Getting Your Message Across

Communicating With People Who Have Intellectual Disabilities

Acknowledgements

This manual is dedicated to Deborah Lisi-Baker, Pam Putnam and people with intellectual disabilities who survive sexual violence, many times on their own. Deborah is our mentor with a determined voice speaking truth to power. Our words are also written to honor the memory of Pam Putnam, a self-advocate and survivor whose leadership directed Green Mountain Self-Advocates (GMSA) to address sexual violence.

Our goal is for teams of consultants with and without intellectual disabilities to work together using this manual to provide technical assistance on cognitive accessibility. GMSA adapted information from the following resources to create this technical assistance manual:

1. Changing Attitudes: www.selfadvocacy.org/toolsforchange/attitudes
2. Guidelines For Creating Understandable Information: www.govoter.org
3. Understanding and Addressing Disability: www.accessingsafety.org

Major contributions to the writing of this manual were made by Karen Topper and Karen Noone.   Additional contributions were made by Skye Peebles, Lindsey Hescock, Nicole Leblanc and Stirling Peebles.   We are grateful for the stimulating discussions, comments and support from the Vermont Center for Independent Living, Vermont Department of Aging and Independent Living and Vermont Network Against Domestic and Sexual Violence.

 The information in this manual was written as guidance and is not to be used to determine an organization's legal rights and responsibilities under Section 504 of the Rehabilitation Act of 1973, as amended; the Americans with Disability Act of 1990, as amended or any other federal, state or local laws written to protect the rights of people with disabilities.

People who do not use conventional print may access this manual by contacting GMSA.

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Table of Contents

How to Use this Manual

This manual is a reference guide on cognitive accessibility. The goal is for state and local self-advocacy groups to build genuine partnerships with advocacy and provider organizations, such as domestic and sexual violence programs. People with developmental disabilities will work together as equals with people who do not have disabilities to build collaborative relationships. These relationships will be based on understanding, trust and respect. Together we will improve services and support for people with developmental disabilities.

1 - 2 - 3 ... GO!

This manual has areas of focus. The first part of the manual describes everyday misconceptions about disability and explores a new definition of disability. We recommend you read this section to understand self-advocacy as a civil rights movement.

The next piece uses this new definition of disability to define how an environment can enable people to function better—or hold them back. We define these environments and describe how to adapt them to minimize the experience of disability.

The final section of the manual includes the checklists and handouts we use throughout the manual for easy reference. We encourage you to find ways of continuing to use these long after you first discover this manual.

We have tried to write this manual in Plain English as a resource for consultants with a variety of learning styles. Note that throughout the document, we chose to alternate between using he/she and his/her pronouns. Although most survivors are female, men are survivors, too.

There are several reasons to use this manual, depending on who you are.

If you are building collaboration between organizations… recognize that building collaborative relationships takes time, communication, and staying power. We recommend that you establish a regular time to meet once a month for the first 6 months. Be prepared to:

- Give equal time for each group to speak at every meeting

- Establish group agreements

- Talk about what your organizations do

- Review portions of information from this manual at every meeting

- Set aside informal time before or after the meeting for people to share a meal and explore opportunities to work together on a project or event

- Share organizational goals

- Create a formal agreement on how to share information and work together over time

If you are a disability advocate, this manual will help you provide technical assistance on cognitive accessibility. In the spirit of "nothing about us without us," people with developmental disabilities are taking a leadership role in educating people without disabilities.

Activities, stories, and other teaching tools are included throughout the manual. Placing these within each section makes it easier for people with a variety of abilities to use the manual when providing technical assistance.

If you are using this manual to answer a specific question, we celebrate your interest in expanding how you welcome and include People with developmental disabilities! Your openness sets you apart as someone who is willing to listen to people who are not always heard.

By skipping over the activities, stories, etc., you will be able to go through the section headings to easily find the topic you're looking for. You can also look at the collection of checklists at the back.

𝄃𝄃 Activity: Establishing Group Agreements

Time: 5 minutes

Establishing a collaboration that is safe and fair for all typically begins by making group agreements. These aren't "rules;" these are "agreements." All are agreeing to these ideas. Here are our suggested group agreements:

- Keep it confidential. Personal stories stay in the room.

- It is okay to feel whatever you feel: embarrassed, shy, etc.

- Respect. We don't all have to agree, but
  we do need to respect each other.

- All questions are good questions.
  We all have different experiences.
  Support each other to ask what you want to know.

- Talking about our jobs can be fun, but it also can be tough work!
  We agree to do our best to listen, to share and to be respectful.
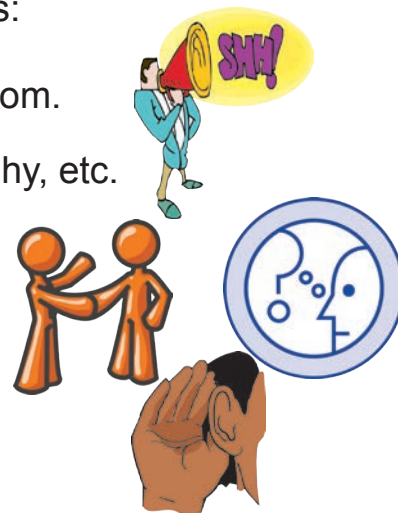
We invite you to add anything that will help build a positive working relationship. But most importantly we ask,

"Can we all agree to these group agreements?"

Take a moment to introduce yourself.

Listen and Share

- When it's your turn, please say your name.

- Tell us one thing you remember from your first day on the job.

- Tell us how or why you got involved in this organization.

If there is time, invite folks to describe a time that they worked with a person with a disability. Share a positive outcome and maybe something you would do different next time.

Purpose of this Manual

Office on Violence Against Women (OVW) Grant

In 2006, the Vermont Network Against Domestic and Sexual Violence (the Network) was awarded a grant by the Office on Violence Against Women (OVW). The purpose of the grant is to bring together Network programs and disability organizations to improve support for people with disabilities who have experienced domestic and sexual violence. The goal is not to "fix" one organization or the other, but to work together. We are sharing information and skills so all can provide a better response. The end goals are:
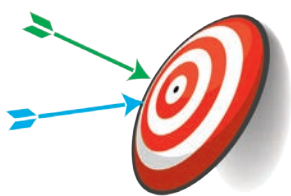
- Disability providers and advocates get better at recognizing and responding to sexual violence

and

- Network programs refine their accessibility

Understanding Needs of Victims and Survivors with Disabilities

We began by conducting a Needs Assessment, talking to advocates, providers and people with disabilities. They described how people face many barriers to disclosing and receiving support after experiencing violence. Sometimes a person was sexually assaulted when they were breaking "rules" set by "their" team.

FEAR

Maybe the person was using substances or out after curfew. Perhaps they were hanging out with someone considered unsafe or in a prohibited place in town. Fear of getting in trouble can prevent a person from reporting abuse.

Some people with developmental disabilities said that they were concerned about their personal information getting out to the community or to other people at an agency. Others voiced concerns about not being able to make decisions when it came to having a relationship. Many said they lacked information about sexuality. Several people experienced being judged, not believed, or feeling afraid of potential "backlash" when reports were made to police or Adult Protective Services.

The bottom line is that people with developmental disabilities need and want the respectful and responsive services provided by the Network programs. A typical person who receives long-term disability services will most likely have hundreds of staff supporting them in their lifetime. However many support staff do not receive training on how to provide trauma sensitive services. This contributes to an overall environment in which a person is afraid to disclose sexual violence.

We need the Network advocates to do exactly what they do best. We need their trauma sensitive approach and knowledge of how to survive domestic and sexual violence.

Our Manual

This manual includes suggestions on how to provide support in a way that most people with a developmental disability can understand. However, before we get into specific suggestions we will begin with a brief history of society's viewpoint of disability.

This will shed some light on what has influenced the attitudes of providers over time and why advocates have pushed for change. We also feel it is helpful to describe some common characteristics experienced by people with developmental disabilities. We will rely as much as possible on stories written by people with disabilities to describe these characteristics.

Understanding Disability

Let's begin by describing self-advocacy. Self-advocacy is the civil rights movement for people with intellectual and developmental disabilities. In Vermont, it refers to people with developmental disabilities in partnership with allies, families and friends:

- Speaking-up

- Becoming leaders

- Working together

- Making a difference on issues that are important to them

Vermonters with developmental disabilities are often some of the most powerless members of our communities. They are more at risk of abuse because they are socially and physically isolated. Studies consistently show people with developmental disabilities are more likely to experience sexual abuse than people without disabilities.

The self-advocacy movement seeks to reduce the isolation of people with developmental disabilities by providing opportunities to speak up.

What is an "Ally"?

An ally is a person who does not have an intellectual disability and supports the self-advocacy movement.

Increasing a person's advocacy skills often results in greater control over one's life. There is still a wide gap between the self-advocacy movement and many other civil rights efforts, such as those related to race, gender, or physical disability. This is due to many factors such as difficulties with reading and communicating, combined with other challenges faced by people with developmental disabilities.

Green Mountain Self-Advocates

Green Mountain Self-Advocates (GMSA) is Vermont's self-advocacy network run and operated by people with intellectual and developmental disabilities. We support over 600 members who belong to 18 local self-advocacy groups. Together we work to change attitudes that hold people back from achieving their dreams. Our goal is for people with developmental disabilities to make their own decisions and speak for themselves. We are building a movement for self-advocacy through public education and awareness, peer mentoring, support, advocacy, and direct action.

Myths About Disability

Question: What do members of GMSA say is the most frustrating?

❒ **A:** Attitudes and myths about who I am and what I can do

❒ **B:** Barriers in the environment

❒ **C:** Everyday hassles

❒ **D:** Actually nothing, I am accepted and fit in just fine

The answer is **A**. The attitudes and myths about people with developmental disabilities are strong.

Answer:

✓ A: **Attitudes and myths about who I am and what I can do**

What are some of these myths? People with developmental disabilities:

- Cannot work or live on their own

- Are not sexual beings

- Are innocent, childlike and need protection

- Are not responsible

- Cannot solve problems or learn from mistakes

- Are unable to make good decisions

- Are not good parents and, therefore, should not be sexually active

As someone who wants to support people with developmental disabilities, it is good to know what these myths are, how you feel about them, and what messages you want to give to your co-workers and to the wider community.

The first step to being a "myth buster" is to start noticing these false assumptions. We recommend that becoming an ally begins with training ourselves to see and hear the attitudes and myths all around us. Once we catch a glimpse of these myths, we can work against them.

Here are three common viewpoints of disability: moral, medical/professional, and the World Health Organization definition. These viewpoints are described on the following pages.

Moral Viewpoint of Disability

What are the roots of the many myths about people with developmental disabilities?

A parent of a teen with Downs syndrome said, "People always say my daughter is so special, she will go straight to heaven. But then there are the days when she comes home in tears; frightened and angry because kids on the bus call her four-eyes and r#tard."

There are lots of confusing messages about people with disabilities. Throughout history people of many cultures have determined their self-worth by comparing themselves to others competing for the perfect body or the sharpest mind. At different points in time this has resulted in violence and abuse of people with disabilities. In ancient Greece babies born with disabilities were abandoned in the woods to die. According to the United States Holocaust Memorial Museum, the Nazis in Germany began their mass murder program by killing over 200,000 people with disabilities.

You may feel some relief knowing this is in the past but how many times a day do you hear someone use the word "r#tarded?" It is a common insult that is usually ignored and rarely corrected. Likewise people with developmental disabilities continue to be seen in the media as the evil character further promoting the idea that disability is "bad."

Consider how religious beliefs over time have shifted from claiming disability is a "punishment for past sins" to the opposite idea that people with disabilities are special and blessed holy innocents. The effect has been to move away from sanctioning outright harassment but people with disabilities are still seen as "atypical" and not "like us." They are viewed as different, requiring special treatment. This most often happens in segregated settings. They become recipients of charity and pity. Segregation is an unfortunate result of the myths that disability is bad or special.

As an advocate against domestic and sexual violence you are well aware of societal tendencies to devalue and disregard groups of people. The history of domestic and sexual violence reveals similar atrocities against women. Our intention is not to overwhelm you by revealing cruelties inflicted on people with disabilities but to recruit you as an ally.

Our discussion is geared towards opening eyes, ears and hearts to recognize the stereotypes advanced by the moral viewpoint of disability as being "bad" or "special." It can be natural to not know what to say or do when faced with one of these myths. By practicing what to say, one can move beyond paralysis to debunk false ideas about people with disabilities. We welcome the opportunity to work together to stop the injustice supported by these labels.

Medical and Professional Viewpoint of Disability

This popular, but at times harmful, idea says a person with a disability has something "wrong" with them that should be diagnosed and treated by experts. It gives decision-making power to professionals who focus on finding a cure and prescribing treatments to fix the person. It refers to people with disabilities as "clients," "consumers," and other terms that are disempowering. This makes it difficult for individuals with disabilities to be part of the solution.

But people with developmental disabilities say they want to be treated just like everyone else. "Label jars, not people. I am a person first." We recognize that medical treatment can and has helped people with and without disabilities. In spite of this, searching for the "right" treatment to overcome a disability cannot be the sole focus in a person's life. The medical model often results in segregation and keeps a person from accepting their disability.

People with disabilities and their allies find it more helpful to focus on a person's strengths and seeking out the many ways a person can be a contributing part of their community.

From the 1600's onward, doctors and researchers have experimented with ways to "improve" treatment. Nevertheless, reports of abuse from harmful treatment are still found today. On May 19, 2009 Congress held a hearing to highlight the abusive, and sometimes deadly, use of restraint and seclusion with children who have disabilities attending public and private schools. The Government Accountability Office released a report citing hundreds of allegations of such cases in the past 20 years. These cases almost exclusively involve children with disabilities. Here are excerpts of testimony given by two parents to Congress during the May hearing.

Story

Toni Price said her son Cedric was physically restrained repeatedly by a teacher, simply for misbehaving. "Cedric struggled as he was being held in his chair, so the teacher put him in a face or prone restraint and sat on him. He struggled and said repeatedly 'I can't breathe,'" Price said. Minutes later, Cedric stopped breathing and died.

Ann Gaydos brought her daughter Paige to the hearing. Paige has Asperger's syndrome. Now a teenager, her mom recalled the abuse Paige suffered from a teacher while in elementary school. "She came home bruised and told me, 'Mommy, my teacher hurt me and I can't breathe.' She had restrained Paige for refusing to stop wiggling a loose tooth while in time out," Gaydos said.

One national study released prior to the hearing estimated that 70% of the time parents were not notified when restraint and seclusion were used as behavior modification of their children. Now more than ever, it is crucial that people with developmental disabilities of all ages are supported to speak up and insist on equal treatment in a world that is slowly trying to change.

World Health Organization's Definition of Disability

The definition of "disability" has changed over time. These changes emerge from the evolving way we think about disability. After ten years of hard work, the United Nation's World Health Organization (WHO) developed the 2001 International Classification of Functioning, Disability and Health (ICF). The 191 member states voted to approve this new definition of disability. It is beginning to reshape thinking about disability worldwide.

The new definition of disability states that a disability is not something that a person "has" but it occurs when the person, their functional limitation, and the environment interact. The word environment is used to refer to several different types of environments. A person's environment can be the:

- Social environment and policy environment

- Physical environment

- Communication environment

- Information environment

The main focus of the new definition is a person's ability to function over a medical diagnosis. It does not oversimplify "disability" and assume every person has the same experience.

This new definition helps us to understand that disability is a matter of degree. A person is more or less disabled based on what she can and cannot do in the many types of environments she encounters. Moreover, the experience of disability can be decreased by designing environments to accommodate varying abilities.

One is more or less disabled based on whether the physical, information, communication, social and policy environments are accommodating and welcoming of people with a variety of abilities. The new definition "mainstreams" the experience of disability as an ordinary part of the human experience. The new definition of disability is a powerful and thought-provoking framework for reducing disabling experiences for all women and men who seek access to services and other supports.

Benefits of the New (WHO) Approach

There are benefits to the new way of thinking about disability. Let's look at 5 of them.

The new approach is a useful way to solve problems and remove barriers.

It's important to understand the practical issues about how a person functions. With this information, you can map out what she can do and what she needs to fully participate.

Example: "This woman has a developmental disability"

Becomes: "This woman needs support to maintain concentration and follow instructions."

Knowing limitations helps you address the issues. Being an ally to people with disabilities becomes a process of building skills and comfort.

It meets the needs of people who don't tell you about their disability.

Some people feel comfortable saying they have a disability and will tell you what they need to participate. Many more people may not. In fact, the fear of negative treatment often influences a person to say they don't have a disability. If you create environments that anticipate a wide range of abilities, then you will be ready to give support and services to everyone.

3   **It improves services for all the people you are serving.**

As we said above, many people with disabilities do not say they have a disability. If that is the case, then you are most likely already serving people with developmental disabilities. This new way may help improve services for the people you are already serving.

4   **It makes service providers' work positive, cooperative and energizing.**

You can look for ways to change the things you have control over:

- Physical environment

- Communication environment

- Information environment

- Social and Policy environment

You will not be prepared to meet every need of every person. It will be easier if you anticipate that everyone has a wide range of abilities. You will be providing a welcoming and supportive environment. All people will feel accepted for who they are.

5   **You will be interacting differently with the people you serve.**

- Interact with people not their disability

- Involve people with disabilities when creating welcoming environments

- Rely on people with functional limitations to be experts on what works best

- Respecting the knowledge that people with disabilities can share is the first step towards finding solutions

- This new approach to thinking about disabilities is exciting. The next step is to follow these ideas and work alongside people with disabilities to bring changes. These changes will remove the barriers and make positive experiences possible.

On the next page, we have included a chart contrasting the moral and medical/professional model with the new approach to disability.

Contrastic Paradigms Chart[1]

OLD | NEW

Chart that Contrasts Approaches[1]	Moral and Medical/ Professional Approach ("Old" Approach)	World Health Organization Approach ("New" Approach)
How disability is described	A person has something wrong. She or he is limited by deficits or a condition.	A person with a different way of functioning needs accommodations to live life.
Attitude about helping out	Find a cure. Solve the problem. Fix the person. Correct the deficit.	Remove barriers; create access through universal design; make accommodations; promote acceptance, wellness, and health
Ways to address disability	Provide medical, vocational or psychological rehabilitation services.	Provide supports: job coach, assistive technology, personal assistance services, etc.
Who helps out	Professionals, clinicians, and other rehabilitation providers	Peers, typical service providers, information and referral services
Entitlements	Eligibility for benefits based on severity of deficit	Eligibility for accommodations seen as a civil right
Role of person with disability	Patient, client, research subject, object of charity or interventions	Customer, empowered peer, research participant, decision-maker
Area of focus	A medical "problem"	A social and environmental issue involving access, accommodations & equity

1 Vera Institute. (2006). Contrast of Approaches. Retrieved August 13, 2009 from Website: http://www.accessingsafety.org/index.php/main/main_menu/understanding_disability/a_new_definition/contrast_of_paradigms

What We Mean By Intellectual Ability

The new definition of disability talks about working with people rather than their disability. In order to do this, people need to understand the practical issues of the disability. We have broken this down by types/forms of disabilities in this next section.

Throughout this manual we use the terms "cognition," "cognitive accessibility," and "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

Green Mountain Self-Advocates, 2009

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 below:

1. Autism
2. Learning Disability
3. Intellectual Disability

Autism

Story by Conor Cleveland

It has been difficult for me. I had been mainstreamed, but that did not always work because I am loud. Therefore I have to be by myself, so I don't distract others. Being alone has been hard because I am a social person. I can't help being so loud. I am loud because of my Autism. I am "stimulus aware." This makes me need to drown it out. The stimulus that bothers me is light, noise, sounds from the lights, and people in the room. I love people, but they make too much noise. I spent too much time going away in my head to escape the people in the room.

People do not understand and need to be educated on how to yap with a person like me. They assume that I am strange and stay away. This behavior hurts my feelings. Talking about disabilities is okay. I want to tell people why I behave the way that I do. My brain requires that I drown out excess stimulation so I can think. My hand movements help me to measure the world. I need to measure it. Measuring helps me to see because my sight is poor. As I measure, I program my brain for the future memory.
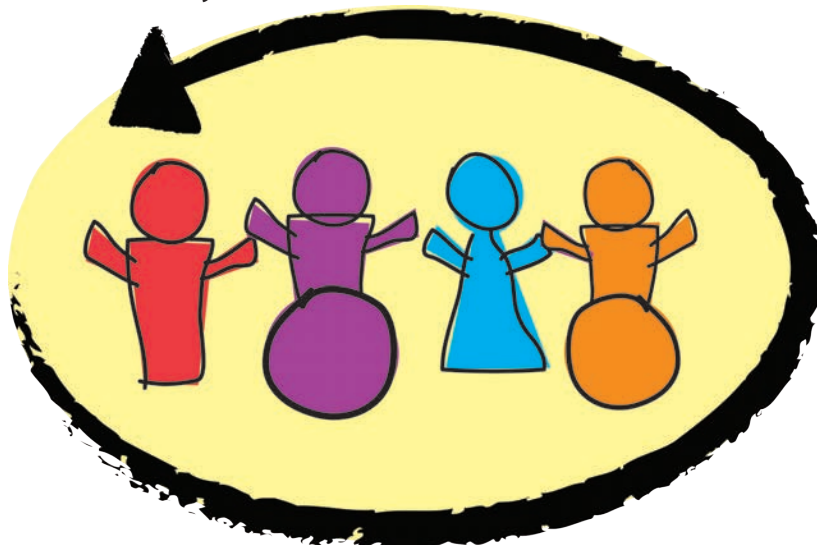
I would have mainstreamed better if I was in smaller classes of about 5 people and had the lights turned off. I loved being in the class "Community Connections" at high school because I liked going to help others and felt important. We went to the Lane Shops apartments and volunteered by giving food to the elderly, and helped at the craft class.

I did not know that I could walk or communicate before good teachers came along. I felt trapped in a dead man's body. Good teachers encouraged me to try new things and I learned that I am able. Now I can walk, run, lift weights, and communicate by typing. I am alive and every day is a party. Open more doors for me to run through.

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
  One student told us, **"I would have to be outside on the days they would have a fire drill at school."**

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.
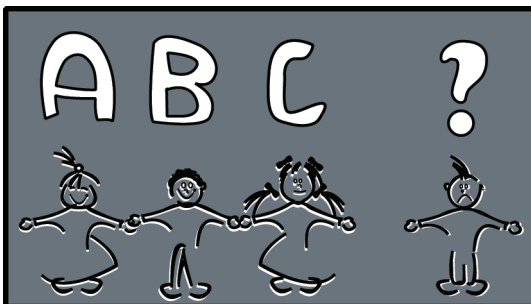
Learning Disability

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 r#tardation." 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 r#tarded." 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

"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. Society often expects adults with intellectual disabilities to act childlike. People may find it surprising or upsetting that a person with a disability has adult feelings of sexuality, anger, caring, anxiety, etc.

"IQ"?

Facts:

- Some people with intellectual disabilities have physical disabilities; most do not.

- Some people with intellectual disabilities have psychiatric disabilities; most do not.

- Most people with intellectual disabilities have experienced abuse, neglect and/or exploitation.

- Virtually all people with intellectual disabilities have experienced discrimination, stigma and/or disadvantage because of their intellectual disability. They develop their own individual emotional response and coping skills.

A Vermonter with an developmental disability has the same rights as anyone else to live and function in the community. This includes enjoying full inclusion, living independently, enjoying self-determination, making choices, having relationships, contributing to society and having meaningful jobs and careers. We will end this section with comments from one of the authors of this manual.

Story by Stirling Peebles

I want people to know that I have Down syndrome. I am proud to have a disability, because I love who I am as a person. I've always known that I was different, but I always wanted to fit in no matter what.

What We Mean by "Environments"

Policy Environment looks at the organization to see:

    1. If the policies and procedures are there,

      and

    2. If there is enough flexibility in the policies and procedures for you to effectively support people with developmental disabilities

Social Environment refers to the knowledge and attitudes of people who work in your organization.

Physical Environment refers to the actual space you are in. We want to create spaces that are cognitively accessible and welcoming for all people.

Communication Environment refers to the methods we use to give and receive information. Communication breaks down when the method we use to give information does not match the receiver's needs. It also breaks down if we require people to give information using methods that do not match their needs. We cannot assume a person with an developmental disability will have the skills necessary to communicate in the manner we typically use. The person may be nodding that they understand but are missing much of what is being said. A person may not have the verbal skills to give you the information you need to help.

Information Environment includes such things as:

- Presentations

- Web pages

- Telephone calls or messages

- Videos

- Face-to-face interactions

- Brochures

- Accessible office equipment

- Computer communication (blog, Facebook, email, IM, etc)

- Agendas and minutes

- Flyers

- Interactive television

Policy Environment and Intellectual Ability

"Policy" refers to the written guidelines that an organization adopts to put law into action. Policy helps groups make decisions. Policies determine the steps or procedures for employees to follow. Does your organization have a policy of nondiscrimination? Does your organization have a policy of full inclusion?
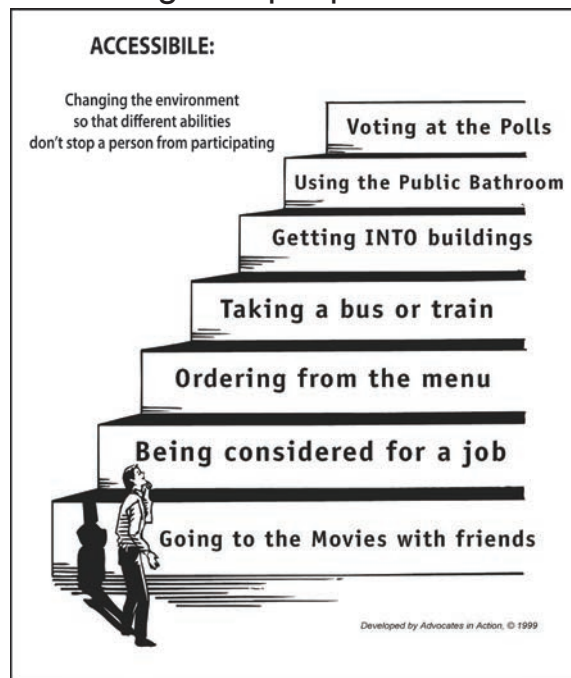
What is the ADA?

President George H. W. Bush signed the Americans with Disabilities Act (ADA) of 1990 into law on July 26, 1990. It was reauthorized in the Amendments Act in 2008. The purpose of the ADA is to protect the rights of over 54 million Americans with disabilities. ADA does not allow discrimination against people with disabilities.

The ADA opens doors to:

- Employment

- Public transportation

- Public accommodations

- Telecommunications

- Miscellaneous provisions

ACCESSIBILE:

Changing the environment so that different abilities don't stop a person from participating

Voting at the Polls

Using the Public Bathroom

Getting INTO buildings

Taking a bus or train

Ordering from the menu

Being considered for a job

Going to the Movies with friends

Developed by Advocates in Action, © 1999

It is amazing that it has been almost 20 years since the ADA became a law. There has been a lot of progress to include people with disabilities in our communities. There is still a lot of work to do. We believe if we work together, we will make more progress, more quickly. The ADA provides the muscle for full inclusion. Now communities are left to find ways to make it work.

✔ Checklist: So What Can You and I Do?

Ask questions.

❒ Does our agency have a policy about making services and programs accessible?

❒ Have we included people with disabilities in writing the policy?

❒ Do we have protocols or procedures to help bring the policy to life?

❒ Advocate (speak up and ask) for the policies and procedures we need to do our jobs better.

❒ Ask for training to help you with your day-to-day work.

❒ Network with organizations that advocate for people with disabilities such as GMSA, Vermont Center for Independent Living (VCIL), Vermont Protection and Advocacy (VP&A) to name a few.

❒ These are all suggestions for how we can make the ADA come alive in our own agencies or places of business.

Social Environment and Intellectual Ability

What we mean by "social" is the feelings and attitudes that influence relationships within an organization. Looking at the social environment of an organization you might ask: "has it created barriers in developing relationships with people with intellectual disabilities?"

Earlier in this manual we described some myths about people with intellectual disabilities. These myths have led some people to develop a negative attitude toward people with disabilities. We would like to explore these attitudes and how they affect the way people act toward people with disabilities.

Activity: Exploring Attitudes[2]

Time: 10 minutes

Discuss situations when you have noticed people reacting in these ways to a person with an intellectual disability.

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2   Information modified from learning activity Retrieved August 16, 2009 from Website: http://www.couragecenter.org/ContentPages/publications. aspx?FromNavPK=434

Arrogance

Example: Talking down to a person with a disability, talking to an adult like he is a child.

Discrimination

Example: Asking questions like "Why should we spend so much money for so few?" or avoiding people with disabilities.

Fear

Example: Being afraid of a person with a loud voice or who moves in unpredictable ways, afraid of the unknown.

Oversensitivity

Example: Seeing only the disability, focusing on the physical traits and not seeing the person inside, feeling bad when you say things like "Do you see?" to a person with a visual impairment.

Nuisance

Example: Thinking about accommodations makes me work harder, or it will costs more money, or it will take longer, or not him again.

Invisibility

Example: Pretending the person is not there.

Contagious

Example: Thinking that a person's respiratory or skin condition may be "catchy."

Special, Courageous, Inspirational

Example: People are looked upon as different because of their disabilities, not like a typical person.

Any person who is treated in these ways may feel angry, shameful, blamed, pitied, child-like, dependent, and invisible. We have included two checklists:

1. **The Key Is We**

2. **Using People First Language**

These handouts provide some ideas on how to create an open social environment in your office or organization.

In summary, these first two sections describing how **Policy and Social Environments** affect a person's intellectual ability refer to:

- Attitudes towards people with intellectual disabilities

- How they impact supports and services provided, and

- Existence or absence of policy to put ADA and other disability laws into action

Disability Etiquette

✓ Checklist: The Key is We!

Inclusion is about all of us. We all can play a role in removing barriers.   Chances are you frequently have opportunities to interact with people with developmental disabilities. Perhaps you have questions about what to say or do. Throughout this manual we have a number of checklists with specific suggestions about getting your message across. Here are a few general tips to consider.

Common Courtesies….

❐ People prefer to be called by their name, and referred to just as a "person." People with disabilities have made it clear that they do not want people to use the term "mental r#tardation."

❐ If you need to mention a person's disability, use People First Language. Say a "person with a disability" not a "disabled person."

❐ Always ask before giving assistance and let the person tell you what you may do to be helpful.

❐ Treat adults as adults. Use the same tone of voice you use when speaking to anyone else.

❐ 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 her off. Listen until she has finished talking, even if you think you know the end or can say it faster.

❐ Limit the use of sarcasm or subtle humor because it might leave some people out of the conversation.

❏ You might not be able to see some one's disability. There are many disabilities that are hidden within a person. Relax and just be you.   Let common sense and friendship guide you to break down any barriers you encounter.[3]

❏ Avoid using stereotypes in your thinking. People with disabilities have different personalities and different preferences about how to do things. To find out what a person prefers, ask them directly.

❏ It can be difficult for people with developmental disabilities to make quick decisions. Be patient and allow the person to take their time.

❏ 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.

❏ Do not worry about saying or doing something "wrong" when you meet a person who has a disability. If you are unsure what to say try "hello" or "I'm glad to meet you."

_____

3   Information was modified from handout created by National Organization on Disability. August 13, 2009 Retrieved from http://ieccil.org/disability-and-independent-living/disability-etiquette

What is People First Language?

- People First language is using words that show you respect the person you are talking with or about.

- People First language is putting the person before their disability.

- People First language is using words that everyone can understand.

Why use it?

- Words hurt when they are not used correctly.

- People with disabilities are looking for increased acceptance.

- You can show respect for people's abilities.

- You can help to change how the community thinks.

Checklist: People First Language

DON'T SAY...	SAY...
He is retarded; a slow learner	He is a person with an intellectual disability or developmental disability
The blind	People who are blind
He suffers from or is afflicted with	He is a person with
She's an autistic	She is a person with autism
They are handicapped or disabled	They are people with disabilities
He is a Downs kid or mongoloid	He is a kid with Downs Syndrome
She has a birth defect	She was born with that disability
He's wheelchair-bound or confined to a wheelchair	He uses a wheelchair
She's a dwarf or midget	She's a person of short stature
Handicapped rooms or parking	Accessible rooms or accessible parking
He is an epileptic/ She has fits	He has a seizure disorder or epilepsy
She's mute	She is unable to speak; non-verbal
He's crazy, psycho or a nutcase	He is a psychiatric survivor or has dealt with mental health issues
She is normal	She is a person without a disability
He is courageous	He is successful or productive

Physical Environment and Intellectual Ability

Story by Nicole LeBlanc

> You're in a big airport, trying to figure out where to go. There are signs for gates everywhere. There's so much unfamiliar noise. The gates aren't easy to find. You are surrounded by a bunch of people you don't know. You are worried something may happen to you. You feel scared and unsure of yourself. You just don't know where to go or who you can ask for help.
>
> You get shoved and rushed through security. It's very intimidating. The people are rude to you. You know they have many people to keep track of, but it takes you longer. It takes your brain a little time to figure out what's going on. Being rushed makes it worse. You can figure things out, but it takes a moment to figure out where you're at and what to do next.

Many people feel overwhelmed like this in places that you might not expect. What seems like a simple hallway or entrance can cause a person to lose focus or make it harder to communicate.

The physical environment can be stressful. Some things that can be confusing and make it harder are:

- Noise
- Harsh lighting
- People moving around, and
- Clutter

Ways to Adapt Physical Environments

We want to make the physical environment more accessible to people with developmental disabilities. These changes can also make the environment better for everyone. Some people call changing the environment to be more comfortable, an "accommodation." An example of an accommodation is to provide detailed directions, a map or personally show someone where to go.

When you're looking to modify the physical environment to make it more cognitively accessible, it will typically involve:

- Minimizing distractions

- Reducing noise

- Adjusting lighting

??? Activity: What Bothers You?

Time: 5 minutes

Take a moment to think about 3 things that might interrupt your concentration, making it difficult to think.

Let's go around and share one thing that distracts you. We will write your responses down on a flip chart.

✓ Checklist: Distractions

Hearing, seeing, smelling, feeling, thinking…these are some of the ways a person can be distracted. If you have something important to talk about, consider how things happening inside and outside the room can overwhelm a person's senses. Here are some factors to consider.

- ❐ Smells can trigger memories. Perfume, scented candles, and other smells can be hard for people with respiratory problems to tolerate. Consider making your office a scent-free place, or talk with people about limiting the scents they use.

- ❐ Uncomfortable chairs, tables, and other furniture can make it harder to work. When a person is comfortable physically, it can make it easy to focus. Having chairs in a hallway or outside can create a welcoming environment. Some people choose to sit apart from a group at first. Having a choice of places to sit is comforting.

- ❐ People coming through the room, talking within earshot, and cell phone calls should be avoided. When people share a space, plan ahead to minimize these distractions. Agree to silence cell phones.

- ❐ Room temperature can effect concentration. If a room is often too hot, leave a fan in there. If it tends to be cold, get a space heater or small throw blankets for the room.

- ❐ Looking at clutter, over-flowing stacks of papers, closets, desks, and rooms can be confusing. Even if you don't notice it, some people will.

- ❐ Excessive patterns, decorations, and plants on walls, floors, and furniture can shift a person's focus away from what she needs to be doing. Some colors and patterns can even give people a headache.

Activity: Sounds of Silence

Time: 1 minute

We are going to be absolutely quiet for one minute.

During that time, **LISTEN**.

Notice how many different sounds you hear.

Checklist: Noise

Here is a list of suggested ways to improve noise environments:

❒ Noises happen all the time, even when it seems quiet. Spend time in the room where you will be meeting. Listen for noises that aren't obvious, like lights buzzing and office machine cooling fans.

❒ Avoid having meetings in some places. Rooms near heating and cooling systems are not ideal for meetings. Meeting in public places can be nice, but it can be hard to listen and ask questions.

❒ If you can hear other people, they can probably hear you. If you need to talk about private things, find a private place to meet.

❒ There are simple things you can do to make a space quieter. Some examples are putting sound-absorbing materials on the ceiling, walls, or doors; sticking pads on the legs of chairs; or using storm windows and sealing window frames to block out street noise.

❒ Have a microphone available to help everyone hear and be heard.

✓ Checklist: Lighting

❒ Many people are sensitive to light. Some people need brighter light. Others need dim lighting. Some prefer natural light. Give people a say about lighting if you can. Consider getting floor and table lamps in addition to (or instead of) overhead lights.

❒ Flashing and flickering lights can give people headaches and make it hard to focus. Check frequently and replace bulbs as needed.

❒ Reduce glare from the windows during meetings. Try to have even lighting in the room, so nobody is straining to see.

❒ Good lighting feels safer. A dark hallway can be scary. A bright window looking onto a busy street can also be intimidating. When you're working with survivors, provide a private place to meet and talk.

??? Activity: Makeover Time

Time: 5 minutes

We are going to show you some photos. Is there anything in these photos that would be distracting or uncomfortable to you?
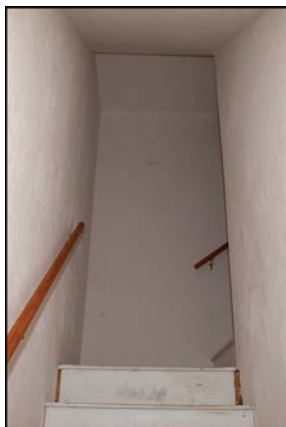
Use the checklists to identify suggestions on how to make these spaces more cognitively accessible. Can we think of 3 or more things to change so everyone would be more comfortable?

Communication Environment and Intellectual Ability

"Not being able to speak is not the same as not having anything to say."

By Rosemary Crossley

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 everyday – 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.

Issues Related to Communication

When communicating with someone, always begin by asking the person how they want to be supported. Check with trusted people in his or her life to see what ways of communicating will get good results. Many people with intellectual disabilities have difficulty focusing when listening. Sometimes what was perfectly clear one day can be hard to remember later. As an advocate, you already know that a person may be too upset or scared to speak. Someone who is stressed out may not ask for help. Your role as a communication partner is to constantly check for understanding. Keep reminding yourself to go slowly and wait a long time for a response.

✔ **Checklist: Generic Communication Tips**

❐ Presume competence. All people are "smart" and have things to say.

❐ Make eye contact. Tell the person who you are and why you are here.

❐ Speak directly to the person, not to a companion or support person.

❐ Introduce yourself at the beginning of each meeting to make it easier to learn people's names and roles.

❐ Speak slowly and clearly.

❐ Use words everyone understands.

❐ Leave out details that are not needed.

❐ Use a typical tone of voice, just as if speaking with a friend or co-worker.

❐ Say important information in a logical order, one step at a time.

❐ Avoid assuming a person can't read, but also do not assume they can. Ask the person if they would prefer you to read aloud any important information.

❐ Use the same word to describe the same things even if it sounds boring.

Checklist: Asking Questions

- ❒ Ask one question at a time.

- ❒ Avoid yes or no questions. Ask "what, where, when, why and how" questions.

- ❒ If stuck, ask forced-choice questions like, "Do you think we should buy new chairs or a new computer?"

- ❒ Take time. Wait for a response. Give a person a chance to explain completely. Ask more questions, even if it takes time.

- ❒ Avoid trying to guess what the person is saying or cutting him off. Wait until he has finished a sentence or story. Do this even if you think you know the end or can say it faster.

- ❒ Avoid abstract questions about the time or date. Steer clear of questions about the order things happened or reasons why.

- ❒ Use visual or concrete examples. Try to connect an issue to a personal experience or regular routine, such as "Did you go in the morning before work or at night after dinner?"

Checklist: Answering Questions

- ❒ Smile, nod your head and say something positive to let the person know it is good to ask questions; any kind of question.

- ❒ Give correct information and then get the other person involved. If you just give an answer, it may end the conversation. By asking questions like, "What do you think?" or "What have you heard?" it will help you find out what the person knows and what they want to know about.

- ❒ Ask if they have any other questions.

✓ Checklist: Listening

❑ Know that a person communicates things with their body. These can be important things.

❑ Be patient. Wait for the person to finish talking, even if it takes awhile.

❑ Be clear when you are expecting a response.

❑ Respond to any attempt the person makes to communicate.

❑ Keep the right pace. Consider asking if you are going too fast or too slowly before moving on to another topic.

❑ Check to make sure that the person understands what you are talking about. This can be done by asking the person to explain in their own words. Consider asking the question another way if needed.

❑ Use creative ways to communicate. For example, regular phone calls, personal visits, tapes, and e-mail.

❑ Recognize difficult or aggressive behaviors as one way people communicate.

❑ Do assume a person who has limited or no speech cannot understand what is being said. People can often understand more than they can express. Using visuals (a picture, object, or drawing) can help.

❑ Watch for signs of frustration. Suggest taking a break. Provide short, frequent breaks. A 7-minute break every hour works better than 15 minutes after two hours.

✔ Checklist: Supportive Decision Making

❒ 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.

❒ Remind the person often what topic you are talking about. Try not to suddenly change the topic.

❒ Because 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.

❒ Keep in mind what the person said they do not want help with. Don't "over-support." Too much help may not be helpful.

❒ Let a person make their own decisions. Don't take over and make decisions for them.

✔ Checklist: When Giving Directions

❒ Give one direction at a time.

❒ Make sure the person understands before moving on to the next direction.

❒ Give the person lots of time to follow a direction.

Remember

It can be helpful to do something together while you are communicating. A routine or activity can make it easier to have a conversation. Pace the activity so a conversation can happen. Next, we have an activity that focuses on how it feels to have difficulty when communicating.

??? **Activity: What Is It Like To Have Difficulty Communicating?**

Time: 10 minutes

Instructions:

1. Work in groups of 3: a survivor, an advocate, and an observer.

- The survivor will attempt to communicate the written message without using speech and by following the instructions on the slip of paper.

- The advocate will attempt to understand the survivor's message.

- The observer will watch the conversation and observe how well the survivor and advocate communicate.

2. Hand out papers with messages to survivors.

3. Begin activity.

Here are the messages you will use for this activity. Make copies and cut them so that only 1 message is on each piece of paper:

Message:
"My brother is upsetting me."

Instructions: no talking, may use grunts, no writing, can use gestures and facial expressions

---

Message:
"Did you see the news last night?"

Instructions: no talking, no writing, can draw and use gestures

---

Message:
"I live in Shelburne."

Instructions: may only vocalize (no words/word approximations), no writing, may use gestures

---

Message:
"I like to eat ice cream for breakfast."

Instructions: may only say "me" and "ice cream," no writing, no eye contact

---

Message:
"Hello my name is Anita and
I am 32 years old."

Instructions: no talking, no writing

Message:
"What time is the next
bus downtown?"

Instructions: no facial expressions, no
talking, may use gestures

Message:
"Your hair looks great today."

Instructions: no talking, except
for saying "ga" or "ka," no writing or
gestures, can use eye contact

Message:
"I had a great summer.
We went camping."

Instructions: no talking except to say
"uh," no writing but can gesture, can
use facial expression and eye contact

At the end of the activity:

- Ask survivors… What was it like trying to rely on limited means to communicate your message? How well did your communication partner do with trying to understand your message?

- Ask advocates… How easy/difficult was it to understand the person's message? How did it feel to be the listener?

- Ask observers… How did the interaction seem to you? Who was successful in message passing? If there was a breakdown, what do you think contributed to it?

Teaching Note - Discussion might include the following points:

- Slower pace

- Frustration

- Partner assuming what message was

- Not being able to communicate exactly what you wanted to say,

- Partner needing to take a more active role than usual, easy to see why communicator might become passive because it takes so long to communicate.

Story by Tracy Thresher

There is a need for those "supporting" a person with a disability to slooow dooown and step back. It may seem to some that it is more efficient to take an active role in getting things off the ground. But it is a hollow effort that simply reinforces passivity and apathy on the part of the person. It seems much better for us to support the meeting happening and then allow it to unfold at its own pace. It may sometimes be necessary for us to remind each other of this."

Other Forms of Communication

Many people think that if a person uses a computer or picture board to communicate, they cannot speak. That is not the case. Most people use some sounds or parts of words to communicate. A close friend or family member may be more familiar with what they are saying. Some speech may be combined with the following to communicate a message:

- Gestures
- Touching/pointing to pictures, symbols, words and letters
- Writing
- Facial expressions

- Eye pointing
- Headshaking
- Drawing
- Signing

There is a wide variety of equipment that people use to communicate. They include things as simple as a pencil and paper, tape recorder, computer, and text messaging on a cell phone. This also includes more elaborate devices such as:

communication board

eye-gaze board

pocket comm. book

elec. comm. device
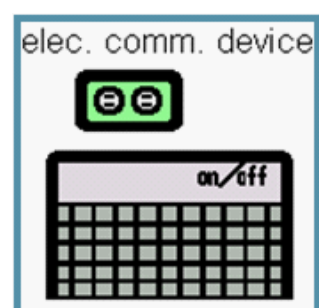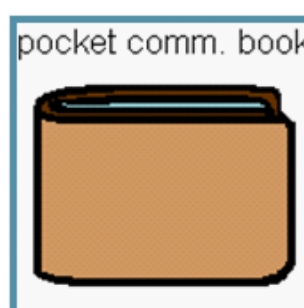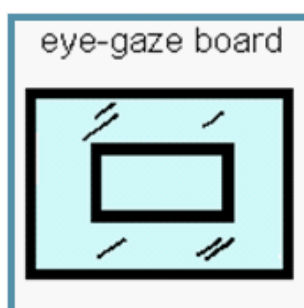
Communication (FC)

Some people with autism and other intellectual disabilities need emotional and physical support to type or point to letters/symbols on a communication board. The amount and type of support varies from person to person, and changes over time. The person assisting an individual to point is called a facilitator. The assistance with pointing is required because a person may experience a variety of neuro-motor difficulties including:

- Poor eye-hand coordination

- Being able to start or stop pointing

- Regulating movement in general

The use of facilitated communication has been controversial at times, especially if a person is using this type of support to disclose abuse. Here is a link to a video clip of someone using facilitated communication. You can decide for yourself.

http://www.cnn.com/video/?/video/health/2007/ 11/21/gupta.finding.amanda.cnn

Information Environment and Intellectual Ability

The information environment includes such things as:

- Web pages

- Brochures and flyers

- Presentations, agendas and minutes

- Videos

- Telephone calls or messages

- Accessible office equipment

About 25% of people in the US have difficulty reading. This is the case with many people with intellectual disabilities. They may be able to read the words, but not always understand what they are reading.

The following suggestions can minimize problems faced by someone who has difficulty reading.   They are useful when:

1. Writing information

2. Ordering materials

3. Making signs or displaying information

4. Using computers and the internet to communicate

Each of these 4 topics includes activities and checklists to assist you in making your information more accessible to all people. In the back of this manual are shorter versions of the checklists for you to use once you become familiar with these tips.

1. Written Information

Writing accessible information requires us to consider:

- The "look" of the page (also called the layout)

- The language we use

- Providing alternative formats

??? Activity: The Look of the Page

Time: 5 minutes

Instructions:

1. Hand out the sample document and the "Checklist for Written Information."

2. Get into groups of 3.

3. Look over the sample and use the checklist to see if it is well laid out.

4. I will be glad to answer questions you may have about an item.

5. Ask for the number of the item there is a question about.

6. Tell the groups to compare their answers.

7. Ask if there are any disagreements?

8. Discuss.

Checklist: Written Information

Your writing will be easier to read if you:

☐ 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.

☐ 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 with matte (not glossy) finish. Thick paper will not show the information on the other side as much. The matte finish keeps the glare down. This goes for laminated information, too.

☐ 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.

??? Activity: The Language Used

Time: 5 minutes

In addition to the way words look, we also need to use simple, clear language to help people with reading difficulties understand the information. We will now do another exercise to evaluate how to make sure the language we used is accessible:

Instructions:

1. Use the "Clear Language Handout" and "Checklist for Clear Language."

2. Stay in groups of three.

3. Evaluate the sample document to see if it follows the suggestions on the "Checklist for Clear Language."

4. Be sure to ask questions about any suggestion you don't understand.

KEEP IT CLEAR

KEEP IT SIMPLE

Checklist: Clear Language Looks and Sounds Like This:

❐ A summary at the beginning will give the reader a preview.

❐ Highlight important information.

❐ Both 1 & 2 can be done automatically with Microsoft Word. You click on "Tools". You will see "AutoSummarize" in the dropdown menu. Click on it. You decide if you want the summary at the beginning, end or on a separate page. You can also highlight the important ideas.

❐ Present information in a logical manner. This may be chronologically. This gives the reader information they need to go on.

    Example: First, fill out the application
                Then, mail it to the manager

❐ Write information for the widest audience first. Then explain any exceptions or conditions.

    Example: Call 802-223-0000 for information (widest audience)
                If you use TTY, Call 802-223-1111 (exceptions/conditions)

❐ Do not use acronyms unless everyone knows what they stand for. Jargon refers to specialized vocabulary. Some people do not know what it means. Have a glossary of terms if they must be used. Define difficult words on the spot.

    Example: Say "Green Mountain Self-Advocates"
                Do not say "GMSA"

❐ Use text boxes to highlight important information. Do not use too many because it can get confusing

❐ Use vertical lists instead of sentences.

Example: "You need to bring your calendar, a pen, the folder of information, money, and a change of clothes to the event on Friday."

Becomes:

Items to bring to the event on Friday:
- ○ your calendar
- ○ a pen
- ○ folder of information
- ○ money (be specific – example "bring $5 for lunch")
- ○ a change of clothes

❐ Use pictures to explain the main ideas. Many people depend on pictures to remember key messages.

Example: This: "Public transportation is available."
Becomes: "You can take the bus."

This example shows a picture that lets the reader know you are talking about transportation. It is important to use the same symbol every time. The pictures should be to the left of the writing. Pictures are not used to make the document flashy.

❐ Use People First Language. This puts the person before the disability.

Example: The r#tarded man crossed the street.
Becomes: The man with an intellectual disability crossed the street.

❐ In Vermont we use the term intellectual or developmental disability. People with developmental disabilities do not want to read or hear the word "r#tarded."

We want the "R" word to disappear.

It is a put down.

❒ Use active verbs. Use verbs in their simplest form.

    Example: "The woman was attacked by a strange man." (Passive)
    Becomes: "A stranger attacked the woman." (Active)

❒ Use pronouns like "I" and "we," as if you are talking to your readers.

❒ Use everyday words. Write like the person is sitting across the table from you.

    Example: "commence"
    Becomes: "start"

❒ Use sentences that are short and to the point. Limit sentence to 15 or 20 words. Each sentence has one main idea.

❒ Do not use 2 negatives in one sentence. They cancel each other out.   It is hard to figure out if the sentence is really positive.

    Example: "We will go to New York if no fewer than 15 people sign up."
    Becomes: "We need at least 15 people to go to New York."

❒ Leave out unnecessary words. Fewer words make the writing clearer.

    Example: "is able to"
    Becomes: "can"

❒ Use consistent wording. Use the same word for an idea or object every time. The reader becomes familiar with the word. It helps to develop long term memory. This means the short term memory doesn't have to work as hard.

    Example: An organization decides to use the word "survivor" to refer to an abused woman.

❒ Ask a person with an intellectual disability to read the document. They will know best how clearly it is written.

A Helpful Tool on Microsoft Word to Check Reading Level

It checks:

> ► readability (how easy or difficult writing is to read)
> ► if there are any passive sentences
> ► how many words per sentence

You do this by:

1. On the Tools menu, click **Options**, and then click the **Spelling and Grammar** tab.

2. Select Check grammar with spelling check box.

3. Select **Show readability statistics** check box & then click **OK**.

4. On the **Standard** toolbar, click **Spelling and Grammar**.

When Microsoft Word finishes checking spelling and grammar, it displays information about the reading level of the document.

Providing Alternative Formats

Alternative formats are needed for some people with intellectual disabilities. The best idea is to have alternative formats of your information prepared ahead. This will provide a more welcoming environment for those who need them. People with disabilities know the formats that work best for them. They may not offer the information, so you will need to ask.

Alternative formats include:

- Braille
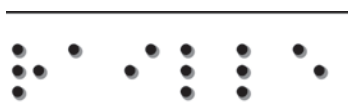
- Large print (18 point type)

- Audio

- Accessible digital

There is information at **(http://www.acb.org/accessible-formats.html)** the American Council of the Blind website about making documents accessible for people who are visually impaired.

Checklist: Alternative Formats

❐ The easiest way to enlarge a few pages is by photocopying at 120%.

❐ Use 18 point type if you are word processing. Short sentences are important for comprehension.

❐ An audio tape or CD may work for people with low vision or who have reading difficulties.

❐ Digital format is quickly becoming the most frequently asked for alternative format. Using this format allows a person to use a screen enlarger, screen readers and software that zoom in on areas. Zoomtext is one program a person can buy. "Imagezoom" from Foxfire is a free tool to zoom in or enlarge text from the toolbar. If your information is on web pages, there are websites to test accessibility. One of them is called "Bobby". Find out more about it at: **http://bobby.watchfire.com/bobby/html/en/index.jsp.**

❐ These are just a few of the tools available. New ones are developed all the time.

❐ You can put a symbol on information you have in alternative formats to let people know. There are a series of symbols to use at http://www.graphicartistsguild.org/resources/disability-access-symbols/.

Think about having your organization's forms in alternative formats. Imagine how a registration or intake form in alternative formats could be a more welcoming environment right from the beginning of a relationship.

2. Ordering Materials

The easiest way to be sure materials are accessible is to think about accessibility before buying them.

  Checklist: Ordering materials

❐ The material should be at a 4th or 5th grade reading level including the clear language that we have discussed already. You can check by typing part of the writing in Word and running the readability check. We discussed this in the "Clear Language" section of this guide.

❐ Look at the layout. Is it inviting to read? Is it too "busy?"
Are the main points clear?

❐ Materials that use People First Language show respect to all.

❐ Do the graphics help with understanding? Looking flashy does not help with accessibility.

❐ The font of the materials is at least 14 point. Many times brochures use small fonts to cover all the information. Information is lost if it is not accessible.

❐ Think about the pictures. Do they show diversity? This would include people with disabilities.

❐ Find out if the materials are available in alternative formats. This will save you a lot of time and effort.

❐ Buying videos that are already closed captioned will mean you are prepared for people who have hearing losses.

3. Making Signs and Displaying Information

Finding your way around a building the first few times can be challenging. The environment will be more welcoming if it is clear where to go and where the restrooms are. Have you ever seen a sign where the print was too small to read from a distance? Some signs are hung where you do not really notice them. Being sure signs are easy to read from a distance (at least 6 feet) is important.

 Checklist: Signs and Displaying Information

❒ Check before the meeting to be sure there are clear signs telling people where they need to go. Put up signs if they are not there or are unclear.

❒ The office will be more welcoming if it is clear how to use the copier or the microwave. Do you need to dial "9" to get an outside line? Some machines come with instructions that include text and symbols. If not, you can make your own.

❒ Having Braille and symbols on signs is very helpful.

❒ Post visuals on the wall at about 54 inches high. This is a good height for people who are standing and people who are using wheelchairs.

❒ Brochures should be displayed at no more than 48 inches high. This will increase the chances of people seeing them and being able to reach them.

❒ Again, all information displayed should use People First Language, which we reviewed on pages 30-31 in the Policy and Social Environment section of this manual.

4. Office Machines/Computers/Internet

Office machines include computers and the internet. The easiest way to have accessible machines is to think about them before buying equipment. The accommodations required will depend on individual needs. The purpose of this section is to increase awareness that welcoming environments include machines, too.

✓ Checklist for Office Machines/Computers/Internet

☐ Look for big buttons on machines.
Instructions for use should include written or graphic cues.

☐ This checklist refers to alternative computer equipment and software. You may want to consider buying some of these items to increase accessibility in your office. Many of the tools can be found online for free.

☐ Email has become an important communication tool for many of us. Confidentiality is a consideration with email. Be sure confidential or personal information is not being sent via email. Remember, just because it has been deleted, does not mean it is gone.

☐ When a group decides to use email, blogs[4], wikis[5] or IMs (instant messages) there are issues to consider:

- Is People First Language being used? This will go a long way in showing respect for the readers.

- Is clear English used? This is a fast paced communication style. We need to slow down a little and think about all the readers.

- Consider the types of accommodations people in the group need before we decide to use blogs, wikis, etc for communication. We do not want to exclude people by mistake.

Note: Today, organizations depend more and more on technology. Remember that everyone does not have access to technology.

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[4] What is a Blog? a blog is a website where people write their opinions in journal-type format. New entries are added often.

[5] What is a Wiki? a wiki is a website where many people can update and add information.

Accessible Meetings

Attending a meeting with a new group of people can be a confusing process for most people. We have found that some groups use mentors to introduce new members to the inner workings of a group. A mentor might describe the current members, the role of the person as a member of the group, existing priorities and the culture of the organizations.

This final section of Getting Your Message Across suggests strategies to prepare for and conduct meetings and discussions that strive to include people with developmental disabilities. Representatives with developmental disabilities might need to get necessary support before, during and after meetings, including reliable transportation to and from meetings. This support may come from another member of the organization, other attendees, and/or other support people. Aim to create opportunities for all to express their opinions and make suggestions and informed decisions.

Inclusion is more than just being present; it involves active participation. You are now ready to begin!

✓ Checklist: Before a meeting…

☐ People with disabilities have said,
   "Give us some idea what we are talking about and why we are there."

☐ Ask the person what specific accommodations they need.

☐ Locate a meeting space that is;

○ physically accessible
○ comfortable, with few, if any distractions
○ in a familiar location if possible

☐ Make a reasonable agenda.

☐ Be open to a person bringing a friend or support person so they won't be uncomfortable. (An individual chooses their support person.)

☐ Send materials, directions, and agenda out at least one week before.

☐ Written material needs to be in Plain English. Use graphics, large print, (minimum 14 point font size) and double space. A brief summary can help. Highlight critical information.

☐ Print names on name tags or tents.

☐ Support may include help with scheduling transportation.

☐ Let people know ahead of time if lunch will be provided at a **meeting.**

☐ Arrange tables (in a circle) so you can see everyone.

☐ Use microphones in large spaces.

☐ Do not assume everyone uses email. Find out a person's preferred way to get information and respond.

☐ Clear signs with pictures can help a person find their way around a building.

❒ If a barrier cannot be avoided, let the person know ahead of time.

❒ Check in with the person. Make sure folks have support, if needed, to go over the upcoming agenda and materials. Discuss issues or questions they might want to bring up at the meeting. The person might want to prepare a statement ahead of time (e.g., written, dictated, recorded).

✔ **Checklist: During a meeting…**

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.

❒ 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.

❒ 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.

✔ Checklist: After a Meeting…

❒ Write clear and understandable minutes. Highlight key decisions and next steps. Minutes need to include the next meeting date and a tentative agenda.

❒ Follow-up with the person after the meeting to go over what took place. Review major decisions and next steps. Provide an opportunity for the person to give feedback about the meeting. Some people find it helpful to do this right after the meeting ends while others may want to go over the meeting when they get together to prepare for the next one.

❒ Send out the minutes within two weeks after the meeting. This allows the person to meet with others if needed to discuss the last meeting and prepare for the next one in a timely manner.

❒ Work with the person to find out what adaptations will work best for him/her.

Conclusion: Nothing About Us Without Us

Inclusion is not just a disability issue. Organizations promoting the wellbeing of gays and lesbians typically involve their constituents in planning and providing services. Most student groups addressing racism include racially diverse leaders. Likewise, involving people with developmental disabilities at all levels of creating and sustaining change will result in more accessible services responsive to the realities of peoples' lives. After all, the only person who can speak from the perspective of a person with a disability, is a person with a disability.

Many people with developmental disabilities live and work throughout Vermont. An effective approach for recruiting state and local peer leaders is to establish a relationship with Green Mountain Self-Advocates.   It is our goal to assist Vermont organizations as they continue to develop their groups to reflect the philosophy of inclusion and to model active participation.

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Green Mountain Self-Advocates

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