

First Words

*A First Steps Communications Tool for Families
From Family to Family*

Speaking of Disabilities

"People with disabilities would prefer to be seen as people, not as objects of pity or as heroes who have overcome adversity,"

Alphabet Soup

Each month we cover a few abbreviations, terms or acronyms parents might hear or see while in First Steps. Sometimes it is awkward for families to ask. Here are some terms you may hear while learning about disability issues.

The Americans with Disabilities Act (ADA) (P.L. 101-336) is federal civil rights legislation adopted to prohibit discrimination against people with disabilities. Public and private businesses, state and local government agencies, private entities offering public accommodations and services, transportation and utilities are required to comply with the law. The ADA was signed into law by President George Bush on July 26, 1990, extending civil rights protections to individuals with physical or mental disabilities.

A **504 plan** is a legal document falling under the provisions of the Rehabilitation Act of 1973. It is designed to plan a program of instructional services to assist students with special needs who are in a regular education setting. A 504 plan is not an Individualized Education Program (IEP) as is required for special education students.

**Editor's Note: March is Disabilities Awareness month, so we thought we would bring two articles to your attention this month, published by staff at the Indiana Institute on Disability and Community, that speak to important disability issues. We thank the authors, Vicki Pappas and Sharon Hauss, for giving their permission to reprint their articles in First Words.*

"People first" is the most important principle in communicating with and about people with disabilities, said Vicki Pappas, director of the Center for Planning and Policy Studies at the Indiana Institute on Disability and Community. This standard applies in a literal sense when describing people – "person with autism" is appropriate; "autistic person" is not – and in a figurative sense when interacting with someone who has a disability. "People with disabilities would prefer to be seen as people, not as objects of pity or as heroes who have overcome adversity," she said. "When you meet someone who has a disability, say hello, make eye contact, and give yourself time to get to know that person like you would with any new acquaintance." Below are more of Pappas's tips for effective communication.

- **DO** use person-first language, especially in print. Regardless of the particular disability, put the person before the condition in every description. For example: "man who has cerebral palsy," "girl who is deaf," "teacher with epilepsy."
- **DON'T** mention a disability if it is not relevant. "If you are writing an article about a professor's research, and that person happens to use a wheelchair, you don't need to mention it unless it relates somehow to the research process. This is just the same principle you would use in deciding whether to mention that someone is Jewish or Latino," Pappas said.
- **DO** use specific terminology. If it is important to describe a person's disability, be straightforward and avoid terminology like "handicapable," "differently abled" or "special." This type of verbiage comes across as condescending, Pappas said.
- **DON'T** make someone a hero for an ordinary feat. Avoid characterizing everyday activities as huge accomplishments for people with disabilities. "I'm all for including a bride with hearing loss in a wedding special, but when the headline is 'Deaf Woman Gets Married,' that's insulting," Pappas said.
- **DO** greet people at their eye level. When talking with a person who uses a wheelchair, it is appropriate to sit or crouch down in order to talk face-to-face, Pappas said. "Even if you are speaking through an interpreter, it's important to make that direct eye contact," she said. Similarly, it is best to approach a person who is blind by announcing your presence.
- **DON'T** worry about common phrases. "It is not a big deal if you say 'See you later' to someone who is blind. No one is going to be offended by these types of



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Speaking of Disability

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expressions. Relax and use your natural manner of speaking," she said.

- **DO** respect personal space. "It's okay to offer assistance in a polite manner such as holding a door open. Beyond that it is best to ask first rather than to rush in and grab a person who appears to be struggling," Pappas said. A final note on personal space: a wheelchair should be approached as though it were part of the body – don't sit or lean on someone's wheelchair unless you know them very well.

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Resources for Families

Check out these great resources on disability issues:

[Kids Together](http://www.kidstogether.org)

<http://www.kidstogether.org>

[Disability is Natural](http://www.disabilityisnatural.com)

<http://www.disabilityisnatural.com>

[Americans with Disabilities Act](http://www.ada.gov)

<http://www.ada.gov>

[Indiana Governor's Council on People with Disabilities](http://www.in.gov/gpcpd/publications/InteractingBrochure.pdf)

<http://www.in.gov/gpcpd/publications/InteractingBrochure.pdf>

Advocacy Tip Of The Month

It may be important to give thought to how you and your child will or will not answer questions from others regarding his or her disability. Setting parameters and modeling behavior by the way answers are given can not only address an immediate question, but in some cases, impact the way adults and children interact in the future. Some families are comfortable answering questions from anyone; others choose not to answer questions from strangers at all. Some have the policy of answering any questions children ask in as clear and direct terms as possible, acknowledging the common experience of children learning acceptance of others. Other families may be less willing to answer questions of adults, depending upon how those questions are asked. How and what you answer is a personal decision and one that may change over time.

Siblings of Children with Disabilities

Non-disabled children may feel overlooked when much of the family's time is devoted to caring for a child with a disability. "Often, siblings are dealing with emotions that are difficult to talk about such as guilt, jealousy and feelings of inadequacy," said Sharon Hauss, a family support specialist with the Indiana Institute on Disability and Community. "Being aware of the needs of siblings can help improve relationships and the whole family's peace of mind," she said. Below are her tips on helping siblings feel included and valued.

- **Keep siblings informed.** "Parents can help reduce stress and anxiety by keeping siblings in the loop about their brother's or sister's disability and being willing to answer their children's questions," Hauss said.
- **Encourage emotional expression.** "It may be difficult for children to express their worries and fears about their sibling's disability. It can take a lot of courage to bring up the topic and reveal their feelings about it. It's important to be supportive when siblings want to talk, even if they have negative things to say," she said.
- **Let siblings choose whether to be involved in caregiving.** "Often, siblings of children with disabilities want to help and be involved with meeting the needs of a sibling with a disability. It is important that siblings feel included – but they should not be forced to take on the role of caregiver," she said.
- **Attention and rewards.** Remember to acknowledge milestones and achievements for children without disabilities. Sometimes the accomplishments of children without disabilities go unnoticed because normal development is expected, Hauss said, but celebrating and rewarding progress is important for all children. She noted that one-on-one time with parents also is essential.
- **Make connections with other siblings.** "Sometimes the best support is found by making connections with others in similar situations. Siblings may find it easier to talk about their concerns and feelings with others who have siblings with disabilities," she said. Computer-savvy kids can check out the Sibkids Listserv, an online resource to help young siblings of children with disabilities connect with one another: <http://www.siblingsupport.org/connect/index.html>

A more in-depth resource on this topic is available from the IIDC at <http://www.iidc.indiana.edu/irca/family/SibPerspect.html>

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