



Green Mountain Self-Advocates

www.gmsavt.org

- Bringing The Voices Of People With Intellectual And Developmental Disabilities Into Our Conversation
- Presume Competence
- What Is Meant By Intellectual Ability
- Barriers People Face Accessing Services And Supports
- Brief Introduction To Strategies To Promote Supportive Decision, Making With The Goal Of Maximizing Self-determination
- Making Information More Accessible To People With Intellectual Disabilities

Look Through Our Eyes



Green Mountain Self-Advocates has 21 local groups throughout Vermont. We have over 600 members who have an intellectual and developmental disabilities. We have been collecting stories and comments from our members, examples of the attitudes and actions that people with disabilities face every day.

We are going to share some comments we have heard. If we were together, face-to-face we would be passing around a backpack loaded with rocks. We typically write a comment on a piece of paper and attach it to a rock. Each rock in the backpack has a story on it. We pass the bag around the room. Each person takes out a rock and reads what it says aloud.

Look Through Our Eyes

- What if when someone asked you a question, and while you are thinking of your answer, somebody decided for you?
- What if you were 54 years old and you were told when to go to bed?
- What if someone said you could not have sex or even hold hands with the person you love?
- What if people talk or write things about you behind your back?
- What if at lunch you were told to eat your vegetables even though you didn't like them?
- What if one day you had to clean your room before you could go see a movie?
- What if you made an embarrassing mistake and everybody where you work and live, including your family knows it?
- What if people tried to run your life instead of letting you make choices?
- I stutter...and people just answer for me. I just need time to answer.



Look Through Our Eyes



- What if you made an embarrassing mistake and everybody where you work and live, including your family knows it?
- What if when you show your emotions or tell people how you feel you get more meds?
- What if there are team meetings about your life but you never get to invite who you want to be there?
- What if you were constantly judged because of something you did in the past?
- What if you had a disability and you heard people use the word “retarded” all the time?
- What would you do if people took your things (your computer, your phone, your ipod) away from you when you make a mistake?
- What if people tried to run your life instead of letting you make choices?
- They told me I could never go to college. Why not? I have dreams too.

Look Through Our Eyes

- What if you were told you could never be your own guardian?
- What if you were told you could not have pets?
- What would you do if people said you are not allowed to go to a bar?
- What would you say if people said you could never have children?
- I was right in the room when everyone was making decisions about my life.
- Even if an activity is fun, that doesn't mean I want to go do it every day.
- My disability causes my hands to be twisted. But I still want to write things down on paper or handle my own money. I just need extra time to do this but everyone grabs things from my hands and does it for me.
- I have another new case manager. They were hired before I even met them. They got to look at my whole life and no one even asked me about this person.
- I have my own way of doing things. So why do people tell me to do things their way?



Look Through Our Eyes

- I have my own way of doing things. So why do people tell me to do things their way?
- I know my support staff has been doing this for 15 years, but that doesn't mean there's nothing more for them to learn.
- I've made mistakes in the past, it is true. And I have learned some things from my mistakes. But I never get another chance.
- I want to see my girlfriend on Friday night but no one will take me. Why do I only get to spend time with them during the week at public places like bingo?
- They took my kids away because they said I had a disability and I wasn't able to raise them.
- Whispering about me...I can still hear you, whether or not I am able to tell you with words.
- People care about me and want to protect me. And I appreciate that, but I don't want to be protected from living my life.

Look Through Our Eyes – Debrief Questions

Sometimes people say that having a disability is a burden.

But we encourage people to be proud of who they are and that includes having a disability.

The real burden is the attitudes, words and actions of others.

That is what weighs us down.

Any thoughts about what you heard?



What We Mean By Intellectual Ability



We are basically talking about people using their brains to:

- Learn
- Remember
- Put things in order
- Make a plan
- Set priorities
- Solve problems
- Focus or keep attention on something
- Shift attention to something else if needed
- Understand and use language
- Do math
- Deal with information gathered by the five senses
- Find a word
- Make a decision
- Pick up on social cues and respond accordingly

The general measure of intellectual ability is a person's ability to use these various functions to live successfully.

Three types of intellectual abilities are described in the following slides:
1. Autism 2. Learning Disability 3. Intellectual Disability

Autism

- Each person experiences autism in different ways and at different intensities. It depends on the person, but he or she may:
- Find it hard to look at a situation from another person's perspective • Have trouble speaking • Avoid eye contact • Have special interests that capture their attention. This intense focus on one topic or "love of routines" may make it difficult to change gears and move on to do something else. • Need support to organize their day and write things down • Have no real fear of danger • Have difficulty reading facial expressions • Not understand how to follow pointing or gestures • Be frightened by certain sounds or the way things look. We end this section on autism with a vivid description written by a person with autism describing why some people with autism may suddenly express a burst of energy.

After a busy day at work and being around people, my brain needs a moment to release energy that builds during the day. I call it an energy release, shaking the energy out of me. I need a break from the real world, into my own world.

Learning Disability

- Learning disabilities can be explained as a “short-circuit” in one of several parts of the brain. This can disrupt the way the brain gets information, makes sense of it, stores it and comes up with a response. As in people with autism, there are great differences in how a person may experience a learning disability. Here is a list of things that may be difficult for people with learning disabilities to do:
- Reading and writing (words may blur or move around the page) •
Listening to a lot of information • Doing math • Remembering what someone said • Following many directions • Staying focused when there are distracting noises • Evaluating different options before making a decision • Giving directions or recalling what happened in accurate order •
Listening without becoming distracted • Paying attention to details •
Completing a task quickly in the time they are given

Intellectual Disability

The older term for intellectual disability used by some doctors and professionals is “mental retardation.” We are pleased to report that there has been a thriving campaign across the country to change the name. What is all this fuss about changing the name?

For generations, people with developmental and intellectual disabilities have been labeled “mentally retarded. This term is frequently used as an insult and many call it hate speech. Advocates have been organizing campaigns to “spread the word to end the word.” They believe that the only “R” word people with developmental disabilities deserve is respect.

Here is a list of the most common qualities that are associated with having an intellectual disability. A person may:

- Take extra time to learn, think and solve problems
- Need assistance to read, write, tell time and change money
- Require support remembering what to do on the job or during daily routines at home
- Be easily influenced to do or say something
- Need support to communicate
- Prefer information based on concrete examples
- Have less opportunities to be physically active and tend to have poor muscle tone and balance
- Be isolated and need support to make friends
- Have difficulty finding the right words
- Require assistance to weigh options when making decisions
- Appreciate a relaxed pace to keep up with tasks or conversations
- Need help keeping appointments

Presume Competence

**WHEN YOU SEE,
MEET, OR THINK
ABOUT A PERSON
WITH A DISABILITY
PRESUME
COMPETENCE**

Presume Competence

A really important concern while interacting with persons with disabilities is what we call “presuming competence.” You might think a person can’t do things, but do not assume that. This is important because while persons with disabilities need support at times, they want to have the opportunity to accomplish things in their lives. Everybody wants to feel confident when it comes to solving problems.

For example, it may be easy for someone to assume that people who have limited speech don’t put much thought into the world. But using other ways to communicate, such as typing can bust that myth. That person may appear to not understand by first impression when in reality; they are expressing themselves in a different way.

Presume Competence

Keep this in mind when you interact with persons with disabilities. When it comes to intelligence, everybody is in their own way. One reason people with disabilities are not included is because people make false assumptions about their abilities to learn and grow. The question is no longer who can be included or who can learn, but how can we achieve inclusive communities. We begin by presuming competence.

“If you want to see competence, it helps if you look for it.”

–Douglas Biklen

Comments by Kyle Moriarty

I would say that having people see me as smart is hugely important and works to calm my anxiety. I feel that if you are treated as a person with intelligence you are hope magnified and you will respond in positive ways. I know that being treated like I was unintelligent or illogical was not helpful and caused me a great deal of anxiety. That didn't work!

I want you to know that I am intelligent and have something to say but I was not able to let people know until I was introduced to typing, Facilitated Communication (FC). Erratic times before typing my thoughts, I was seen as not literate, not very likely to be included in regular classes or go to college. Without FC I was expected to rely on broken, habitual speech that was not relevant to anything I really wanted to say. It made me feel like I was not smart. I dealt with a lot of anxiety. Many years past with me taking in information and not being able to share what I knew. I could think and read but no one understood that.

The point here is to label jars not people and to believe in the intelligence. My friend, Tracy Thresher, tells us to presume competence and not limit children to life without hope or purpose. I want more than anything to support others to go with a voice. In having a voice they are able to have a future. Please understand we are all individuals and each one has needs that are as individual as we each are. We need to have options to fit our needs not the other way around.

Story by Tracy Thresher

I am Tracy Thresher. I have been using Facilitated Communication (FC) and having a voice since 1990. Not being able to express myself was like being in a world of silence. I couldn't tell people what I liked and didn't like. People thought that I didn't understand what was being said to me. It was frustrating and made me angry and I withdrew.

The experience of the world looks different from my experience. Most people take their ability to talk for granted and I take my inability to talk quite seriously. I live with it every day – it is always there each time someone wants to read my thoughts.

The impact of learning to speak up and have a voice has been quite meaningful for me. I have typed life goals and dreams that have actually come true. This would never have happened without FC.

Hope is essential for dealing out success. When I first met Kyle I felt his despair and anguish with time lost - he did not have hope. He came to a FC workshop I was helping to teach. Kyle could not enter the room that first day and stayed downstairs the whole time. On the next workshop he came in the room but stood in the back the whole time and on the third day he sat with his team.

The next year Kyle hit the road running. Thoughts that had been trapped inside for years had a place to go. Letting out lost thoughts is moving out of despair into life and fulfilling life's hope. With a strong voice you can move from anguish and lost time darkness into a world of fun and life.



Tips For Presuming Competence

- Always ask before giving assistance and let the person tell you what you may do to be helpful.
- Treat adults as adults. Use a typical tone of voice, just as if speaking with a friend or co-worker.
- In general do not assume a person can't read, but also don't assume they can.
- Speak to the person directly, not the support person or companion.
- Don't assume a person who has limited or no speech cannot understand what is being said. People usually understand more than they can express.
- Never pretend you understand what is said when you don't! Ask the person to tell you again what was said. Repeat what you understand.
- Do not try to finish a person's sentence, or cut them off. Listen until they have finished talking, even if you think you know what they might say.

Tips For Presuming Competence

- You might not be able to see someone's disability. There are many disabilities that are hidden within a person.
- Avoid using stereotypes in your thinking. We all have different personalities and our own ways of doing things. To find out what a person prefers, ask them directly.
- Offer compliments but avoid giving a lot of praise when people with disabilities do typical things.
- Most people with disabilities want to help others, as well as be supported, and enjoy making a difference in someone's life.
- Look for something that indicates a person understands. Respond to any attempt the person makes to communicate.
- Avoid speaking for others. Encourage a person to speak on their own behalf. If you must restate something, be careful not to change the meaning.

Tips For Presuming Competence

- Because some people like to please others, it is important to be mindful of your body language, tone of voice, and other gestures that may influence a person's decision.
- Have your support of the person be low-key, almost “invisible” to others. Don't “over-support.”
- Let a person make their own decisions. Don't take over and make decisions for them. It can be difficult for some of us to make quick decisions. Be patient and allow the person to take their time.
- Focus on what a person can do. All people want a chance to live a typical life, just like everyone else.
- Find ways to include a person in a conversation. Do not talk about the person to others as if they're not there.

What Are The Barriers People Face Accessing Services?

- Socially Isolated
- Mental Age Trap: “Mental Age” is an outdated concept sometimes used to describe people with intellectual disabilities. Avoid using this concept. An adult with an IQ of 60 may read or do math on a third grade level, but she does not have the emotions and feelings of an 8-year-old.
- Lack of Privacy
- “Low Expectation Syndrome”
- Being on time because people rely on public transportation or support workers who may not show up on time.
- Having multiple disabilities that get in the way
- “Frustration can get in my way because I keep trying and nothing happens”
- “Having to fight for education”
- “Learning new skills takes me awhile if they want me to work”

What are the Barriers people face accessing services?

- “When I have seizures it affects my ability to remember things and I am confused”
- “My parents do not want me to work and be independent. But I try hard to prove myself everyday to the world.”
- “Myself, I like to procrastinate”
- “People look at my disability and don’t give me a chance.”
- Type of Disability
- A person’s payee for their social security/benefit checks
- Higher risk to abuse and being a victim of a crime
- Not allowed to make any mistakes
- May not seek out information or emotional support because they fear mandatory reporting

What are the Barriers people face accessing services?

- Many people require clear, concrete information talked about often so they learn.
- Many folks live where there are a lot of rules. They have few opportunities for social interaction. So their ability to observe, develop and practice social skills is limited.
- People with limited reading skills cannot get information from books or the internet.
- Many people with disabilities lack close friends, or the friends they have may not be reliable sources of good information.
- Many learn to be submissive and do what is asked in order to please others.
- Some are physically dependent on others in such private areas as dressing, toileting, and bathing.

Strategies To Promote Supportive Decision

There are different types of questions you may get asked. These are:

- **Information Questions:** Keep it simple. Give information that answers the question and is useful to the person.
- **How Do Questions:** Usually questions that start with "how do" are ones that you can give information, but it's good to get them involved right away.
- **What do you think Questions (asking for advice):** They are seeking out your opinions or values. It can be easy to answer this, but this doesn't help them. We need to help them figure out what they think by asking questions or giving them some information.
- **Personal Questions:** It may be a way to get to know you better, but more likely it's to find out if their concerns are typical. It is okay to give general comments, but it is important not to answer personal questions when you are a staff person because it doesn't matter what you did or what you would do. It is about helping them, not telling your stories



Step One - Give positive messages

No matter what kind of question you get, it's important to let them know that the question is a good question. You can do this by saying "good question" or by smiling and nodding your head at the person. This gives the message that they deserve information and that asking questions is okay to do.

Step Two – Give correct information AND get them involved. You could just give them correct information, but that can sometimes end the conversation. Getting them involved by asking the person questions helps you find out what they know and what they want to know about. For example ask:

- What have you heard?
- What is important to you?
- What do you think helps?
- What has worked for you before?
- What do you think you'd like to do?
- It sounds like you want to ... Do you have some ideas about how to do that?
- What parts do you think you will do well or not so well?



KEEP IT CLEAR

KEEP IT SIMPLE

Step Three - Find out if they have other questions ASK Am I making sense? Do you have other questions?

What suggestions do you have for making meetings more understandable?



- Do introductions to remind folks who is there. Introductions make people feel “not left out.”
- Let folks know where things are, like the restrooms.
- Speak clearly. Use words that everyone understands, no abbreviations.
- Stop frequently. Clearly outline each issue as it comes up for discussion.
- Summarize what has been said. Make sure everyone understands what is going on.
- Have people raise hands and one person speaks at a time.
- Use People First Language..

What suggestions do you have for making meetings more understandable?



- Provide time to ask questions. Give a person a chance to explain things.
- Take short, frequent breaks. A 7-minute break each hour works better than 15-minutes after two hours. If you sit too long, your attention goes down.
- Let the person set the pace in talking. Be patient for a response.
- Keep confidentiality.
- Help folks understand a complex idea by breaking it down into smaller parts.
- Avoid abstract concepts (references to time, dates, sequences or reasons). Use visual or concrete examples. Try to connect an issue to a personal experience. Avoid the use of numerical or quantitative concepts.

What suggestions do you have for making meetings more understandable?



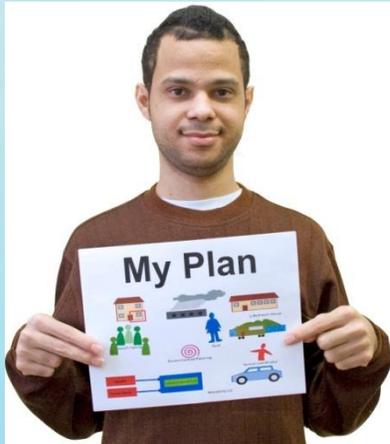
- If any written information was not sent out ahead of time, read it aloud at the meeting.
- Encourage people to speak on their own behalf, to make their own decisions to disagree, to do things on their own, and in their own ways.
- Be mindful of your body language, tone of voice, and other gestures that may influence a person's decision.
- Ask the person if they have anything to say about a specific issue.
- It is especially important to have a short break just before a final decision is made to allow time for people to review the issue before making a decision.
- Restate clearly each decision that is made.

How can we make written information easier to understand?



- Use a clear font like Arial or Verdana. Fancy type is harder to read. Do not use handwriting or fonts that look like handwriting.
- Use a font size of 14 point or larger. People with visual impairments may need it even larger.
- Do not write in all capitals. People who have difficulty reading may think the capital indicates a new word.
- Use the left-aligned option and keep the right side unjustified (the right edge is ragged). It is harder to read right-justified text because the spacing is uneven and it may split words to another line.
- Do not split words with a hyphen at the end of a line. This makes the word harder to read. Some people will pause at the end of the line and treat the next line as a new sentence.

How can we make written information easier to understand?



- Keep sentences short. Consider breaking long sentences into two.
- Do not let sentences go onto the next page. Remembering the information already read while turning the page may be difficult.
- Use bold for important information. Italics or underlining make it harder to read.
- Use clear headings, left-aligned to separate short chunks of text. Headings will help people keep or find their place.
- Use thick paper and consider printing on matte vs. glossy finish paperstock. Thick paper will not show the information on the other side as much. Glossy paper will make the colors more vibrant, but matte paper can cut down on glare. This goes for laminated information, too.

How can we make written information easier to understand?



- Use good contrast between paper and print. Avoid using light colored print
- or dark colored paper. This will make it difficult for people with vision problems.
- Black and white is best.
- Double-space writing. This makes the information stand out.
- Have white space between paragraphs or chunks of information. This will set important information apart.
- Use the same layout throughout the whole document. The format becomes predictable and easier to read.
- Do not have text go over pictures or other images. This is harder to read and becomes confusing.

When planning a meeting what are some of the steps you go through to plan an accessible meeting?

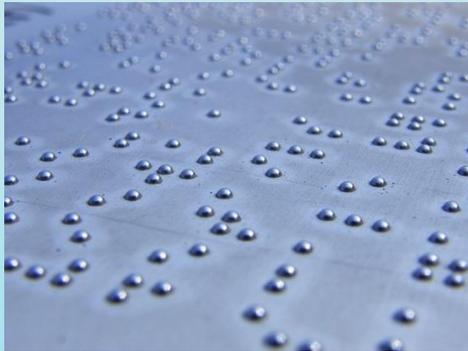
Meeting on a Level Playing Field

Accessible Meeting Location:



- Seating Locations: Set up the meeting room to provide access to all participant seating location, the speakers' area and refreshments.
- Registration Table : Make sure that people with mobility disabilities can approach it and turn around easily to move away again.
- Refreshment Table: Arrange items for people who have limited hand mobility
- One element of a barrier-free meeting space is to make sure protruding objects can be detected by a cane.
- Arrange seating to optimize communication
- Make sure people understand the role of service animals

We have some tools we recommend that give us the details of crating alternative formats and setting up accessible meetings?



A great resource for setting up meetings is a publication called Meeting on a Level Playing Field

<http://www.ada.gov/business/accessiblemtg.pdf>

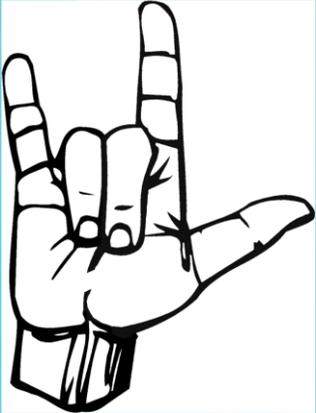
Another great resource for understanding alternative formats and assistive devices is National ADA Center Fact Sheet On EFFECTIVE COMMUNICATION.

<http://adata.org/factsheets/national/en/National%20ADA%20Center%20Fact%20Sheet%20%20EFFECTIVE%20COMMUNICATION.pdf>

There have been changes to the ADA on providing appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities.

Examples of common auxiliary aids and services include:

- qualified sign language interpreters in person or through video remote services;
- note takers;
- real-time computer-aided transcription services;
- written materials;
- exchange of written notes;
- telephone handset amplifiers;
- assistive listening devices and systems;
- telephones compatible with hearing aids;
- closed caption decoders;
- videotext displays; qualified readers;
- taped texts;



There have been changes to the ADA on providing appropriate auxiliary aids and services where necessary to ensure effective communication with individuals with disabilities.

Examples of common auxiliary aids and services include:

- audio recordings;
- Brailled materials and displays;
- screen reader software;
- magnification software;
- optical readers;
- secondary auditory programs (SAP);
- large print materials;
- accessible electronic and information technology
- open and closed captioning, including real-time captioning; voice, text, and video-based telecommunications products and systems, including text telephones (TTYs), videophones, and captioned telephones or equally effective telecommunications devices

