realistic sense about their disability are more likely to cooperate and participate.

### **Common perceptions, beliefs and feelings that prevent open communication**

- *Children should not have to carry the burden of the disability on their shoulders.*
- *There is no good reason to tell children about the life long nature or the consequences of their disability.*
- *I don't believe my child has the problem or disability that has been diagnosed, so why should I talk to him about it?*
- *My child already knows she has a problem, she doesn't have to be told.*
- *I am just too uncomfortable to talk with my child about his disability.*
- *I feel so sorry for my child that it is difficult to be open and honest with her about the disability, and I am afraid I might break down.*
- *Kids ask for more information than they want or are ready for.*
- *It is my spouse's job to answer questions.*
- *I want my child to be happy and I will keep secrets if it helps him to be happy.*

### **Start talking with the child early, and keep on talking...**

It is imperative that parents start talking to their child about his/her disability and its impact when they are young. Starting early:

- Makes the parent and their child more comfortable talking about the disability and it isn't such a 'big deal' for the parent or child.
- Shows their child the disability isn't something to hide or feel ashamed about.
- Makes it easier for their child to come to them with questions, concerns or confide personal feelings.

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### Use age and developmentally appropriate information

When choosing the most suitable approach, consider both the child's age and developmental level.

#### For younger children

Children of this age are concrete in their thinking. Discuss specific, observable problems that the child is experiencing such as:

- *Trying to run is hard for you.*
- *It is difficult to talk when people have trouble understanding you.*
- *You would rather ride the big/regular bus.*

#### For older elementary students

Children of this age understand cause and effect. Use statements such as:

- *Damage to the brain caused your cerebral palsy and that is what makes it hard for you to walk.*
- *Part of your eye was damaged and that is what is causing the difficulty seeing.*

#### For middle school students

A strong emotional component enters the picture at this time, children often feel inferior to their peer group. Discussing symptoms along with suggested coping techniques such as:

- *You get very angry sometimes and I know that is why you have the outburst. Could we talk about some ways that might help you deal with the difficult situations?*
- *I understand you are being teased, so what are some ways you could respond? Decide which would work best.*
  - giving information
  - moving away from them
  - seeking help, depending on what is most appropriate.

#### For high school students

At this age the child begins to question things such as conventional approaches to medical treatments, educational approaches and family traditions and expectations. It is important to identify personal concerns. Provide clear information and explanations and if needed enlist the aid of appropriate professionals and close friends.

- ***I know you want to stop the treatment.** I would like to talk about why you are getting the treatment and what we expect them to do. If you still have questions or would like to talk to the doctor about it, let's set up an appointment.*
- ***Taking the test in a format with large print is different than the other kids.** The large print is used because of your vision challenges. The large print helps because... Maybe we could visit with the vision teacher and have you answer a few questions in regular print and then in large print.*

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### Questions to ask as parents prepare to talk to their child

1. *What is my level of acceptance of my child's disability? (Children generally mirror their parents' attitude.)*
2. *How well do I understand my child's disability, status and treatment?*
3. *What are my emotions currently about this disability? (anger, guilt, hostility, sadness, etc.?)*
4. *How do I handle talking about such a tough issue? Will I get too emotional?*
5. *Am I able to talk with my child at his/her level of understanding?*
6. *Can I be objective in talking about my child's disability?*
7. *Can I be optimistic and hopeful, yet realistic?*

### Steps parents can take in order to communicate openly, honestly and effectively with their child

- Take advantage of impromptu opportunities to talk with their child
- If the child doesn't ask questions, parents need to initiate the discussion.
- Commit to answering all the questions the child asks.
- Work on improving listening skills.
- Make a list of the questions the child has already asked and those he might ask.
- Gather the information necessary to answer these questions in an age appropriate manner.
- Prepare a script for the tough questions the child may ask. Expect variations of the following questions.
  - *Will I ever be like everyone else?*
  - *Why won't the other kids play with me?*
  - *Why aren't I in regular classes like other kids?*
  - *Why do I have to ride in that special bus?*
  - *Were you and daddy unhappy when you first saw me?*
  - *Why do my younger brothers and sisters get to do things I am not allowed to do?*
  - *Why do other kids call me names and laugh when I am around them?*
  - *Why do I have to go to those classes? They are for dumb kids!*
- Set aside a specific time to talk privately without interruptions

### Tips and strategies to use while talking to children about their disability

- Listen carefully:
  - Tune into their feelings
  - Reflect their feelings back to them
  - Clarify what they are saying and feeling
- Be nonjudgmental about what they are saying and feeling.
- Share personal feelings about the disability with her.
- Give honest, truthful and precise information for what is "really" being asked.
- Get down on his level, touching or holding him while talking.

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- Keep eye contact and smile at her while talking to her.
- Teach him to take responsibility for his own life.
- Be realistic and build on her strengths.
- Sort out feelings from the content/root of a problem.
- Brainstorm and sort out solutions to a problem.
- Evaluate alternatives with him.
- Teach her to think on her feet.
- Teach him to be assertive with those who are infringing on his rights.
- Model and maintain a sense of humor.
- Check in with her to see what she understood from the discussion.
- Use people first language. (*See Attachment A*)

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### *Attachment A*

## **People First Language describes what a person HAS, not what a person IS!**

Are you myopic or do you wear glasses?  
Are you cancerous or do you have cancer?  
Are you freckled or do you have freckles?  
Are you handicapped/disabled or do you have a disability?

### **Who are “the handicapped”... the “disabled”?**

Society’s *myths* tell us they are:

- people who “suffer” from the “tragedy” of “birth defects”...
- paraplegic “heroes” “struggling” to become “normal”...
- “victims” of diseases “fighting” to regain their lives...
- categorically... “the disabled, the retarded, the autistic, the blind, the deaf, the learning disabled” and more.

### **Who are they, really?**

They are moms and dads and sons and daughters... employees and employers... scientists (Stephen Hawking)... friends and neighbors... movie stars (Marlee Matlin)... leaders and followers... students and teachers... they are... people. They are **people**.

**They are people, first.**





### People First Language

#### Examples to Use and to Share

by Kathy Snow

#### Examples of People First Language

**Say:** People with disabilities (or disability labels). He has a cognitive disability (label). She has autism (or an autism label). He has a diagnosis of Down syndrome. She has a learning disability (label). He has a physical disability (label). She's of short stature/she's a little person. He has a mental health diagnosis (or label). She uses a wheelchair/mobility chair. He receives special ed services. She has a developmental delay. Typical kids or kids without disability labels. Communicates with her eyes/device/etc. Customer. Congenital disability label. Brain injury. Accessible parking, hotel room, etc. She needs. . . or she uses.

**Instead of:** The handicapped or disabled. He's mentally retarded. She's autistic. He's Down's. She's learning disabled. He's a quadriplegic/crippled. She's a dwarf/midget. He's emotionally disturbed/mentally ill. She's wheelchair bound/ in a / confined to a wheelchair. He's in special ed. She's developmentally delayed. Normal or healthy kids. Is non-verbal. Client, consumer, recipient, etc. Birth defect. Brain damaged. Handicapped parking, hotel room, etc. She has a problem with. . ./She has special needs.

**Keep thinking - there are many descriptors we need to change.**

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