



Introduction to Persons with Intellectual and Developmental Disabilities



For people with intellectual and developmental disabilities and their families

Welcome to an Introduction to Persons with intellectual and developmental disabilities. Our learning objectives are:

- 1 - Learn what is an intellectual and developmental disability
- 2 - Important components to a welcoming place
- 3 - Considerations for talking with people with intellectual and developmental disabilities
- 4 - Learn what is plain language, how to create accessible written materials and meetings

The online training will give you information that can help you at The Arc. The Arc was the first grassroots organization to advocate for the rights of children with disabilities.

- To this day, The Arc continues to be an organization of families, volunteers, donors and staff that together to support people of all ages.
- People that include:
 - Amalie and Abby, pictured in the upper right who are learning how to use their voice to communicate their choices.
 - And Nathan, pictured on the left, who was able to access health

care with the support of The Arc

- Or Tricia and Kelly, pictured on the lower right who are demonstrating their leadership to fight for the rights of all people with disabilities.



About The Arc



The Arc is a nonprofit, grassroots advocacy organization founded in 1946 by parents of children with disabilities.

Mission

The Arc promotes & protects the rights of people with intellectual & developmental disabilities, actively supporting them & their families in a lifetime of full inclusion & participation in their communities

For people with intellectual and developmental disabilities and their families

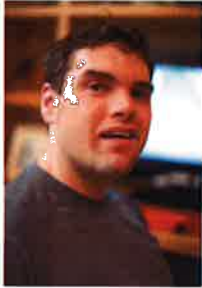
The Arc supports the rights of people with intellectual and developmental disabilities and their families. We help them to be included and participate in their communities.

Simply stated, we're here to help individuals and families achieve a good life. When parents of kids with disabilities first founded The Arc 70 years ago, there really were no services. Many parents at that time were told at the time they welcomed a new baby into their family, to put them in an institution and forget about them. But many of them said no and instead they used their own creativity and collective strength to achieve opportunities for their children. They literally changed the world through grassroots action, and today that power is still the bedrock of The Arc. When people share their passion and work together, they can achieve great things.

So what exactly does The Arc do?

The Arc Minnesota serves many counties throughout the state. There are different regions throughout the state where staff and volunteers are there to support the mission of the Arc. The Arc nationwide has more than 700 chapters.

Our services span the lifetime and address issues such as early intervention, education, the transition to adulthood, employment, housing, health care, guardianship and more.



Who We Serve



Individuals with intellectual & developmental disabilities & their families across the lifespan

- Down syndrome
- Autism
- Fetal Alcohol Spectrum Disorder
- Cerebral Palsy and more

For people with intellectual and developmental disabilities and their families

So what is intellectual and developmental disabilities?

Intellectual and developmental disabilities are lifelong and include persons with Down syndrome, Autism, Cerebral Palsy, Fragile X Syndrome and more. With the exception of Fetal Alcohol Spectrum Disorder which is caused by a mother drinking alcohol during pregnancy, the cause for intellectual and developmental disabilities is often unknown – it can and does happen to anyone.

Intellectual disability is a below-average cognitive ability with three characteristics:

- Intelligent quotient (or I.Q.) is between 70-75 or below
- Significant limitations in everyday life activities
- The onset of the disability occurs before age 18.
- Intellectual disability is diagnosed through the use of standardized tests of intelligence and adaptive behavior, it is not determined by IQ alone.

Sometimes intellectual disability is also referred to as **developmental disability** which is a broader term that includes autism spectrum disorders, epilepsy, cerebral palsy, developmental delay, fetal alcohol syndrome and other disorders that occur during the developmental period from birth to age 18.

Intellectual disability can be caused by any condition that impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains unknown. Factors that can impact causes include

Genetic like Down Syndrome Williams Syndrome or Fragile X Syndrome

OR

Problems during pregnancy such as the use of alcohol or drugs by a pregnant mother or malnutrition, environmental toxins or illness that the pregnant mother is exposed to.

Fetal Alcohol Spectrum Disorder is the only known preventable intellectual and developmental disability. There is no cure, but it is preventable. It is caused by drinking during any stage of pregnancy. There is no safe amount, no safe time and no safe kind of alcohol use during pregnancy. Fetal Alcohol Spectrum Disorder causes permanent brain damage.

Cerebral palsy is caused by damage to the motor control centers of the developing brain and can occur during pregnancy, during childbirth, or after birth up to about age three.^[4]

OR

Problems at birth or after birth such as difficulty during the birth process where the infant doesn't get oxygen or after when a child is exposed to a childhood disease that causes brain damage.

And

finally due to poverty or cultural deprivation – children who grow up in poverty are at a higher risk for malnutrition, childhood diseases and receive inadequate health care.

Unknown intellectual and developmental disabilities include autism, we don't know what causes autism. Rates of incidence of autism is increasing, according to the Center for Disease Control most recently 1 in 68 individuals are diagnosed with autism, a 2012 statistic.

Persons with intellectual and developmental disabilities struggle with

- Conceptual skills— using words and reading; managing money, time, and number concepts; and self-direction.
- Social skills—developing interpersonal skills, understanding social responsibility, having a good sense of self-esteem; they may be gullible, lack life experiences compared to people without disabilities. They may lack the ability to follow typical social norms and rules and struggle to obey laws and unable to avoid being

victimized.

- Practical day to day skills they may struggle with include activities of daily living such as brushing teeth, bathing. Also occupational skills, managing their own healthcare, making arrangements for transportation, being able to manage schedules or routines that get them ready for work or school, understanding how to maintain their safety, use of money, use of the telephone.

The Arc serves people with “intellectual and developmental disabilities” and say that instead of saying “the mentally retarded.” Sometimes people ask – well, doesn’t the “R” in Arc stand for retarded? It once did, but in 1991, we changed our name from the Association of Retarded Citizens to simply The Arc. It is no longer an acronym.

We made the change because the term “retarded” has become an offensive and hurtful label for people with disabilities. In addition, the diagnosis of mental retardation refers to individuals who have low IQ’s. The Arc serves all types of developmental disabilities, and often individuals with disabilities like autism or cerebral palsy have normal or high IQ’s.

How Many People?



Approximately 4.6 million Americans have an intellectual or developmental disability.⁵

For people with intellectual and developmental disabilities and their families

How many people are at risk?

One in ten families in our community has a member with an intellectual or developmental disability

This is the largest minority group and the most diverse. Today many people with intellectual and developmental disabilities will live to be seniors. This was not true some 50 years ago when many times parents would outlive their children with disabilities.



The Arc's Services Ways We Can Help



**Information, Assistance and Advocacy
Abuse Prevention & Awareness
Community Engagement
Education
Employment
Government Benefits
Guardianship
Health Care Assistance
Housing
Planning Your Future
Self-Advocacy**

For people with intellectual and developmental disabilities and their families

The Arc, like many organizations, provides information and assistance by phone, email or someone can stop in at our office. Advocates from the Arc can also answer questions from individuals or family via our website through Ask an Advocate.

Advocates at The Arc provide one to one assistance and sometimes intensive advocacy for adults with disabilities and family members covering a wide range of topics. The topics listed on this slide represent our current areas of focus. We continually research issues, trends and disability policy to provide current and accurate information and support.

The Arc is one of the rare organizations that also provides one-to-one individual advocacy or support without charge. Government Systems are complex, fragmented and difficult to access. Advocacy helps people through tough situations and gives them the tools and training to overcome challenges. It is the heart of what we do.

What does a welcoming place look like?



For people with intellectual and developmental disabilities and their families

What makes you feel welcome?

A welcoming environment is one in which all people feel included. It is a place where all people are treated equally regardless of difference. These places are where we live, work, shop, exercise, practice our faith, get help when we are sick and enjoy entertainment with family and friends.

It seems ideal doesn't it. Unfortunately many community programs, schools, businesses, faith based communities and other organizations over the years have not created environments that strive for the ideal. They failed to create welcoming environments where all are welcome. Many organizations and individuals have made choices that are based on difference. They have treated others unlike themselves differently than the rest.

Welcoming environments are able to meet people when they are at their best or when they are challenged. An example of this happens possibly weekly for us, the work of the Arc places us in the community where we may come across a parent with a child with a disability or an adult with a disability. You see a child or adult struggling, they may be yelling loudly, crying, basically being very disruptive. What can you do? In a

few slides we will talk about this more.

Our need to belong



- One of our most basic needs is the need to belong, to be accepted & valued
- Only after we experience a sense of belonging can we learn, grow and give back to others to our fullest potential



For people with intellectual and developmental disabilities and their families

Regardless of who we are, what backgrounds we come from, what our ethnicity, we all have one thing in common (pause) and that is the basic need to belong.

Only when we experience a sense of belonging can we learn, grow and give back to others to our fullest potential.

Inclusion is about...



- Having the same choices & opportunities as others
- Being accepted & appreciated for who you are
- Being with friends who share your interests, not your disability



Adapted from: Anderson, L., Brown, C., & Soli, P. (1996). *Inclusion: strategies for including people with disabilities in parks and recreation opportunities*. Bismark, ND: North Dakota Parks and Recreation Department and the University of North Dakota.

For people with intellectual and developmental disabilities and their families

Inclusion is a sense of belonging: feeling respected, valued for who you are.

It is about feeling supportive energy and commitment from others so that you can do your best work. A place or program is inclusive when it uses the richness of who attends as the diversity to achieve it's goals and objectives.

A friend of mine Donna had worked for many years at a fast food restaurant, she became very frustrated with her manager and other employees. She was usually not asked for her thoughts and ideas and many times experienced a lack of a support from her co-workers. Donna quit her job because she didn't feel acknowledged as a contributing member of the team. She took a job at a different location for a few months and then returned to her employer. The time away made her manager recognize how important Donna's positive attitude is towards her work and has created a workplace that includes respect and value for Donna.

Inclusion is about...



- Being a valued person and a welcomed participant in community programs, regardless of ability level
- Having facilities and areas that are accessible and easy to use by everyone
- Provide the individual adaptations, accommodations and supports so every person can benefit equally from experiences in the community with friends

Adapted from: Anderson, L., Brown, C., & Soli, P. (1996). *Inclusion: strategies for including people with disabilities in parks and recreation opportunities*. Bismark, ND: North Dakota Parks and Recreation Department and the University of North Dakota.

For people with intellectual and developmental disabilities and their families

Any community will be stronger when you take advantage of the diversity that is around you. If a community place, business or program is diverse, but the members take little or no advantage of the breadth of that experience, then it is not reaping the benefits that diversity has to offer.

These are the hopes and dreams for persons with intellectual and developmental disabilities, to have a valued social role within community places, work places, faith communities or at school.

How to be inclusive and welcoming when a person is not at their best



- Ask - "How can I help?"
- Offer to do something
- Be supportive
- Let the parent or caregiver take care of their child or adult
- Don't offer advice
- Take no offense if the parent rejects your help

For people with intellectual and developmental disabilities and their families

Some of you may have had the experience of shopping at a store, eating out at a restaurant, or at a concert or special event and have witnessed someone that is not at their best. Many times it may be a child with a parent, but possibly it is an adult that is crying, yelling or possibly threatening to push things over or throw things. Many times in these situations there is a parent or caregiver present, trying their best to manage the situation. The child or person they are with may be experiencing a meltdown.

What are meltdowns?

Put simply, a meltdown is a state of neurological chaos where the brain and nervous system overheat and stop working properly. It's called that because it's the body's equivalent to a meltdown in a nuclear power plant, in which the fuel in the reactor core becomes so hot that it melts and releases energy.

Sometimes it gets so hot that it causes an explosion, and the energy is released outside of the core. It's this explosive reaction (crying, yelling, lashing out) that most people refer to when they talk about meltdowns.

How are meltdowns different from tantrums?

Meltdowns and tantrums can often look the same on the outside, but that's where the similarity ends. A tantrum is a voluntary battle of wills to try and gain control over a

situation. It's designed to draw attention for the sole purpose of satisfying a want (like refusing to leave the supermarket without candy), so once that goal has been met the outburst quickly resolves itself.

Meltdowns on the other hand are almost the complete opposite - an involuntary physical and emotional reaction to being placed in an overwhelming situation from which there is no easy escape. The person isn't in control or trying to get attention, in fact they're often unaware of things happening around them.

Things to consider to help a parent whose child is having a meltdown

1. Offer to help, simply say "How can I help?" They may ask you to move things away OR re-direct others away from their child or adult. They may give you a piece of paper or card which could have some instructions on it on how you can help.
2. Most likely the parent will say they don't need your help. That's OK. Offer to do something specific like offer a bottle of water. RE-direct bystanders away, run interference until the child or person has calmed down.
3. Say something supportive like "You've got this" or "Parenting sure can be tough at times" or "You are a great parent."
4. Let the parent take care of the child having the meltdown.
5. Don't offer any advice. Some examples of what not to say "You need to get your kid under control." OR "Don't take that child out in public." OR "You need to get that child help." OR "If you don't get your child under control, I will have to ask you to leave." All these statements are not supportive in helping.
6. Don't be offended if the parent rejects your help. The child may need space and quiet to calm down.

Parenting a child OR caregiving for a person with public meltdowns feels isolating. From the parent of caregiver perspective the stares and judgment hurt because they want their child or person to be understood and accepted.

When they take their children with unpredictable behavior out in public, they step outside our comfort zones because they endure possible ridicule from others.

Step outside of your comfort zone offering a simple gesture of kindness and connection to a parent helping her child through a challenging moment.

Language reflects attitudes



- Speak of the person first, then the disability
- Emphasize abilities, not limitations
- Do not label people as part of a disability group
- Remember that a person is not a condition




For people with intellectual and developmental disabilities and their families

Our language can reflect attitudes.

Words are powerful. The words we use to refer to people shape our beliefs and ideas about them. Old and inaccurate ways we describe people with disabilities support negative stereotypes and prejudiced attitudes. Like gender and ethnicity, disability is one of many characteristics of being human. When we use labels to describe a person, we devalue and disrespect them as individuals. Our words both define and reflect our everyday life and can promote positive attitudes about persons with disabilities.

It is important to remember that people with disabilities are People First and their disability does not define who they are. It is respectful to always refer to the person first and individual with a disability rather than disabled person.

One of the handouts that was available was the People First Hand Out by Kathy Snow. (go to next slide)



EXAMPLES OF PEOPLE FIRST LANGUAGE

BY KATHIE SNOW; VISIT WWW.DISABILITYISNATURAL.COM TO SEE THE COMPLETE ARTICLE

Remember: a disability descriptor is simply a medical diagnosis.
 People First Language respectfully puts the person before the disability.
 A person with a disability is more *like* people without disabilities than different.

SAY:	INSTEAD OF:
People with disabilities.	The handicapped or disabled.
He has a cognitive disability/diagnosis.	He's mentally retarded.
She has autism (or a diagnosis of...).	She's autistic.
He has Down syndrome (or a diagnosis of...).	He's Down's; a mongoloid.
She has a learning disability (diagnosis).	She's learning disabled.
He has a physical disability (diagnosis).	He's a quadriplegic/is crippled.
She's of short stature/she's a little person.	She's a dwarf/midget.
He has a mental health condition/diagnosis.	He's emotionally disturbed/mentally ill.
She uses a wheelchair/mobility chair.	She's confined to/is wheelchair bound.

For people with intellectual and developmental disabilities and their families

One of the handouts that was available for print out is about People First Language

As you can see from the list there are some great examples

- People with Disabilities instead of the Handicapped or disabled
- He has down Syndrome rather than he's Down's

OR

He has a physical disability instead of he's crippled.

OR

She uses a wheelchair instead of She's confined to a wheelchair OR wheelchair bound.

6 things people with disabilities want you to know



- Accept me for who I am
- Understand that sometimes I need a friend
- Talk to me as you would any other person
- Let me try to do my best
- Don't feel sorry for me
- Be patient when I mess up

Adapted from Focus on the Family - Anita Corrine Donihue

For people with intellectual and developmental disabilities and their families

Here are 6 things people with disabilities want you to know.

Accept me for who I am.... We all are here with gifts and talents, we all want to be valued for how we can contribute

Understand that sometimes I need a friend.... People with disabilities are just like you and I, wanting friendships and relationships...being a friend is an important social role

Talk to me as you would any other person... You may need to ask or confirm with the person OR you may want to ask what works for them in explaining things

Let me try to do my best.,,, we all want to be acknowledged for trying our best, what worked in our attempt and having input in how we might do it the next time.

Don't feel sorry for me..... Once again acknowledge what I did do well and what can I do the next time to do better.

Be Patient when I mess up.... We all mess up in our lives, what is it that you want from others when you mess up....it is the same for people with disabilities. It could be that

the instructions that were provided didn't work for them, ask how it may be explained in the future that will support them.

Communication



- Speak in concrete terms
- Emphasize key words
- Avoid lists of things to do
- Be sure the person is understanding
- Use open-ended & either/or questions
- Don't pretend to understand
- Let the person set the pace

For people with intellectual and developmental disabilities and their families

When talking with a person who has a developmental disability here are some things to consider

- Be specific or concrete. For example, please give me the red hat or do you want an apple instead of a banana
- Key words – if they are attending a meeting, or shopping at a store, what are the key words. Who or what are they looking for, how can I help you?
- Give directions one to three at a time, maybe they need a visual or picture to help them remember
- Ask the person to repeat it back to you. You may say, "I just want to make sure we are understanding each other, here is what I heard you say? ,is that correct?" If you are having difficulty understanding them, apologize and ask them to repeat it again, until you get it. If you are really struggling, you may ask if there is someone that they would invite into the conversation that could help you to understand.
- Avoid a NO or YES???? Give a choice of answers so the person knows what their

options are

- Understand that it may take time for them to think and get what you are sharing, give them time to think, then ask what they understand is the next step. Reassure them that it is okay to ask questions to clarify next steps.
- Important to remember that even if a person doesn't use words to share their ideas, this doesn't mean they can't understand your words. My friend Brian taught me this lesson. Brian used a smile, grimace, nod of his head, thumbs up or down, a wink of his eye, contagious laughter, a sigh and many other ways to let me know exactly what he was thinking. He was patient with me as I learned his language.

Communication



- Treat kids as kids, adults as adults, people as people
- Speak directly to a person
- Keep surroundings free from distractions
- Establish eye contact
- Speak expressively

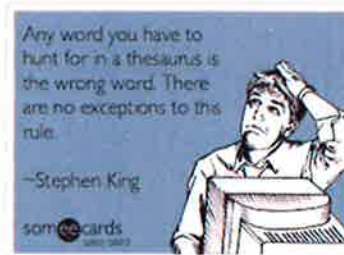
For people with intellectual and developmental disabilities and their families

1. Use proper names and avoid talking down.
2. Speak directly to the person, don't just talk to a person's parent OR the staff member who supports them.
3. Keep eye contact. If a longer conversation a quiet area may be better.
4. Establish eye contact before you begin speaking, this can be tricky in that some cultures establishing eye contact is not a norm. This is also true for some disabilities, you may have to ask what works best for the person for their comfort.
5. Use gestures to help support what you are talking about.

What is plain language?



- Communication that your audience or readers can understand the **first time** they hear or read it
- Also called Easy English, Easy to Read



For people with intellectual and developmental disabilities and their families

Plain Language has been around in the US since the 1940s.

In 1978 Jimmy Carter signed an executive order that each regulation is "written in plain English and understandable to those who must comply with it."

Most recently President [Barack Obama](#) signed the [Plain Writing Act of 2010](#), which required federal executive agencies to put all new and revised covered documents into plain language.

Goals of plain language



- Help people **find** the information
- Help people **understand** the information

If a document does not do both, it is not plain language



For people with intellectual and developmental disabilities and their families

The Goals of plain language are to

Help people **find** the information

Help people **understand** the information

These are important goals to consider when meeting a person with developmental disabilities for the first time and the use of plain language.

Remember...

1. You and the person with a disability are more alike than different...All people have hopes and dreams
2. Believe that you can communicate....Gesture, write a note, read body language
3. Honor each person....Respect and believe in their rights to a whole life
4. Be polite. Ask questions... They will answer if they choose

Main rules for plain language



- Fifth grade reading level (common, everyday words)
- Short sentences, short paragraphs
- Active voice
- Use "You" for the reader and "we" for the organization
- Use nouns instead of pronouns
- Lists and tables
- Limit acronyms
- Use headings
- Be specific

For people with intellectual and developmental disabilities and their families

When developing work documents here are some important considerations.

Write to a fifth grade reading level, in other words strive to use common everyday words. To determine the Reading level using Microsoft Word, go to the Review tab and then do a spelling and grammar check and at the end a box will pop up with Readability Statistics and at the bottom of the box there is the Flesch-Kincaid Grade Level. You may find that some technical terms, for example intellectual and developmental disability may increase the level.

-short Sentences: one subject per sentence, 5 words per sentence is ideal

-Short Paragraphs: one subject or step per paragraph

-Use an Active voice: active voice is clear, concise, and direct; passive voice is less clear- the person doing the action usually follows the verb for example: Bob was promoted by his boss.

-Use nouns. A noun names a person, place, thing or idea. For example, father, house, hat, and friendship. Avoid Pronouns, a pronoun is a word used to replace a noun, words like he, me, it and their.

-Lists: make it easy for the reader to identify all items or steps in a process, add blank space for easy reading, it is recommended to have seven items or less in a list

-Tables: using tables saves words, makes structure clear, makes it easy to take in complex materials at a glance

- Acronyms can be hard. Most people struggle to know what they mean, and many times will miss a lot of the conversation or instructions because they get lost in the acronyms.

- Use Headings: This allows the reader to quickly find information, headings also breaks up the information, increases blank space on the page, helps the reader navigate the document, There are three types of headings, question headings, statement headings, and topic headings.

- Question headings are the most useful, they can be written to your audience to help them find the information they need. "Where can I apply?"

- Next are statement headings because they are the next specific. "Applications accepted here."

- Topic headings are the most formal but tend to be vague and sometimes difficult to understand. Examples of this are "General", "Application"

-Be Specific: provide date, time, amount, size

Example of everyday words



- Anticipate
- Attempt
- Commence
- Demonstrate
- Implement
- In the event that
- Submit
- Terminate



- Expect
- Try
- Begin, start
- Show, prove
- Start
- If
- Send, give
- End, cancel

For people with intellectual and developmental disabilities and their families

Here are some examples of everyday words, the list on the right are plain language

Instead of Anticipate use Expect

Instead of commence use Begin or Start

Example Hidden Verbs



- Present a report
- Do an assessment
- Provide assistance
- Came to the conclusion of
- Give consideration to



- Report
- Assess
- Help
- Concluded
- Consider

For people with intellectual and developmental disabilities and their families

Here are examples of hidden verbs. You can change your writing to have less words, which is helpful.

If you compare the list on the left to the list on the right, you will see that the list of the right is shorter. When you are writing, see if you can use less words and still get across what you mean to communicate.

Basic Formatting Rules



- 14 point font minimum
- Sans serif fonts
 - ✓ Arial, Calibri, Tahoma
 - ✓ Not Batang, Times New Roman, Century
- Sentences/ideas not split over two pages
- Always use page number
- Use headings and sub-headings
- Double space and left align all text
- **Use bold for important words and phrases**

For people with intellectual and developmental disabilities and their families

Size of font can make a difference to the reader. Use 14 point font for body text, 16 point font for headings

-Fonts that work are sans serif which is plainer and holds up better when scanning and photocopying. Many individuals prefer the Arial font type

-Headings and sub-headings help break-up the information

-Double space and give wide margins

-Justify left helps, along with breaking up large paragraphs

- Use bold and not italic or underline because they are can be harder to read.

- Bold is easy to read. It helps people to find the important words or with sections.

Using images

- Avoid cartoons



- Include a description (if necessary) directly related to the material



For people with intellectual and developmental disabilities and their families

Cartoons are sometimes seen as being for children so avoid using cartoons if possible. If it is not clear why the picture is there, include a description. The picture should also represent the material.

In the example of the house, the house on the left is clearly a house. The house on the right is too dark and might look like an apartment building or hotel. A simple picture is best.

- If highlighting an area on an image, use a circle, not an arrow
- Do not use pictures that have glare

Accessible Meetings



- Use visuals (PowerPoint, pictures)
- Avoid big words and acronyms
- Take pauses, allow space for questions
- Breakdown complex topics
- Send agenda in advance of meeting
- Offer printed materials

For people with intellectual and developmental disabilities and their families

To make meetings accessible, use pictures and have a presentation if needed.

In the meeting do not use big words or any acronyms. During the meeting use breaks and pauses to allow everyone to have the time to understand what is being discussed and to figure out their questions.

Ask people if they have questions throughout the meeting.

You need to be prepared to break things down just in case someone doesn't understand.

It is helpful to have the agenda in advance of the meeting, ask the person how much time in advance of the meeting do they need it. Some people learn better with visuals so make sure there is a poster board or white board so if someone doesn't understand you can draw what you are saying.

If you have any materials you will be talking about, offer printed copies.

For PowerPoints, print the note pages if they would be helpful to explain the presentation, make sure the notes are in plain language.

If printing just the slides, print two to a page, then the font size will be large enough.

Face to face for the first time?



- Do not assume
- Do not generalize
- Avoid being overprotective or over helpful
- Assist if there is a potential danger
- Be YOURSELF

For people with intellectual and developmental disabilities and their families

- Do not make up your mind about persons with developmental disabilities in advance and set aside past experiences –ask the person what works for them

OR if a child ASK the parent what will work for the child.

Some adults with disabilities may be difficult to understand with their speech, if there is someone who supports them with communication, ask for their help to understand.

- Each person with disability is uniquely different. For example – No two people with Down Syndrome are the same
- Ask if they need or want help. Avoid pity.
- Ask them or their caregiver or parent what is it that they want their child to learn, how you can assist them
- Be Yourself...This means talking, laughing, and giving positive and negative feedback just as you would with anyone else, consider how you want to be treated with value and respect

Making adaptations



- Adapt only when necessary
- View adaptations as temporary
- Adapt on an individual basis
- Adapt for modification

For people with intellectual and developmental disabilities and their families

When should a you make adaptations?

If someone requests an adaptation and it is easy to make, do so.

One thing to consider with adaptations is about Sensory integration.

Kids and adults with intellectual and developmental disabilities and autism may have sensory challenges. As with all of us, our ability to concentrate can be impacted by what goes on around us, be sensitive to understanding that of others.

How many senses do we have?

There Are More than 5 Senses...

Most people are familiar with five senses – sight, hearing, smell, taste, and touch. However, we also receive input through two additional senses:

The **vestibular sense**, or movement and balance sense, gives us information about where our head and body are in space. It allows us to stay up right while we sit, stand, and walk.

Proprioception, or body awareness sense, tells us where our body parts are relative to each other. It also gives us information about how much force to use in certain activities, allowing us to crack open an egg without crushing it in our hands.

Most activities require us to combine information from many different senses at the same time.

Think about a toddler they use touch to explore the texture of their food.

Proprioception or that body awareness brings the food to their mouth, smell and taste to identify different types of food, and the vestibular sense to sit upright during the meal.

As children grow, they learn how to take in and process all this information at the same time, and focus their attention on particular sensations while ignoring others.

Some children and adults have difficulties receiving and processing incoming sensations, making everyday tasks frustrating.

You may have to ask if there is something that is needed to support the person to eliminate something that is frustrating for them. For example, a particular smell of perfume or soap maybe the cause, being in a room with florescent lights, being in a room where there is a lot of noise are examples.

Environmental supports



- Event structures
- Predictable routines
- Visual supports
- Picture schedules

For people with intellectual and developmental disabilities and their families

Ask the question. What kinds of environmental supports already exist for person with developmental disabilities?

When thinking about the office or store where you work, a location in the community where you are meeting with a person with a developmental disability.

- Make sure the place is accessible to the person, if they use a wheelchair are the doors, hallways, and meeting space able to allow for them to move easily around the space. Are there accessible bathrooms available for their use.
- Post signs and charts, or provide easily understandable directions to assist person with disabilities with getting around your office, store or meeting space OR ask them if you can walk with them to show them the way to the meeting space or bathrooms
- You may want to ask the person what type of supports are needed. Some people with physical limitations will have a family member or a personal care attendant or staff available to help with their needs. If they don't you can ask how it is that you can support them. This may be a good conversation to have in an area that allows for some privacy. Ask if they would like to move out of a heavy trafficked area to share with you how best to support them.

- If you have questions regarding a request about how to support them and whether this is something that falls into your responsibilities, check with your supervisor.

For example, I was presenting with Mary who uses a wheelchair. Before the presentation we took the time to make sure the room with the table set up was easy for her to maneuver. This was important so that she could engage the audience in the training.

Transitions

- Be patient about questioning
- Forewarn
- Explain plans for the day
- Allow time for transition
- Give warnings before changing activities

For people with intellectual and developmental disabilities and their families

All of us are sensitive to transitions in our daily lives. For some people with intellectual and developmental disabilities they may need more time to transition. They may be slow to adapt.

They may hate surprises and may find it challenging to shift from one thing to another; transitions or changes are stressful. They will need to know what to expect, because the unknown can cause stress for them.

- Be patient with all their questions about what will happen-They are trying to be comfortable with the situation and seek clarification.
- Forewarn– let the person know what’s going to happen. For example, you may want to find time prior to the meeting to go over the agenda to let them know the timeline for each of the topic areas OR you may want to start your meetings with going through the agenda to highlight what will be discussed and how much time you anticipate spending in each of the areas.
- Explain plans for the meeting they are attending, their work day- this provides structure for the person and helps them know what to expect so there are no

surprises.

- Allow time for transition-transition can be stressful and they may be slow to adjust
- If this applies to your particular circumstance, you may want to give alerts before changing activities-For example, we have 10 minutes before a break, 5 minutes before a break, take 2 minutes to wrap up and now it is time for a break. Use this time to make a phone call, use the bathroom and we will begin again at 1pm.

Tips for success



- Focus on the person
- Be patient; take your time
- Be aware of the surroundings
- Ask what form of communication works best
- If the person uses a wheelchair, ask how you can help
- Accessible materials & plain language

For people with intellectual and developmental disabilities and their families

Tips for Success

- Concentrate on the person, find out as you would with anyone, what works best for them.
- If you do not understand something, ask the person to repeat what he or she said and then repeat it back to them
- Be patient; take as much time as necessary to communicate effectively.
- Avoid communication in noisy, public places. Talk in a private, quiet area when possible, particularly when discussing things that apply only to the person.
- Do not speak for the person or attempt to finish their sentences.
- If you are having difficulty understanding what a person is saying, consider writing or electronic mail as an alternative means of communicating.
- Offer to help (opening a door, carrying packages) if it makes sense. Ask yourself, "Would I want help in a similar situation?"

- Consider a person's wheelchair or walker as an extension of their body. Therefore, leaning on the wheelchair or walker, or placing your foot on a wheel, is not okay.
- Talk to a person who uses a wheelchair at eye-level whenever possible. Perhaps you can sit rather than stand
- Select materials early so that they can be developed into accessible and plain language formats in a timely manner. Using materials which are available in electronic format is a good step toward accessibility



Additional Resources

- **The Arc Guide - [Who We Serve – Individuals with Intellectual and Developmental Disabilities \(I/DD\)](#)**
- [Employing People with Disabilities: Disability Awareness](#)
- [Employing People with Disabilities: Myths, Realities and Job Accommodations](#)
- [Employing People with Disabilities: Workplace Culture](#)
- **Examples of People First Language by Kathie Snow**

For people with intellectual and developmental disabilities and their families

These handouts are additional resources that can support you in your work with The Arc.

Please go to the Survey located below the Online training to take the evaluation.

1. Name one characteristic of a person with an intellectual and developmental disability.
2. Which of the following will you see in a welcoming place? (check all that apply)
 - a. People say “hi” to you
 - b. People engage you in conversations
 - c. People invite you to join them
 - d. People recognize when you are absent
3. What are important things to remember when talking with a person with a disability? (check all that apply)
 - a. Speak directly to the person
 - b. Keep eye contact
 - c. Talk with the parent or staff person instead of the person with a disability
 - d. Avoid talking down to them.
 - e. Give directions 1 to 3 at a time

4. What is the goal of plain language? (check all that apply)
 - a. To write simply
 - b. Help people to find information
 - c. Help people to understand the information
5. What will make your meeting accessible? (check all that apply)
 - a. Avoid using acronyms
 - b. Allow for pauses in meetings for people to understand and figure out their questions
 - c. Serve treats
 - d. Provide the agenda in advance
 - e. Use pictures or visuals
6. We welcome your comments of what you liked and ways we can improve.



**If you would like additional
resources or have additional
questions, please speak with
your supervisor**

The Arc (952) 920-0855
www.arcminnesota.org

For people with intellectual and developmental disabilities and their families

www.minnesotahelp.infoTM

Online directory of human services | information & referral

Disability Linkage LineTM

(866) 333-2466

Disability related information & referrals