#### North Carolina Council on Developmental Disabilities

# Youth guide to understanding disabilities

People . E

# Pid you know...

there's a good chance that *you* or someone *you know* has or will have a disability?



### People with Disabilities

Did you know there's a good chance that you or someone you know has or will have a disability?

Nearly 50 million individuals living in the U.S. have a diagnosed disability making people with disabilities the largest minority group in the entire United States. In North Carolina alone, people with disabilities make up approximately 23 percent of the state's population.

There are many kinds of disabilities. Some people are born with disabilities; others get them as they age or as a result of an accident. Perhaps you've broken a bone or hurt your back and temporarily had a disability as a result. Other people may have permanent disabilities. Some of the causes may be stroke, muscular dystrophy, multiple sclerosis or paralysis.

Some people have developmental disabilities, which are typically more severe. These disabilities involve an intellectual or physical limitation or both. A developmental disability substantially limits one's ability to function in at least three major areas of life activities.\* Developmental disabilities show up at birth or before a person turns 22 and last indefinitely. Some examples of developmental disabilities include Down syndrome and cerebral palsy.

\* The areas of major life activity are identified as mobility, self-care, receptive and expressive language, learning, self-direction, economic self-sufficiency and the capacity for independent living.

Over 49.7 million individuals in the U.S. have a diagnosed disability.

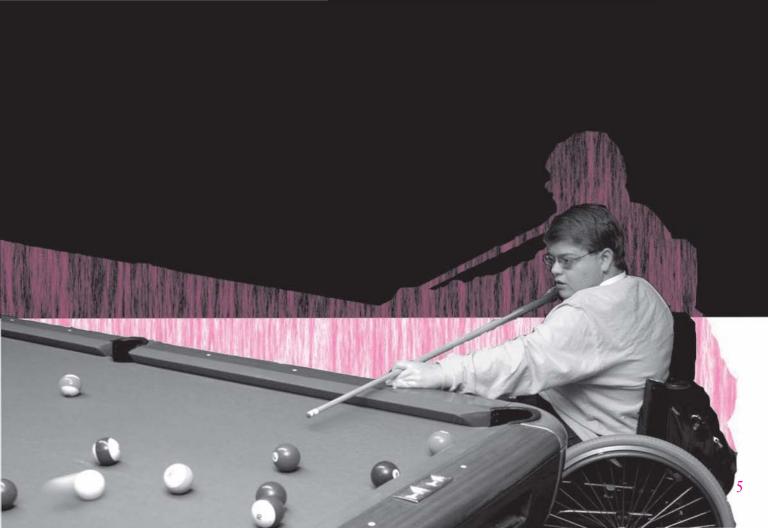
dis-abil·i·ty (noun): the condition of being disabled

# Living with a disability the teen years...

Being a teenager is hard for anybody and it can be even harder for a person with a disability. People with disabilities are often misunderstood. Contrary to popular stereotypes, people with disabilities enjoy and want many of the same things as people without disabilities, including friends, marriage, children, an education and a job. They enjoy sports, the arts and leisure activities. They have hopes, dreams and goals as well as disappointments, loneliness and frustrations.

Getting rid of some common misperceptions is one of the first steps in accepting and including people with disabilities. Let's take a look at some instances where young people with disabilities have dealt with awkward situations and see if we can dispel some myths. ...people with disabilities enjoy and want many of the same things as people without disabilities...friends, jobs, sports...

teen · ag · er (noun): of, being or relating to people in their teens





One afternoon Leeann and Mike were going over their notes for an upcoming biology test. In the midst of reviewing a chapter on the cardiovascular system, Mike looked up from his book and peered over Leeann's Braille writer with a quizzical expression.

"Leeann, is that stuff hard to learn?"

"It's the same stuff you're learning."

"No, I mean that Braille stuff."

"Not really, why?"

"Just curious. Do you ever wish you were normal?"

"What? What do you mean 'normal?' Like you – smelly from playing sports every day? Geesh, I can smell you from two blocks away. What's normal anyway?"

"I don't know. It's um –"

"It's what? Not you, I hope."

"No, I'm not. I guess no one is."

"Yeah, that's how I like to think of it anyways."

nor·mal (noun): a form or state regarded as the norm

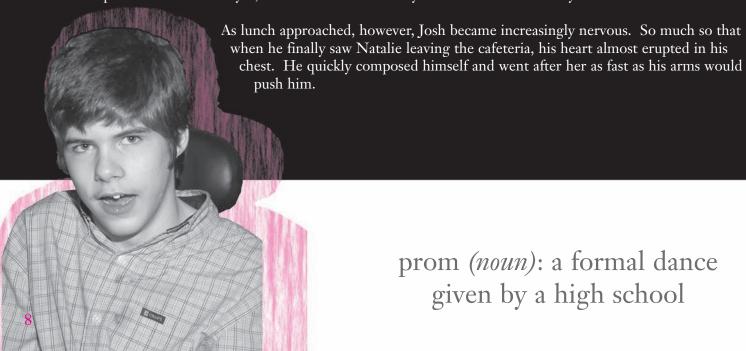
What is "normal" to one person is not necessarily normal to another.

**FALSE:** People with disabilities want to live "normal" lives.

TRUE: People with disabilities want to be themselves – just like everyone else. "Normal" is a relative term. What is normal to one person is not necessarily normal to another. For example, a person who always eats dinner at 9 p.m. may not seem to have a normal lifestyle to someone who eats dinner every night at 6 p.m. People with disabilities don't want others to try to mold them into what they think is "normal," just as people without disabilities wouldn't want that.

#### "Before Prom"

For Josh the big day had come. He felt it that morning as he opened his eyes. He knew that today was the ideal day to ask Natalie to the prom. They'd only spoken on occasion, but it was enough for Josh to know that she was the one he wanted to ask. As he got ready for school, he took extra care to make sure he looked his best. During morning classes, he was distracted by daydreams. He would go up to her after lunch and ask if she would go with him to the prom. Once she said yes, he would whisk her away in his wheelchair as they fell in love.



prom (noun): a formal dance given by a high school

"Natalie!" he called, as he rolled up behind her. "Hi, Josh. How are you?"

"I'm ok. I was wondering, do you have a date for the prom yet?"

"Um. No, not yet." She said with hesitation.

"W-Well, I was wondering if you would, uh, like to go with me."

"Thanks Josh, but I don't think so. Besides, how would we get there?"

"I could work that out, if you wanted to."

"Sorry, but I have to get to class" said Natalie as she turned and walked away.

Later that afternoon, Natalie noticed Josh waiting at the bus stop. She walked over and asked, "So, I was wondering, how would you get us there? That is, if I said yes."

"Well," Josh said with a grin, "I think my car should be out of the shop by then so I figured I'd pick you up."

"Oh, cool, you drive? I thought...I don't know what I thought. Sure, I'd love to go with you!"

"Great! I'll pick you up at seven."

"Ok, see you then."

**FALSE:** People with disabilities don't date or want intimacy. They are "different."

TRUE: Many people with disabilities have fulfilling relationships of all sorts. Just like the rest of the world, people with disabilities decide for themselves what kinds of relationships to have with others. Unless they choose otherwise, people with disabilities flirt, date, get married, have sex and have children – just like everybody else. People with disabilities are heterosexual, gay and lesbian, sharing the same joys and difficulties as others. Some are financially stable while others are poor. They are Republicans, Democrats and Independents. They participate in all types of faith communities and have all sorts of interests, just like the people you are reading about.

People with disabilities "choose" what kind of relationship they want, just like everybody else.

**FALSE:** People with disabilities are handicapped; that's why they're called the "handicapped."

different ways. A handicapped at times, in many different ways. A handicap is an obstacle or something that gets in your way; it's not the disability itself. For example, if you have your hands full of shopping bags and you have to open a round doorknob, then you are handicapped. The round doorknob that you have to twist is your handicap, or obstacle. If you don't spell well, then you are handicapped when you have to write an essay. Your inability to spell is an obstacle for you in making a good grade on your paper. Someone with a mobility limitation may be handicapped by stairs with no ramp that he or she can use.

By the way, it is inappropriate to refer to a person with a disability as a "handicapped" person. Most individuals with disabilities prefer *People First* language in which emphasis is placed on the person, not his or her disability. So, if you have to refer to someone's disability, say "person with a disability" instead of "disabled" or "handicapped" person. You can see more examples of *People First* language and how to use it in the last two sections of this booklet.

hand·i·cap
(transitive verb):
to put at a disadvantage

Everyone is handicapped at times, in many different ways.



Nikkei sat in the back of her seventh-period English class staring aimlessly out the window to the field below. Her mind drifted from the faded green of the grass to how the kids in P.E. looked like worker ants to how the coach reminded her of a colony queen and then to the shape of the clouds and how that also reminded her of ants. Having trouble concentrating in class was almost a daily occurrence for her. In fact, most days she would forget that she was even in a classroom. Today, however, she was caught off guard when her teacher called on her.

looks (noun):

physical
appearance

"Nikkei, what do you think of the scene with the glass?"

"Um... Sorry, where are we?"

"Near the end of the story, when he's playing the piano and the light hits the glass."

"I'm not sure where..."

"Page 157."

"Um, I think... I think it was shiny," Nikkei said as the rest of her classmates gave a muffled snicker.

"Uh, yes. Thank you, Nikkei. Anyone else?"

After class, as the students passed Nikkei in the hall, some of them stared at her and whispered

comments to their companions. Kim, another student in Nikkie's English class, came up to Nikkei after watching the mockings of other peers and asked, "Nikkei, are you ok? Those guys were being so rude."

"Yeah, I'm O.K. it's just that it's so annoying.

They just don't get it. I want to
concentrate but I just can't, and then I look
like an idiot."

"No you don't. Forget about them, they don't know what they're talking about. They just don't understand. It might take them a while, but they'll learn."



in·vis·i·ble (adjective): incapable of being seen

**FALSE:** You can always tell when a person has a disability.

TRUE: Some disabilities, such as hearing, vision, mobility, speech and intellectual disabilities are more visible than others. However, it is important to recognize there are also "invisible" disabilities, such as mental illness, learning differences and serious environmental allergies. Just because a person doesn't "look" like they have a disability does not necessarily mean that they don't have one.

Just because a person doesn't "look" disabled doesn't necessarily mean that they don't have a disability.

**FALSE:** Some people with disabilities should live in institutions.

**TRUE:** Given the appropriate supports or assistance, most people with disabilities are fully capable of living in the community. In fact, most people with disabilities do not live in institutions. They live in a variety of places, including their own home or apartment, alone or with their family, and in homes where several people with disabilities may live together with the assistance of direct support professionals. As support continues to become more readily available, institutions are becoming less common. Political activism in the disability community itself has helped many people get the supports and services they need to grow up, go to school, live, work and retire in communities.

# "Wheelin' & Kickin'"

Nathan was in the locker room changing into his martial arts gi with some help from a personal assistant when several boys from the football team came in to dress out for practice. At first, none of the other boys thought anything of why Nathan would be changing as well, until one of them noticed the color of the belt that Nathan was putting on. One of the guys, Steve, nudged his buddy and pointed at Nathan's black belt.



"Hey Nathan, nice belt."

"Uh, thanks," replied Nathan, feeling a set up coming.

"That's like a karate belt or something, ain't it Nathan?"

"Yeah, kind of," he said, trying not to engage.

"So, how do you do that? Don't you have to stand up to do that stuff?" "Well no, I can do it."

Steve and his friends finished dressing and came over and sat on the bench beside Nathan. "Oh, I get it, it's like a philosophy thing; because you know all about it, they gave you a black belt. Right?"

"No, I earned it. I use my chair to do the techniques the way others use their bodies."

"That's cool. So you could kick all our butts then?"

"I don't know about that, but I'll be testing for my second degree on Saturday afternoon – you should come watch sometime and see for yourself."

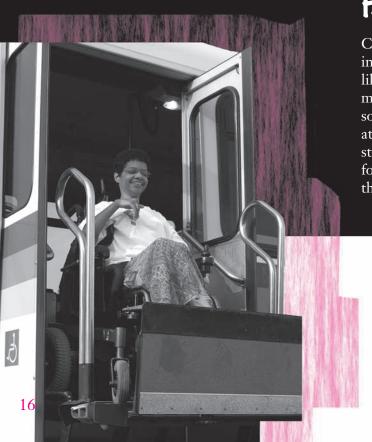
"Cool, maybe we will."

**FALSE:** People with disabilities can't do most of the things that people without disabilities can do.

TRUE: One of the biggest "handicaps" people with disabilities face is when others don't see their abilities. People with all kinds of disabilities have jobs, go to school— earning college and other degrees— and are active volunteers in their communities. They participate in recreational activities and the arts. They may use assistive technology devices.\* There are many different kinds of assistive technology, ranging from pencil grips to computers to wheelchairs.

\*Assistive technology is used by people with disabilities to do things that might otherwise be difficult or impossible. Assistive technology can include walkers and wheelchairs, adaptations to vehicles, hardware and software for computers, and many other aids or devices. For more, see the Assistive Technology Act of 1998. (PL 105-394)

One of the biggest "handicaps" people with disabilities face is when others don't see their abilities.



# "Stop Him: He Helped Me"

Claire loved hanging out at the mall whenever she wasn't in school or having to study. It wasn't the fact that she liked to shop as much as it was the joy she found in meeting new people. Practically every afternoon, she and some friends would take the bus from school and get off at the entrance to the mall, which just happened to be one stop short of her house. They enjoyed hanging out in the food court, even when they didn't care to eat, because they knew there were always cute guys there.



**FALSE:** People with disabilities always need help.

**TRUE:** Many people with disabilities are quite independent and capable of giving help. If you want to help someone with a disability, ask first if he or she needs it. If the person has a personal assistant, address the individual, not the personal assistant.

If you want to help someone with a disability, ask first.

help (verb): to give assistance or support to

One afternoon Claire decided to go grab a bite though none of her friends could join her. When she was getting off the bus, she saw a boy walking towards her. He smiled as they approached each other. She was excited but simply smiled back. Once she was free from the bus's lift, she caught up to him and introduced herself.

"Hi, I'm Claire," she said, beaming.

"Claire, nice to meet you. I'm Aaron. How are you?"

"Good, you?"

"Great! I just finished an exam so I thought I'd blow off some steam."

"Cool, I was just about to grab something to eat.
Want to join me?"

"Sure. Let's go. Can I help you?" Aaron asked as he moved behind her to try to push her powerchair.

"No thanks, I got it," she said as she took off in a cloud of dust.

"Hey, wait for me!"

"Well hurry up then, slow poke," Claire said flirtatiously.

He soon caught up with her after a few steps and off they went. As they weaved through the crowd, Aaron seemed nervous about Claire's driving. He kept saying "watch out" and "careful behind you." When they reached the food court, he ran ahead to hold the door for Claire, which she appreciated. But, when Aaron tried to order for Claire, she became irritated. When they found a table, Claire decided to say something.

"Aaron, I think you're cool and I thank you for your attempts at chivalry, but I think you're trying to help too much. Can you chill out a bit, please?"

"Yeah, sure. I didn't know what I should do."

"Just wait for me to ask you."

"Great! That sounds good. Let's eat."

in·de·pen·dent
(adjective): not
requiring or relying
on something else

People with disabilities are just like people without disabilities.





Luke walked down the hall toward the cafeteria to get his usual, a Reuben sandwich with extra sauerkraut and a bag of peanut M&Ms. When he got there, only a few people were ahead of him in the hot lunch line and he could feel his stomach growl. While he waited, he stared at the beverage list, trying to sound out the words as the line grew behind him. When it came time for Luke to order, he still hadn't chosen a drink. The others in line were starting to get annoyed.

After several minutes of glaring at Luke, Tim, who was next in line, gave him a nudge saying, "Hey, come on man, you're holding up the line!"

"Oh, sorry," Luke said as he moved toward the cashier.

"I want a Reuben with extra kraut and peanut M&Ms. Do you like chocolate milk or Coke?"

hurt (verb): to cause emotional pain or anguish to "What?" asked the cashier. "I like milk."

"Whatever," mumbled the cashier. "Yeah, I want chocolate milk." "Ok, that will be \$4.95."

Luke nodded, reached into both of his pockets and pulled out all his money. He put all the money on the counter, gave the cashier a smile and said, "Can you help me?" and the rest of the kids in line stared until Tim couldn't stand it any longer. "Hey, what is this? Are you a retard or something?" Tim barked. Tina, Tim's girlfriend, gave him a nasty look. "I can't believe you use the "r" word. That's low."

Once the cashier finished counting the change, Luke picked up his meal and turned to Tim saying, "That's a bad word, Tim. I don't like that word."

"You're right, Luke" said Tina, adding, "Later, Tim" as she went to sit with Luke.

**FALSE:** Using the word "retard" is cool, funny and hip.

**TRUE:** Using the word "retard" is just thoughtless. No matter how the word is used, it is hurtful to people with disabilities.

**FALSE:** I don't know anyone with a disability.

**TRUE:** If you don't know someone personally who has a disability, you probably at least know of people with disabilities. Perhaps you've heard of some of the following people who have disabilities.

Using words like "retard" is just thoughtless and hurtful.

#### Famous Faces

Paralysis from a horseback riding accident didn't stop **Christopher Reeve** from being a true superman. Until his death, he continued acting and directing, as well as making public appearances.

North Carolina native **Ronnie Milsap** was born with cataracts that left him blind. He plays the piano, violin, clarinet, cello and guitar, but is probably best known as a country-western singer. Singer/songwriter **Stevie Wonder** also has a visual disability, as did the late **Ray Charles**.

Basketball player **Michael Jordan** and golfer **Tiger Woods**, possibly the world's greatest athletes in their respective sports, have learning differences.

When her name was announced as the winner of the Miss America pageant in 1995, **Heather** 

Whitestone McCallum didn't hear it. This young woman is totally deaf in one ear and profoundly deaf in another as a result of a bacterial infection she had as a young child.

**Stephen Hawking**, one of the most brilliant theoretical physicists and cosmologists today, has amyotrophic lateral sclerosis. His work on the big bang theory and black holes are among his greatest achievements.

Liz Obermayer Weintraub is a nationally known self-advocate. She shares her experiences as a person with an intellectual disability and teaches others how to stand up for their rights. She was appointed by President Clinton to the President's Committee on Employment of Persons with Disabilities and also received the prestigious Elizabeth Monroe Boggs Award for Leadership.

fa·mous (adjective):
widely known,
honored for
achievement

...there are also people with disabilities in your OWN COMMUNITY...leading the lives they want.



#### Famous Faces (continued)

As a self-advocate for his entire life, **Bob Williams** has held many offices from policy associate with the United Cerebral Palsy Association to commissioner for the Administration on Developmental Disabilities. In addition, he is a well-known writer and poet. Because of his cerebral palsy, Williams uses a computer with voice output to communicate.

Chester Finn is another leader in the self-advocacy movement. His visual and intellectual disabilities do not prevent him from seeing his work and the surrounding world clearly. He is a determined self-advocate and is the current chairperson for Self-Advocates Becoming Empowered, a national advocacy group.

**Justin Dart** was an internationally known disability rights activist who had post-polio

syndrome. Recognized as the "Father of the Americans with Disabilities Act," he led the disability rights movement for over three decades and was presented with the Medal of Freedom by President Clinton.

The famous mathematician and scientist **Sir Isaac Newton** is perhaps best known for developing the law of gravity and the study of calculus. He also had frequent epileptic seizures.

Actor and comedian **Robin Williams** has Attention Deficit Disorder (ADD).

**Franklin D. Roosevelt**, the 32nd president of the United States, had polio and used a wheelchair while in office.

strength (noun): the quality or state of being strong Chris Burke who stared in network TV's "Life Goes On" and "Touched by an Angel" has Down syndrome. Geri Jewell who played on "Facts of Life" and now plays "Jewel" on HBO's "Deadwood" has cerebral palsy.

While the achievements of these people with disabilities have gained national and international recognition, there are people with disabilities in your own community who are also leading the lives they want. Their strengths, like yours, make your community a better place in which to live.

we all have Strengths... which make our community a better place to live.





When you think of some of the famous people with disabilities mentioned in the last section, do you talk about them in terms of their disabilities or in terms of their strengths and accomplishments? Unfortunately, too often people with disabilities are labeled or identified by their disability rather than their other attributes.

Remember, the person is not the disability. While someone may have a disability, that's not who the person is; it's just a part of the whole person. People, with or without a disability, have many parts to who they are: funny, smart, fast, have beautiful hair, love games and have a great laugh. There are so many other ways to describe who people are. When you talk about a friend without disabilities, do you describe him as, "That's Joe and he doesn't have a disability"? Probably not. People with disabilities want to be seen for their gifts, abilities, likes and dislikes – just like everybody else.

first (adjective):
preceding all others
in time, order or
importance

Remember, the person is **not** the disability.

Sometimes the way people think about those with disabilities is based on how they hear other people talk.

For example, have you ever heard someone tease or say something mean about a person with a disability? Or have you heard someone being called a name, like "retard" or "spaz?" This kind of language can hurt people's feelings, whether they have a disability or not.

How should you treat your friends with disabilities? Just like you treat your other friends. Using people first language is one way to do that when you need to talk about a person's disability.

When you use people first language, you are emphasizing the person and not the disability. If you were using people first language, then instead of talking about "the disabled" or "the handicapped," you would say, "people with disabilities." You would not say, "Mary is epileptic," because that is not who Mary is. You would say, "Mary has epilepsy (or seizure disorder)."

When you need to talk about a person's disability, there are right and wrong ways of doing it. In the following chart, you will find some of the right, people first, ways of talking about disabilities and some of the wrong ways.

RIGHT: People first language	WRONG
People or individuals with disabilities	The handicapped, special needs, challenged, afflicted with a disability, suffers from a disability
Bridget, who uses a wheelchair	The girl in the wheelchair, wheelchair-bound, confined to a wheelchair
A woman with paraplegia, a man that has quadriplegia	A paraplegic, a quadriplegic, crip, crippled
A class for children with disabilities	A handicapped class
Person without a disability	A normal person
Person with mental illness	The mentally ill, the emotionally disturbed, insane, crazy, demented, psycho, lunatic
Accessible bus/parking spot	Handicapped bus/parking spot
People with intellectual disabilities; people with cognitive disabilities	Retarded people, mentally retarded
A person who has Down syndrome or a person with Down syndrome	Downs kid, Mongoloid
She is a little person, or she is of short stature	She's a dwarf/midget
He has a brain injury	He is brain damaged

right (adjective): being in accordance with what is just, good or proper

Remember, there are **exceptions** ...some people with disabilities choose not to use people first language.

There are, however, a few exceptions. Some people with disabilities choose not to use people first language. For example, some people with hearing impairments refer to themselves as Deaf with a capital "D" because they consider themselves a minority with their own culture and language, called American Sign Language. The best thing to do is to ask what words the person prefers to use. It's a great conversation starter!



# What should I say?

The most important thing is to be yourself. Teenagers with disabilities are just like teenagers without disabilities. They also want to have fun, make friends and study hard. Talk about things that you and your friends are interested in. Don't worry about using ordinary phrases, such as "see you later" to a person with a visual disability or "got to be running along" to someone who can't walk.

In addition to using people first language, here are some other suggestions for talking with people with disabilities.

Teenagers with disabilities are just like teenagers without disabilities.

same (adjective): equal in size, shape, value or importance

- Talk about abilities instead of limitations. Saying, "Ami is wheelchair bound," makes it sound like she can't do much. Instead, you could say, "Ami uses a wheelchair to get around," which emphasizes her *ability* to get places rather than any mobility limitations she has. Unless it's really relevant, don't even refer to the person's disability. The best way to describe Ami may be to say, "Ami is a great artist," which focuses on one of her abilities.
- Don't use words that imply a person with a disability is afflicted with or suffers from their disability. Also, avoid referring to them as special or exceptional.
- Don't assume a person with a disability can't do things. They may use assistive devices or technology to talk, to walk, or even to drive a car. They may have strengths in many different areas.
- When you're talking with someone with a hearing loss, it's okay to tap the person on the shoulder or wave your hand to get his or her attention.

- When talking with someone who reads lips, talk in a normal tone of voice. Using facial expressions and gestures to help the person understand what you are saying is certainly acceptable. But, don't try to talk very slowly or exaggerate the movement of your lips.
- If you're talking to someone with a speech disability, give the person extra time to talk and try not to rush her. Be patient and don't speak for the person. If you don't understand what someone says, don't be afraid to ask the person to repeat it
- Sometimes you might be talking to someone who uses an interpreter, a translator, or a personal assistant. Look at the person with the disability when you're talking to him, not the interpreter, translator or personal assistant.

#### How should I act?

Again, be yourself. If you aren't, both you and the other person will feel uncomfortable and nervous. Here are some tips that should help:

- If you want to help someone with a disability, ask first.
- If you're with someone who uses a guide dog or some other kind of service animal, do not pet or talk to the animal. These animals are working and shouldn't be distracted.
- Don't touch a person's body or any equipment that person uses such as a wheelchair, cane or walker unless you are invited to do so by that person.
- When you talk to someone in a wheelchair, talk directly to the person.
   Try to be at eye level, but don't kneel next to the wheelchair. If you need to, take a couple of steps back so the person doesn't have to strain his neck to look up at you.

ca·pa·ble (adjective): having attributes required for accomplishment

#### Learn More: Important Federal Laws

#### Visit http://thomas.loc.gov/ for more information about the laws listed below.

- Americans with Disabilities Act (ADA) PL 101-336
- Developmental Disabilities Bill of Rights and Assistance Act PL 106-402
- Fair Housing Act PL 100-430
- Air Carriers Access Act PL 99-435
- Individuals with Disabilities Education Act (IDEA) PL 101-476
- Rehabilitation Act PL 93-112
- Assistive Technology Act of 1998 PL 105-394
- Architectural Barriers Act PL 90-480

#### Additional Laws Relating to People First

- National People First Law- Rosa's Law October 5, 2010 <a href="http://www.govtrack.us/congress/billtext.xpd?">http://www.govtrack.us/congress/billtext.xpd?</a> <a href="bill=\$111-2781">bill=\$111-2781</a> required that the words "mental retardation" be replaced by "intellectual disabilities".
- North Carolina People First Law, July 10, 2009 <a href="http://www.ncga.state.nc.us/Sessions/2009/Bills/Senate/HTML/S208v6.html">http://www.ncga.state.nc.us/Sessions/2009/Bills/Senate/HTML/S208v6.html</a> calls for civil and respectful language when referring to people with disabilities. It specifically mentions language that is derogatory, demeaning or implies that the disability defines the person.

#### Resources at the NCCDD Website

For updated disability information go to: nccdd.org

#### **National**

- American Association of People with Disabilities (AAPD) aapd.com
- Self-Advocates Becoming Empowered (SABE) sabeusa.org
- National Association of Councils on Developmental Disabilities (NACDD) nacdd.org
- American Disabled for Attendant Programs Today (ADAPT) adapt.org

#### North Carolina

- North Carolina Disability Action Network (NCDAN) ncdan.org at 336-767-7060 (Keith Greenarch)
- North Carolina Council on Developmental Disabilities (NCCDD) nccdd.org
- **Disability Rights NC** disabilityrightsnc.org at 877-235-4210

Booklets available at the Council include: "We haven't met just yet but... I'M YOUR NEIGHBOR" and "People First K-5." Please call or email the NCCDD office for your copy at 800-357-6916 or info@nccdd.org.

# Notes

# Notes

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Robert J. Rickelman, Ph.D., Chair Holly Riddle, J.D., M.Ed., Executive Director This publication is produced by the North Carolina Council on Developmental Disabilities, which was established by the Developmental Disabilities Assistance and Bill of Rights Act (PL 106-402) to promote interdependence, contribution, self-determination, integration and inclusion into the community for citizens with developmental disabilities. The NC Department of Health and Human Services does not discriminate on the basis of race, color, national origin, sex, religion, age or disability in employment or the provision of services. 5,000 copies of this publication were printed at a cost of \$.52 per copy

North Carolina Council on Developmental Disabilities

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