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Introduction

Being part of a community has many well being benefits: we become interested in connecting with others; feel acceptance through our participation; and gain a sense of security that there are other people here who can help us. Faith community participation for individuals with developmental disabilities does not differ in the sense that all people need connections.

Throughout New York State, houses of worship leaders and their congregations are beginning to realize their capacity to weave individuals with disabilities into the fabric of their worship. Their willingness is more far reaching than building physical accessibility: congregations are opening up the worship to individuals for participation in the liturgy and serve as contributing members in different ministries. Congregations who have opened doors and hearts to individuals with developmental disabilities express how their worship experiences have been enriched by the presence and spiritual gift sharing with those who have developmental disabilities. In fact, these individuals have shared their experiences of “being closer to God” and finding strength and comfort in their faith community relationships.

The purpose of this book is to:

- Assist faith leaders and congregations by providing them the information they need to become comfortable in welcoming and providing spiritual supports for people with developmental disabilities who live in their community.
- Provide educational awareness opportunities to help faith leaders and congregations to interact with people with developmental disabilities.
- Support individuals, family members, friends, and caregivers to gain comfort about being “visible” in their faith community as valued, active members. Help them to identify their interests, skills, helpful supports, and natural connections to make this become a reality and not just a vision.



- Present the current “facts and possibilities” that continue to hinder or provide the opportunity to support “believing, belonging, and becoming” as an attainable endeavor.
- Give recognition to the fact that “all” people want to be “people first”. Each of us desire to be accepted and respected for who we are and not what others might first see or preconceive.
- Show how community involvement is not only meaningful to people with disabilities but rewarding to those that choose to include their friendship, positive energy, and service.
- Recognize existing barriers and have meaningful discussions with “everyone at the table” on ways to overcome them and debunk the myths that surround “disability”.

OPWDD ‘s mission, vision, values, and guiding principles are indicative of having appropriate supports in place----from policies to training----to new as well as recognized solutions. We want to make sure that we respond with the right supports as a matter of routine when an individual makes a faith choice.



Courtney Burke
Commissioner

Mission Statement

We help people with developmental disabilities live richer lives.

Vision Statement

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth, live in the home of their choice, and fully participate in their communities.

Values

Describe how we as employees of OPWDD interact with the individuals we serve, families, staff, the community and each other:

Compassion - The capacity to appreciate what others think and feel.

Dignity - The recognition of the worth of each person and the treatment of individual rights and preferences with respect, honor and fairness.

Diversity - The celebration, respect and embracing of the differences among us because these differences strengthen and define us.

Excellence - The continual emphasis on innovation, increasing knowledge, and delivering the highest quality supports and services.

Honesty - The foundation on which trust is built and truth is communicated.



Guiding Principles that frame how OPWDD conducts its business:

Put the person first - People with developmental disabilities are at the heart of everything we do, and this person-first ethic is embodied in the way we express ourselves, and in the way we conduct our business.

Maximize opportunities - OPWDD's vision of productive and fulfilling lives for people with developmental disabilities is achieved by creating opportunities and supporting people in ways that allow for as many as possible to access the supports and services they want and need.

Promote and reward excellence - Quality and excellence are highly valued aspects of our services. Competency is a baseline. We find ways to encourage quality, and create ways to recognize and incentivize excellence to improve outcomes throughout our system.

Provide equity of access - Access to supports and services is fair and equitable; a range of options is available in local communities to ensure this access, regardless of where in NYS one resides.

Nurture partnerships and collaborations - Meaningful participation by people with developmental disabilities strengthens us. OPWDD staff and stakeholders create mechanisms to foster this participation. The diverse needs of people with developmental disabilities are best met in collaboration with the many local and statewide entities who are partners in planning for and meeting these needs, such as people who have developmental disabilities, families, not for profit providers, communities, local government and social, health and educational systems.

Require accountability and responsibility - There is a shared accountability and responsibility among and by all stakeholders, including individuals with disabilities, their families, and the public and private sector. OPWDD and all its staff and providers are held to a high degree of accountability in how they carry out their responsibilities. We strive to earn and keep the individual trust of people with developmental disabilities and their families as well as the public. Creating a system of supports that honors the individual's right to be responsible for their own life and accountable for their own decisions is of paramount importance.

Visit our website: <http://www.opwdd.ny.gov/>



Faith Initiative Program

People with disabilities want to be active participants and meaningful contributors in their community. They want the same choices to grow spiritually, to enjoy community life, and experience relationships.

The OPWDD Faith Based Initiative Program was instituted in 2007. Its mission is to explore new avenues and expand upon choice opportunities for individuals with developmental disabilities that will **respect** their beliefs, **support** their right to belong to a faith community, and **assist** individuals with developmental disabilities to become a valued member in the house of faith they have chosen.

Our Purpose:

OPWDD in partnership with faith communities and other interested parties will develop opportunities that meet the expectations of individuals with developmental disabilities who make choices to:

- ▣ ***Believe*** -have their faith acknowledge and respected.
- ▣ ***Belong*** – attend the house of worship based upon their faith beliefs and choice.
- ▣ ***Become***- receive supports and assistance that will allow consistent access for faith community participation.



Our strategies will support:

Individuals with developmental disabilities: who want the same choices to grow spiritually, to enjoy community life, and have meaningful relationships as others in the community.

Parents: who struggle to find faith communities that will welcome them and their children.

Congregants: who struggle to find a “meaningful way” to include people with developmental disabilities in their faith community.

State and voluntary agencies: who struggle to find the best ways to offer continuous support and opportunities for person with disabilities to participate in this important part of their life.

Our goals:

1st Goal: Apply person centered planning to faith community inclusion.

Objective: *To provide faith education and community practice for our staff*

2nd Goal: Create a Faith Community Database

Objective: *to create a listing of houses of worship that will be accessible by zip codes in all 62 counties:*

3rd Goal: Work with individuals, families, and self-advocates providing educational and listening forums for the community.

Objective: *To help the faith communities welcome and support individuals to become valued members in their congregation.*

4th Goal: Build support systems that will assist an individual’s access and inclusion to their faith community:

Objective: *To increase participation in faith community worship and other activities on a consistent basis.*

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ABOUT FAITH INCLUSION



Self-advocates have made it clear that they want *“a life” and not “a program”*-- A real life based upon the four primary person centered outcomes that support the mission of OPWDD: a home, employment, meaningful relationships, good health and other activities that allow people to contribute to their community. **“OPWDD intends to do everything it can to deliver on this promise by transforming the service system once again in support of these outcomes.”** – **Commissioner Courtney Burke**- One way is by expanding opportunities for individuals through faith-based choice and assisting them in becoming a valued member of their community.

Faith Community Inclusion

All of the services we (OPWDD) provide are not enough if individuals with developmental disabilities do not feel they are a valued member of their community. Our services are not enough if they don't have access to restaurants, libraries, movie houses, parks, and, especially, our churches, halls, synagogues, temples, and mosques.

OPWDD and the Voluntary Agencies offer services and supports for individuals to live in their community - we can't make them feel a part of the community; only community people can do that. If individuals with developmental disabilities cannot participate and flourish in their community they still remain isolated.

- The Centers for Disease Control released a report in April, 2010 and found that an estimated 1 in 5 U.S. adults (47.5 million people) reported a disability.
- The National Organization on Disability estimates people with disabilities continue to be less likely to attend religious services at least once per month when compared to people without disabilities (50% versus 57%, respectively).
- As with many of the indicators, the degree of one's disability has an impact on how often people worship. People with slight and moderate disabilities (58% each) attend religious services more often than do people with somewhat or very severe disabilities (49% and 43%, respectively). This difference is the same as it was in 2004, suggesting that not much has changed in the way of removing architectural, communications, and attitudinal barriers that prevent people with disabilities—especially people with severe disabilities—from regular attendance.



- The NYS Commission on Quality of Care and Advocacy for Persons with Disabilities (CQCAPD), in partnership with members of the Quality Coalition, heard from nearly 450 people with disabilities and their family members across New York State about their quality of life. Their final report was issued in 2010. The report summarizes what these individuals said about a wide variety of life areas - including employment, education, transportation, housing, health, community participation and more. Overall, participants said that they want to have the opportunity and freedom to make choices in all areas of their lives.

In the report the things most important to people related to spirituality were:

1. **Acceptance and support**

Faith-based communities varied in the level of acceptance and support participants with disabilities said they experienced. Some spoke of efforts that their places of worship made on their behalf: one individual said that her church provided an aide for her child during the service; another was in a church program designed for individuals with developmental disabilities; and yet another person said that their synagogue provided disability awareness training for rabbis. Other individuals talked about places of worship that provided sign language interpreters or large screens for people with visual disabilities. Participants stated they would like their faith-based organization to be more understanding of people with disabilities and recommended education on disabilities for faith-based communities.

2. **Choice**

Individuals said they wanted choice in where to worship and that choice was limited when places of worship were not accessible or welcoming to people with disabilities.

3. **Accessibility**

Churches, synagogues and other places of worship are exempt from the Americans with Disabilities Act and many places of worship are not accessible to persons with disabilities. As noted above, some places of worship have made accommodations, and participants said they thought more education regarding the needs of people with disabilities would be beneficial and help improve their quality of life.

If we build a bridge between individuals and houses of faith in their community, individuals with developmental disabilities can be valued as well as participating members of the faith community.



Facts about Faith Community Inclusion

Facts	Possibilities
People with disabilities are much less likely to attend religious services compared to people without disabilities (50% versus 57% respectively) ¹	When people with disabilities are connected to their chosen faith community, their quality of life is enhanced
Some people with disabilities have never had the chance to explore their spirituality	People with disabilities have the opportunity to express their right to a full life of faith
SOME congregations WELCOME people with disabilities	ALL congregations VALUE people with disabilities as active and contributing members
People with disabilities have to think creatively just to get through their day successfully	Congregations tap the creativity of people with disabilities to identify ways to remove barriers
Lack of community connections is often a source of frustration for people with disabilities and is related to increased safety and health consequences	Congregational inclusion creates natural connections that enable faith belonging <u>and</u> community belonging

Taken from the DDPC/OPWDD Spirit Project/2007

¹ N.O.D. Harris Survey 2010



“PUTTING PEOPLE FIRST”



use for a person.

Describing People with Disabilities

What Do You Call

educator, home owner, renter, man, woman, adult, child, partner, participant, member, voter, citizen, amigo or any other word you would

People with Disabilities? Friends, neighbors, coworkers, dad, grandma, Joe's sister, my big brother, our cousin, Mrs. Schneider, George,

Who Are People with Disabilities?

People with disabilities are -- first and foremost, people -- people who have individual abilities, interests and needs. For the most part, they are ordinary individuals seeking to live ordinary lives. People with disabilities are moms, dads, sons, daughters, sisters, brothers, friends, neighbors, coworkers, students and teachers. About 54 million Americans -- one out of every five individuals -- have a disability. Their contributions enrich our communities and society as they live, and share their lives.

Changing Images Presented

Historically, people with disabilities have been regarded as individuals to be pitied, feared or ignored. They have been portrayed as helpless victims, repulsive adversaries, heroic individuals overcoming tragedy, and charity cases who must depend on others for their well being and care. Media coverage frequently focused on heartwarming features and inspirational stories that reinforced stereotypes, patronized and underestimated individuals' capabilities.

Much has changed lately. New laws, disability activism and expanded coverage of disability issues have altered public awareness and knowledge, eliminating the worst stereotypes and misrepresentations. Still, old attitudes, experiences and stereotypes die hard.

People with disabilities continue to seek accurate portrayals that present a respectful, positive view of individuals as active participants of society, in regular social, work and home environments. Additionally, people with disabilities are focusing attention on tough issues that affect quality of life, such as accessible transportation, housing, affordable health care, employment opportunities and discrimination.

Eliminating Stereotypes -- Words Matter!

Every individual regardless of sex, age, race or ability deserves to be treated with dignity and respect. As part of the effort to end discrimination and segregation -- in employment, education and our communities at large -- it's important to eliminate prejudicial language.

Like other minorities, the disability community has developed preferred terminology -- People First Language. More than a fad or political correctness, People First Language is an objective way of acknowledging, communicating and reporting on disabilities. It eliminates generalizations, assumptions and stereotypes by focusing on the person rather than the disability.

As the term implies, People First Language refers to the individual first and the disability second. It's the

difference in saying the autistic and a child with autism. (See the other side.) While some people may not use preferred terminology, it's important you don't repeat negative terms that stereotype, devalue or discriminate, just as you would avoid racial slurs and say women instead of gals.

Equally important, ask yourself if the disability is even relevant and needs to be mentioned when referring to individuals, in the same way racial identification is being eliminated from news stories when it is not significant.

What Should You Say?

Be sensitive when choosing the words you use. Here are a few guidelines on appropriate language.

- Recognize that people with disabilities are ordinary people with common goals for a home, a job and a family. Talk about people in ordinary terms.
- Never equate a person with a disability -- such as referring to someone as retarded, an epileptic or quadriplegic. These labels are simply medical diagnosis. Use People First Language to tell what a person HAS, not what a person IS.
- Emphasize abilities not limitations. For example, say a man walks with crutches, not he is crippled.
- Avoid negative words that imply tragedy, such as afflicted with, suffers, victim, prisoner and unfortunate.
- Recognize that a disability is not a challenge to be overcome, and don't say people succeed in spite of a disability. Ordinary things and accomplishments do not become extraordinary just because they are done by a person with a disability. What is extraordinary are the lengths people with disabilities have to go through and the barriers they have to overcome to do the most ordinary things.
- Use handicap to refer to a barrier created by people or the environment. Use disability to indicate a functional limitation that interferes with a person's mental, physical or sensory abilities, such as walking, talking, hearing and learning. For example, people with disabilities who use wheelchairs are handicapped by stairs.
- Do not refer to a person as bound to or confined to a wheelchair. Wheelchairs are liberating to people with disabilities because they provide mobility.
- Do not use special to mean segregated, such as separate schools or buses for people with disabilities, or to suggest a disability itself makes someone special.
- Avoid cute euphemisms such as physically challenged, inconvenienced and differently abled.
- Promote understanding, respect, dignity and positive outlooks.

-- Revised February 2007

"The difference between the right word and the almost right word is the difference between lightning and the lightning bug."
Mark Twain

husband, wife, colleague, employee, boss, reporter, driver, dancer, mechanic, lawyer, judge, student,



you would use for a person.

People First Language

What Do You Call People

People First Language recognizes that individuals with disabilities are -- first and foremost -- people. It emphasizes each person's value, individuality, dignity and capabilities. The following examples provide guidance on what terms to use and which ones are inappropriate when talking or writing about people with disabilities.

People First Language to Use

- people/individuals with disabilities
an adult who has a disability
a child with a disability
a person
- people/individuals without disabilities
typical kids
- people with intellectual and developmental disabilities
he/she has a cognitive impairment
a person who has Down syndrome
- a person who has autism
- people with a mental illness
a person who has an emotional disability
with a psychiatric illness/disability
- a person who has a learning disability
- a person who is deaf
he/she has a hearing impairment/loss
a man/woman who is hard of hearing
- person who is deaf and cannot speak
who has a speech disorder
uses a communication device
uses synthetic speech
- a person who is blind
a person who has a visual impairment
man/woman who has low vision
- a person who has epilepsy
people with a seizure disorder
- a person who uses a wheelchair
people who have a mobility impairment
a person who walks with crutches
- a person who has quadriplegia
people with paraplegia
- he/she is of small or short stature
- he/she has a congenital disability
- accessible buses, bathrooms, etc.
reserved parking for people with disabilities

Instead of Labels that Stereotype & Devalue

- the handicapped
the disabled
- normal people/healthy individuals
atypical kids
- the mentally retarded; retarded people
he/she is retarded; the retarded
he/she's a Downs kid; a Mongoloid; a Mongol
- the autistic
- the mentally ill; the emotionally disturbed
is insane; crazy; demented; psycho
a maniac; lunatic
- he/she is learning disabled
- the deaf
- is deaf and dumb
mute
- the blind
- an epileptic
a victim of epilepsy
- a person who is wheelchair bound
a person who is confined to a wheelchair
a cripple
- a quadriplegic
the paraplegic
- a dwarf or midget
- he/she has a birth defect
- handicapped buses, bathrooms, hotel rooms, etc.
handicapped parking

Prepared by the Texas Council for Developmental Disabilities, 6201 East Oltorf, Suite 600, Austin, Texas 78741-7509; 512-437-5415 or 1-800-262-0334 toll-free; <http://www.txddc.state.tx.us>

blondes, brunettes, SCUBA divers, computer operators, individuals, members, leaders, people, voters, Texans, friends or any other word

with Disabilities? Men, women, boys, girls, students, mom, Sue's brother, Mr. Smith, Rosita, a neighbor, employer, coworker, customer,

chef, teacher, scientist, athlete, adults, children, tourists, retirees, actors, comedians, musicians,

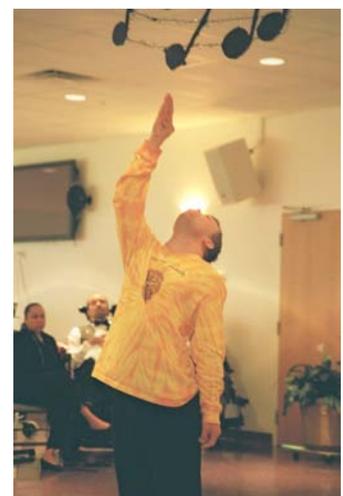


Faith



Community Inclusion

DISABILITY ETIQUETTE





What Do We Mean by the Term "Disability"?

Disability includes a wide range of conditions. A few examples:

- paralysis
- blindness or visual impairment
- deafness or hard of hearing
- mental retardation
- learning disabilities
- psychiatric disabilities and mental health conditions
- epilepsy
- chemical sensitivity
- head injuries
- cerebral palsy
- HIV/AIDS
- and many others

Disability impacts people's lives in a wide variety of ways, and the level of impact can range from minimal to extensive

In some cases, a person's disability is a minor inconvenience; something that is controlled through medication or requires some simple adaptations. In other cases, a person's disability plays a major role in their lives, impacting their ability to earn a living, to participate in activities in the community, and to do many of the things that many non-disabled people take for granted in their daily lives.

Disabilities are often not apparent

Learning disabilities, psychiatric disabilities, epilepsy, and multiple sclerosis are just a few of the many disabilities that are often hidden. Never presume that someone doesn't have a disability just because it is not readily apparent.



Disability is a natural part of the human existence

There has been a major shift in our society's view of disability. Disability used to be seen as an aberration, something that had to be fixed before a person could fully participate in their community. A more progressive view is that disability is simply part of a person's identity, not something to be fixed, and that people with disabilities have the same right as anyone else to full participation in society.

Often times when people are injured (such as a broken leg) they temporarily leave work on disability, and return when they are fully recovered. However, this manual is not intended to apply to people whose disability is extremely temporary. This material focuses people whose disability has ongoing, possibly life-long, impact.

Legal definitions vary considerably.

A person may be considered disabled under the Americans with Disabilities Act but not by their states vocational rehabilitation agency. Also, particular conditions specify the criteria that a person must meet in order to have that condition. For example, not all people who wear glasses have a visual impairment. The following are some important legal definitions of disability:

Americans with Disabilities Act (ADA)

- a physical or mental impairment that substantially limits one or more of the major life activities of such individual;
- a record of such an impairment; or
- being regarded as having such an impairment.

Social Security

- The inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment(s) which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months.

Rehabilitation Act

The term individual with a disability means any individual who

- has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment and
- can benefit in terms of an employment outcome from vocational rehabilitation services.



Debunking the Myths

In spite of significant changes in the world of disability, it is important to recognize that some people still have negative stereotypes and misconceptions about people with disabilities. One of the first steps in improving communications with people with disabilities is to discard and disprove these myths that can put people with disabilities in a separate “class.”

Following are some common misconceptions and facts about people with disabilities.

Myth 1: People with disabilities are brave and courageous.

Fact: Adjusting to a disability actually requires adapting to a lifestyle, not bravery and courage.

Myth 2: Having a disability means you cannot be healthy.

Fact: Persons with disabilities can experience good health and full participation in community life. They benefit from the same health-enhancing activities as the general population.

Myth 3: Wheelchair use is confining; users of wheelchairs are “wheelchair-bound.”

Fact: A wheelchair, like a bicycle or an automobile, is a personal assistive device that enables someone to get around.

Myth 4: Curious children should never be allowed to ask people about their disabilities.

Fact: Many children have a natural, uninhibited curiosity and ask questions that some adults might find embarrassing. But scolding children for asking questions may make them think there is something “bad” about having a disability. Most people with disabilities won’t mind answering a child’s questions, but it’s courteous to first ask if you can ask a personal question.

Myth 5: People with disabilities always need help.

Fact: Many people with disabilities are quite independent and capable of giving help. But if you want to help someone with a disability, ask first if he or she needs it.

Myth 6: The lives of people with disabilities are totally different than those of people without disabilities.

Fact: People with disabilities go to school, get married, work, have families, do laundry, grocery shop, laugh, cry, pay taxes, get angry, have prejudices, vote, plan and dream, just like everyone else.



Myth 7: There's nothing one person can do to help eliminate the barriers confronting people with disabilities.

Fact: Everyone can contribute to change. You can help remove barriers by:

- Understanding the need for accessible parking and leaving it for those who need it;
- Encouraging participation of people with disabilities in community activities by making sure that meeting and event sites are accessible;
- Understanding children's curiosity about disabilities and people who have them;
- Advocating for a barrier-free environment;
- Speaking up when negative words or phrases are used in connection with disability;
- Writing producers and editors a note of support when they portray people with disabilities as they do others in the media;
- Accepting people with disabilities as individual human beings with the same needs and feelings you might have; and
- Hiring qualified persons with disabilities whenever possible.

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Sally McCormick, Woodward Communications



BARRIERS TO FAITH COMMUNITY INCLUSION

Individuals with developmental disabilities are present in your community---are they present in your congregation? If not, you might want to consider asking yourself “why not?”

- **Attitudinal:** The manner in which we interact with people with developmental disabilities speaks volumes about our perspective of their worth and welcome to faith congregations:

Survey:

- Do People with disabilities feel welcome in our service?
- In our congregations are there people with invisible disabilities?
- Do we recognize people with disabilities have gifts, skills, and talents to share with us?
- Are individuals with disabilities given opportunities to serve others through our ministries?
- Do we have individuals with disabilities participating in our worship service?
- Do we have people with disabilities in leadership roles?

Response:

- Hospitality begins with a warm greeting: say hello or offer a handshake
- Some people feel uncomfortable of how to address a person with a disability. Refer to them the same way you want to be referred to: Mr., Mrs., Brother/sister in Christ.
- Adults with developmental disabilities are still adults--treat them as adults.
- Individuals with developmental disabilities may take longer to say or do certain things. Be patient and only offer assistance when requested. Never speak for them.
- Give an individual the opportunity to do as much for themselves as possible.
- Do not assume a person’s capabilities to read. Give them the bulletins, prayer books, hymnal, pew bible, et cetera
- If you observe a person engaging in inappropriate behavior, provide feedback that is non judgmental in tone.



- **Communication Barriers:** “Communication is the interchange of thoughts, ideas, feelings, and facts. There is a barrier to communication when the content of the communication is not understood.”

Survey:

- Are services presented through more than one medium (verbally, visually, dance, music)
- Are there large (giant, jumbo) print religious books, music books, other liturgical materials?
- Amplified sound system
- Sign or language interpreters
- Services on tape or CD
- Adequate lighting
- Audio loops and other assisted devices

Response: (if the items listed above are not available)

- Have printed copies of Sermon/Scriptures available*
- Use larger fonts on programs
- Print hymns to be sung in larger fonts
- Encourage all speakers to use a microphone

**Look for volunteers to help prepare these items so as not to overwhelm church staff*

- **Architectural Barriers**

Survey:

- Parking and pathways
 - Ramps and stairs
 - Doors and doorways
 - Worship space
 - Bathrooms
 - Elevators and lifts
- Do they meet ADA regulations? (see ADA checklist at the end of this book)



Response: there are basic remedies in addition to ADA checklist

Entrances and other areas of building:

- Look for community volunteers (or for reduced cost groups) to assist in building ramps (Habitat for Humanity, organizations building homes for disabled vets)
- Look for large stores to donate supplies (Wal-Mart, Lowes, Home Depot)
- Fund raisers for particular needs (think person, not program, one step at a time)

Inside worship area:

- Scattered seating spaces in the church (or pew cuts) throughout sanctuary, rather than in front or in back, so individuals can sit in the main body
- Lectern/and mike stand on main floor for individuals to use
- Book stands/ lap boards for those who cannot hold books for a period of time
- Lighted areas so speakers can be seen by individuals who may be reading lips
- Some houses of worship use monitors so that readings, songs, speakers, et cetera, can be viewed by the whole congregation.



Disability Etiquette

People who live with disabilities often face fear, discomfort, and hostility at a rate that far exceeds that encountered by those who do not have a disability. The vast majority of such treatment is rooted in a basic lack of understanding about the challenges that come with having a disability, and the experience of sharing the world with people who do not. People often seek to fill in gaps in their knowledge, and when information is lacking, confusion and even fear may result.

Anyone wishing to overcome this experience in themselves will be best served by first recognizing that a disability is a limited phenomenon. A physical disability may have a large impact on how an individual interacts with the physical world. A sensory disability may alter the gathering of information. These conditions, however, in no way prevent the individuals who live with them from having unique personalities, talents, knowledge, humor, and lives. People who live with disabilities have more in common than not with those who have no disability. We all share the same existence and the same basic needs.

In order to establish a foundation, the top three considerations repeated in the vast majority of lists of disability etiquette concerns are:

- Ask if a person needs assistance before attempting to assist them. All people, whether or not they live with a disability, take pride in what they are able to do. Making any assumption about a person's abilities in any given situation can rob them of this feeling.
- Speak directly to a person with a disability, even if he or she has an interpreter. While a person with a hearing impairment may have to look at an interpreter for communication, it is discouraging to everyone to be looked around or over when communicating with someone.
- Ask permission before touching an assistive device or service animal. These are the tools that the user needs to live their life. They are very important and very personal.

**Watch Your Language**

The words we use to describe one another can have an enormous impact on the perceptions we and others have, how we treat one another, mutual expectations, and how welcome we make people feel. The following are guidelines for talking with, and about, a person with a disability. While these guidelines can be helpful, keep in mind the following:

- If you're unsure of the proper term or language to use, ask!
- The best way to refer to someone with a disability is the same way we all like to be referred to: "by name".

GENERAL GUIDELINES

OUTDATED OR OFFENSIVE:	REASON(S):	CURRENTLY ACCEPTED*:
"The" anything: The blind The disabled The autistic	Views people in terms of their disability; Groups people into one undifferentiated category; Condescending; Does not reflect the individuality, equality, or dignity of people with disabilities.	- People with disabilities - Deaf people - People who are blind - People who are visually impaired - People with autism
Handicapped	Outdated; connotes that people with disabilities need charity. Disabilities don't handicap: attitudes and architecture handicap.	People with disabilities
The disabled	An individual is a person before one is disabled. People with disabilities are individuals who share a common condition.	People with disabilities
Admits she/he has a disability	Disability is not something people admit to or needs to be admitted to.	Says she/he has a disability
Normal, healthy, whole (when speaking about people without disabilities as compared to people with disabilities)	People with disabilities may also be normal, healthy and whole. Implies that the person with a disability isn't normal.	- Non-disabled - Person without a disability
Courageous	Implies person has courage because of having a disability.	- Has overcome his/her disability - Successful, productive



SPECIFIC DISABILITIES & CONDITIONS

OUTDATED OR OFFENSIVE:	REASON(S):	CURRENTLY ACCEPTED*:
Deaf and dumb Dumb Deaf-mute	Implies mental incapacitation; Simply because someone is deaf does not mean that they cannot speak	- Deaf - Non-verbal - Hard of hearing - Person who does not speak - Unable to speak - Uses synthetic speech
Hearing impaired Hearing disability Suffers a hearing loss	Negative connotation of "impaired", "suffers"	- Deaf - Hard of hearing
Slurred speech Unintelligible speech	Stigmatizing	- Person/people with a communication disability - Person/people with slow speech
Confined to a wheelchair Wheelchair-bound	Wheelchairs don't confine; they make people mobile	- Uses a wheelchair - Wheelchair user - Person who uses a wheelchair
Cripple Crippled	From Old English, meaning "to creep"; was also used to mean "inferior"; Dehumanizing	- Has a disability - Physical disability - Physically disabled
Deformed Freak Vegetable	Connotes repulsiveness, oddness; Dehumanizing	- Multiple disabilities - Severe disabilities
Crazy Insane Psycho Maniac Nut Case	Stigmatizing Considered offensive Reinforces negative stereotypes	- Behavior disorder - Emotional disability - Person with mental illness - Person with a psychiatric disability
Retarded Retardate Mentally defective Slow Simple Moron Idiot	Stigmatizing; Implies that a person cannot learn	- Cognitive disability - Developmental disability (the term "mental retardation" should be used sparingly)
Mongoloid	Considered offensive	Person with Down syndrome
Stricken/Afflicted by MS	Negative connotation of "afflicted", "stricken"	Person who has multiple sclerosis
CP victim	Cerebral palsy does not make a person a "victim"	Person with cerebral palsy



Epileptic	Not "person first" language; Stigmatizing	- Person with epilepsy - Person with seizure disorder
Fit	Reinforces negative stereotypes	Seizure
Birth defect	Implies there was something wrong with the birth	Congenital disability
Deinstitutionalized	Stigmatizing; groups people into one category; not focused on the individual	Person who used to live in an institution
Midget	Outdated term; considered offensive	Person of short stature

* All currently accepted terms should be used with "people first" language - i.e., "people with...," "person with...," the exception to this are "deaf people" and "deaf community," which are fine.

“Adapted from material developed by; Mid-Hudson Library System, Outreach Services Department, 103 Market Street, Poughkeepsie, NY 12601 (914) 471-6006.”



Developmental and Cognitive Disabilities

Developmental and cognitive disabilities are an extremely broad but a very interconnected category. Both types of disability frequently occur together as a result of a single causal factor, though they just as frequently occur individually. While an experienced and compassionate person may be able to recognize that a person has a developmental disability, there is often no way of knowing whether the person also suffers from a cognitive disability without interacting with that person. Likewise, cognitive disabilities may occur in people who do not appear externally to have any disability whatsoever. It may take observation of behavior and interaction to determine how to communicate most appropriately with someone.

Further, a basic recognition that a person's behavior differs from the range that is considered mainstream may not absolutely indicate a cognitive disability but could be a result of a mental illness (see below) or simply a personality quirk that does not constitute a disability. Lastly, a person with a cognitive disability may not be recognizable in casual interaction. Conditions such as dyslexia and attention deficit are classified as cognitive disabilities and can reasonably require both accommodation and sensitivity; but neither will necessarily be immediately apparent. It is in this broad category that the most care must be taken in making assumptions about what a person is or is not capable of doing on their own or with assistance.

Basic Etiquette: People with Mental Retardation/Cognitive Disabilities

- 1. People with mental retardation are not "eternal children."** Adults with mental retardation should be treated and spoken to in the same fashion as other adults. Do not "talk down" to a person with mental retardation. Assume that an adult with mental retardation has had the same experiences as any other adult.
- 2. Like everyone else, people with mental retardation are extremely diverse in their capabilities and interests.** Avoid stereotypes, such as the assumption that all people with mental retardation enjoy doing jobs that are repetitive or want to work in fast food restaurants or supermarkets.
- 3. Many people with mental retardation can read and write.** Don't assume that a person with mental retardation lacks academic skills, such as reading, writing, and the ability to do mathematics. While an individual's disability may significantly impact these areas, many people with mental retardation have at least some level of these academic skills.



- 4. Even if people's academic skills are limited, they still have much to share and contribute.** A low level of academic skills does not mean that people don't have valuable ideas and thoughts. Provide opportunities for people with limited academic skills to contribute verbally, and take what they have to say seriously. Ensure that people who have difficulties reading or writing have equal access to written materials (for example, by taping them or having someone review the materials with them orally). Use pictures or simple photographs to identify rooms, tasks, or directions.
- 5. Treat the individual as you would anyone else.** If engaging in a conversation with someone with mental retardation, bring up the same topics of conversation as you would with anyone else such as weekend activities, vacation plans, the weather, or recent events.
- 6. Giving instructions.** People with mental retardation can understand directions if you take your time and are patient. Use clear language that is concise and to the point. When giving instructions, proceed slowly, and ask the person to summarize the information to ensure that it has been understood. You may have to repeat yourself several times in order for the individual to take in all the information. "Walk through" the steps of a task or project. Let an individual perform each part of the task after you explain it and/or model it.
- 7. Don't defer to a staff person or caregiver.** When a person with mental retardation is accompanied by another person such as a staff person, caregiver, or family member, don't direct questions and comments to them. Speak directly to the person with mental retardation. Also, don't allow someone else to speak for the person with a disability.
- 8. Avoid the term "mental retardation."** If you need to speak about a person's disability, people with mental retardation prefer the term "developmental disability" rather than "mental retardation." (Mental retardation is one type of developmental disability.)



Basic Etiquette: People with Visual Impairments

1. Blind doesn't mean blind--having a vision disability does not necessarily mean that a person lives in total darkness.
2. Saying Hello & Good-bye
 - Don't assume that people with vision disabilities will remember your voice.
 - It is considered rude to ask a person with a visual disability "Do you remember my voice?"
 - Identify yourself by name when you approach a person with a vision disability and tell them when you are leaving the conversation or area.
3. Communication
 - Use a normal tone of voice (for some reason, people with vision disabilities are often shouted at).
 - It is okay to use vision references such as "see or look".
4. Orientation
 - It is considered polite to indicate your position with a light tap on the shoulder or hand.
 - However, keep your physical contact reserved.
5. Give a person with visual impairment a brief description of the surroundings. For example:
 - There is a table in the middle of the room, about six feet in front of you; or
 - There is a coffee table on the left side of the door as you enter.



6. Use descriptive phrases that relate to sound, smell, and distance when guiding a visually impaired person.
7. Mobility Assistance
 - Offer the use of your arm.
 - If your assistance is accepted, the best practice is to offer your elbow and allow the person with the vision disability to direct you.
 - Don't grab, propel, or attempt to lead the person.
 - Do not clutch the persons arm or steer the individual.
 - Walk as you normally would.
8. Do not be offended if your offer to assist a visually impaired person is declined.
9. Service Animals
 - Guide dogs are working animals and should not be treated as pets.
 - Do not give the dog instructions, play with, or touch it without the permission of its owner.
10. Avoid clichéd phrases such as "the blind leading the blind," "What are you... blind?" "I'm not blind, you know."
11. Do not grab or try to steer the cane of a person with visual impairments.
12. Always determine the format in which a person with visual impairments wants information.
 - The usual formats are Braille, large print, audiotape, or computer disk/electronic text.
 - Do not assume what format an individual uses or prefers.
13. Direct your comments, questions or concerns to the person with a visual impairment, not to his or her companion.
14. If you are reading for a person with a visual impairment:
 - First describe the information to be read.
 - Use a normal speaking voice.
 - Do not skip information unless requested to do so.



Basic Etiquette: People Who Are Deaf or Hard of Hearing

1. Hearing disability, hard of hearing, and deaf are not the same.
 - Hearing disability refers to both persons who are hard of hearing and persons who are deaf
 - Deaf people utilize their vision skills for communication
 - Hard of hearing persons seek ways to retain their listening and speaking skills.
2. It is okay to use the terms: “the deaf or deaf person”. This is an exception to the person-first language rule.
3. There are a wide range of hearing losses and communication methods. If you do not know the individual’s preferred communication method, *ASK*.
4. To get the attention of a person with a hearing loss, call his/her name. If there is no response, you can lightly touch him/her on the arm or shoulder or wave your hand.
5. When using an interpreter:
 - Always address your comments, questions, and concerns directly to the person with whom you are talking and never to the interpreter.
 - Always face the individual and not the interpreter.
6. Always look directly at a person who has a hearing loss. Use eye to eye contact.
7. Use facial expressions and body language to communicate the emotion of a message, such as displeasure or approval.
8. Watch the individual’s eyes to ensure understanding - do not depend on affirmative head nodding only.
9. If possible, use e-mail to communicate
10. Tips in using a TTY (Teletypewriter):
 - Make your communication clear, simple, and concise.
 - Typical abbreviations:
 - GA - Go ahead - means that the person has finished their statement and the other person can start typing
 - Q - Use instead of a question mark
 - SK - Means you want to conclude your conversationWhen you read SK, type SKSK if you are completely finished talking.



11. Can the person read lips?

- Not all people who are deaf can read lips
- Speak clearly, slowly, and expressively to determine if the person can read your lips
- Do not exaggerate your speech
- People who read lips only understand 20 to 25% of what is being said
- Be sensitive to the needs of people who lip read by facing the light source and keeping hands, cigarettes, and food away from your mouth when speaking.

12. If you are asked to repeat yourself several times, try rephrasing your sentence.

13. When providing information that involves a number or an address, consider alternative ways to provide it: writing, faxing, or e-mailing are great ways to ensure accuracy and decrease frustration.

14. Have pencil and paper available and use them if necessary.

15. If you are experiencing extreme difficulty communicating orally, ask if you can write. Never say: “Oh, forget it, it is not important.” Keep messages simple and direct.

16. Be aware of the environment:

- Large, crowded rooms and hallways can be very difficult for hearing impaired persons
- Bright sunlight and shadows also present barriers.

17. In group settings:

- let the deaf individual determine the best seating arrangement in order for them to see the speaker and interpreter
- watch for signals that the deaf individual wishes to contribute
- ensure that one person speaks at a time
- do not pace while giving a presentation
- do not talk with your back to the audience while writing on a flipchart or blackboard
- incorporate visual aids, demonstrations, flip charts, written agendas, and handouts in presentations.

18. Do not change the topic of conversation without warning. Use transitional phrases such as: “Okay, we need to discuss. . . .”



Basic Etiquette: People with Speech Impairments

1. Take your time, relax, and listen.
 - With a little time and patience, you can comfortably converse with a person who has a communication disability.
 - Don't try to rush the conversation or second-guess what a person has to say.
 - Plan for a conversation with a person with impaired speech to take longer.
2. Its okay to say: "I don't understand".
3. Solicit and provide feedback. If necessary, repeat your understanding of the message in order to clarify or confirm what the person said.
4. Do not ignore a person with speech impairment because of your concern that you will not understand them.
5. Do not pretend you understand what is being said if you do not. Instead, repeat what you have understood and allow the person to respond. The response will clue you in and guide your understanding.
6. Do not interrupt a person with speech impairment. Be patient and wait for the person to finish, rather than correcting or speaking for the person.
7. If necessary, ask short questions that can be answered with a few words, a nod, or a shake of the head.
8. Face the individual and maintain eye contact. Give the conversation your full attention.
9. If the individual is accompanied by another individual, do not address questions, comments, or concerns to the companion.
10. Do not assume that a person with speech impairment is incapable of understanding you.
11. Some people with speech impairments have difficulty with inflections. Do not make assumptions based on facial expressions or vocal inflections unless you know the individual very well.
12. Do not play with or try to use someone's communication device. Such aids are considered an extension of an individual's personal space and should be respected as such.
13. If you are having trouble communicating, ask if an individual can write the message or use a computer or TTY.



Basic Etiquette: People with Mental Illness

1. The terms mental illness and psychiatric disability are essentially interchangeable. Some groups and individuals prefer one term to the other, but in general both terms are considered acceptable. A possible alternative is to describe a person as someone who has mental health issues.
2. Do not assume that people with psychiatric disabilities are more likely to be violent than people without psychiatric disabilities; this is a myth.
 - o The wide ranges of behaviors associated with mental illness vary from passivity to disruptiveness.
 - o When the illness is active, the individual may or may not be at risk of harming him or herself, or others.
3. People with mental illness do not have mental retardation; however, some people who have mental retardation also have mental illness. Do not assume that people with psychiatric disabilities also have cognitive disabilities or are less intelligent than the general population. In fact, many people with mental illness have above-average intelligence.
4. Do not assume that people with psychiatric disabilities necessarily need any extra assistance or different treatment.
5. Treat people with psychiatric disabilities as individuals. Do not make assumptions based on experiences you have had with other people with psychiatric disabilities.
6. Do not assume that all people with psychiatric disabilities take, or should take, medication.
7. Do not assume that people with psychiatric disabilities are not capable of working in a wide variety of jobs that require a wide range of skills and abilities.
8. Do not assume that people with psychiatric disabilities do not know what is best for them, or have poor judgment.
9. If someone with a psychiatric disability gets upset, ask calmly if there is anything you can do to help, and then respect their wishes.
10. Do not assume that a person with a psychiatric disability is unable to cope with stress.



Basic Etiquette: People with Mobility Impairments

1. My Chair, My Body - Wheelchairs are *NOT* footstools, stepladders, or fire hazards. People who use a wheelchair, walker, or cane often consider this technology to be an extension of their body. They are part of an individual's personal space and should be treated with the same dignity and respect. Do not lean on them, push them, or move them without explicit permission.
2. Talk face to face. If an individual uses a wheelchair, sit down and/or position yourself at the same eye contact level.
3. Always ask if you can offer assistance *BEFORE* you provide assistance. If your offer is accepted, ask for instructions and follow them.
4. When given permission to push a wheelchair, push slowly at first. Wheelchairs can pick up momentum quickly.
5. Personally check locations of events for accessibility. If barriers cannot be removed, alert persons with mobility impairments before the event so that they can make decisions and plan ahead.
6. Do not ask people how they acquired their disability, how they feel about it, or other personal questions unless it is clear that they want to discuss it. It is not their job to educate you.
7. It is considered patronizing to pat an individual who uses a wheelchair on the back or on the head.
8. Remember that, in general, persons with mobility impairments are not deaf, visually impaired, or cognitively impaired. The only accommodations that you need to make are those that relate to mobility impairment.

Add-on's from an article "Wheelchair Etiquette"/based on Ric Garren in Challenge Magazine:

9. When giving directions, think about things like travel distance, location of curb cuts and ramps, weather conditions and physical obstacles that may hinder their travel.
10. Don't discourage children from asking questions of a person who uses a wheelchair about their wheelchair. Open communication helps overcome fearful or misleading attitudes.



11. When a person who uses a wheelchair "transfers" out of the wheelchair to a chair, pew, car, toilet or bed, do not move the wheelchair out of reach. If you think it would be best to move it for some reason, ask the person who uses the wheelchair about the best option for them.
12. It is OK to use expressions like "running along" or "let's go for a walk" when speaking to person who uses a wheelchair. It is likely they express the idea of moving along in exactly the same way.
13. People who use wheelchairs have varying capabilities. Some persons who use wheelchairs can walk with aid or for short distances. They use wheelchairs because they help them to conserve energy and to move about with greater efficiency.
14. Don't classify or think of people who use wheelchairs as "sick." Wheelchairs are used to help people adapt to or compensate for the mobility impairments that result from much non-contagious impairment. Some of these are, for example, spinal cord injury, stroke, amputation, muscular dystrophy, cerebral palsy, multiple sclerosis, post polio, heart disease, etc.
15. Don't pet guide dogs or other service animals...they are working.
16. Don't discourage children from asking questions about the wheelchair.
17. Don't assume that using a wheelchair is in itself a tragedy. It is a means of freedom that allows the person to move about independently and fully engage in life.



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THE POWER OF OUR VOICES

Central New York Self Advocates Speaking Out

Lance and I have known each other since we were kids. Our parents were in the same parent group together and we became friends and stayed friends over the years.

I believe that everything is put together by God. I know this is true, because a friend from Northside Baptist Church hooked us up and we started dating a couple of years ago.

Lance proposed to me on Christmas. Our wedding is scheduled for October 29, 2011.



I was so excited to go to my very first bridal show this spring. However, I was so disappointed as the room was too small to accommodate all the guests and it was impossible for me to get around in my chair.

Lance and I love spending

time with each other and our family. The Bible and our church is very important part of our lives and will continue to be after our wedding.

All things work out for the love of God.

—Lori Kelso &
Lance Gonzelez

"I FELT HIM IN MY HANDS, IN MY BODY"

My mom had me, and I was different. She was scared then her friend asked her to bring me to the church. She went home asked my dad. My dad said it is up to you. She took me to church then I got blessed cause I had a hole in my heart. I went to the doctor's to take an x-ray, but they couldn't find the hole in my heart. Then my mom believed in God. Now she calls me the miracle child. The Doctor said I wouldn't talk or read, and it was God who healed me. This is a real story about my life.

Now I love church. I am close to God. I told my mom and Bonnie I want to

be a youth leader at my church.

We had a question day. What do you want to be? I said, "I want to be a youth leader." She was surprised! On Friday my teacher said "What are you doing this weekend?" I said, "I am going to youth prayer meeting. I want to be a youth leader." It was so much fun. I've never been to a youth prayer meeting like this. I felt Him in my hands, in my body. It was so much fun, and I cannot wait for the next one. Then Pastor Aaron said, "We need some youth leaders." I was so happy because God answered my prayer. In that one day God changed



me. Pastor Aaron was talking about changing our life around. My life changed—I don't act like my old self any more. I don't kick or punch walls, and I don't punch myself any more. Thank you for making me understand God now. I feel so happy right now.

—Danielle Gadle
Vice-President
Self-Advocacy for Change

(Articles reprinted with permissions from CNY Self Advocates Speaking Out Vol. 1 issue 4)



“ACCESSIBLE FAITH”



Americans with Disabilities Act

ADA Title III Technical Assistance Manual

Covering Public Accommodations and Commercial Facilities

III-1.5000 Religious entities: *Religious entities are exempt from the requirements of title III of the ADA. A religious entity, however, would be subject to the employment obligations of title I if it has enough employees to meet the requirements for coverage.*

III-1.5100 Definition: A religious entity is a religious organization or an entity controlled by a religious organization, including a place of worship.

Frequently Asked Questions

Q. If an organization has a lay board, is it automatically ineligible for the religious exemption?

A. No. The exemption is intended to have broad application. For example, a parochial school that teaches religious doctrine and is sponsored by a religious order could be exempt, even if it has a lay board.

III-1.5200 Scope of exemption: The exemption covers all of the activities of a religious entity, whether religious or secular.



ILLUSTRATION: *A religious congregation operates a day care center and a private elementary school for members and nonmembers alike. Even though the congregation is operating facilities that would otherwise be places of public accommodation, its operations are exempt from title III requirements.*

Q. What if the congregation rents to a private day care center or elementary school? Is the tenant organization also exempt?

A. The private entity that rents the congregation's facilities to operate a place of public accommodation is not exempt, unless it is also a religious entity. If it is not a religious entity, then its activities would be covered by title III. The congregation, however, would remain exempt, even if its tenant is covered. That is, the obligations of a landlord for a place of public accommodation do not apply if the landlord is a religious entity.

Q. If a nonreligious entity operates a community theater or other place of public accommodation in donated space on the congregation's premises, is the nonreligious entity covered by title III?

A. No. A nonreligious entity running a place of public accommodation in space donated by a religious entity is exempt from title III's requirements. The nonreligious tenant entity is subject to title III only if a lease exists under which rent or other consideration is paid.



Accessibility to church buildings

Providing buildings that are accessible to all persons, including those with physical disabilities and limitations, should be the goal of every church. Defining what is accessible can often be difficult for churches. At times there are multiple standards and sometimes contradictory requirements by local, state and national governments. What then are the guidelines churches should use in providing accessibility?

1. Federal Law

The Americans with Disabilities Act (“A.D.A.”) was enacted in 1990 with the stated purpose of eliminating discrimination against individuals with disabilities by focusing on four areas:

- X Employment (Title I)
- X Public services provided by governmental entities (Title II)
- X Public accommodations and services provided by private entities (Title III)
- X Telecommunications (Title IV)

The section of the act directly related to church facilities is Title III, which **exempts** “religious organizations or entities controlled by religious organizations, including places of worship” (28cfr-part 36-section 36.102 e). However, portions of a church’s facilities may come under Title III requirements as a result of Title I (Employment) regulations. This section could affect churches with 15 or more full time employees, in their workplace areas. Also, churches which lease their facilities to other organizations, such as a school or day care, might be required to incorporate accessibility guidelines in those portions of the church’s buildings.

It is important to remember that A.D.A. was passed as civil rights legislation, not as a building code.

Church Architecture
Baptist General Convention of Texas
Visit the website for ADA 2010 standards and guidance
<http://www.ada.gov>



Partnerships for supporting individuals with disabilities in your congregation

Organization or association	website
NYS Office for People With Developmental Disabilities	www.opwdd.ny.gov
NYS Office of Mental Health	www.omh.state.ny.us
Self-Advocacy Association of New York State Inc.	www.sanys.org/
Parent to Parent of NYS	www.parenttoparentnys.org
NYS Developmental Disability Planning Council	www.ddpc.ny.gov/
NYS ARC	www.nysarc.org/
The American Association on Intellectual and Developmental Disabilities	www.aaid.org
Autism Society of America	www.autism-society.org
Brain Injury Association of America	www.biausa.org
NYS Independent Living Council	www.nysilc.org
NYS Easter Seals	www.ny.easterseals.com
Epilepsy Foundation	www.epilepsyfoundation.org
Cerebral Palsy Association of New York state	www.cpofnys.org
National Down Syndrome Society	www.ndss.org
Muscular Dystrophy Association	www.mda.org
National Organization on Disability	www.nod.org



ADDENDUMS



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Power of Our Voices: Central New York Self Advocacy Speaking Out -1005 West Fayette Street Suite 1A, Syracuse, New York 13204

Describing People with Disabilities-People First Language: Texas Council for Developmental Disabilities, 6201 East Oltorf Suite 600, Austin Texas



WE HELP PEOPLE LIVE RICHER LIVES