

A CURRICULUM FOR SELF ADVOCATES

from The National Autism Resource and Information Center
and the Autistic Self Advocacy Network



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FOREWORD

As the National Autism Resource and Information Center, we are always striving to connect professionals, family members and self-advocates to high-quality resources and timely information on various topics relating to autism and other developmental disabilities. Focus areas include early detection, early intervention, and early education; transition from high school into early adulthood; community-based employment; advocacy for families and self-advocates; community inclusion; family and sibling support; and much more. We accomplish these goals in a variety of ways, which is why we are proud to introduce the Self-Advocacy Curriculum, a collaborative effort between our partners: The Autistic Self Advocacy Network, Self Advocates Becoming Empowered, the Sibling Leadership Network and the National Youth Leadership Network.

The Self-Advocacy Curriculum is a tool that is intended to help individuals with autism and other developmental disabilities learn more about the self-advocacy movement; celebrate neurodiversity; cultivate local self-advocacy groups; and ultimately, become and remain empowered through self-advocacy.

We would like to thank our partners for their hard work on this project and the Administration on Intellectual and Developmental Disabilities for its continued support.

And we thank you for your continual support of The National Autism Resource and Information Center. We hope this curriculum motivates and inspires you to become a stronger advocate for yourself. Remember, you can do it – you, empowered.

This document was supported in part by a cooperative agreement from the Administration on Intellectual and Developmental Disabilities, Administration for Community Living, U.S. Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Intellectual and Developmental Disabilities policy.

AUTISTIC SELF ADVOCACY NETWORK (ASAN)

The Autistic Self Advocacy Network (ASAN) is a 501(c)(3) nonprofit organization run by and for Autistic people. ASAN's supporters include Autistic adults and youth, cross-disability advocates, and non-autistic family members, professionals, educators and friends. ASAN was created to provide support and services to individuals on the autism spectrum while working to educate communities and improve public perceptions of autism. Our activities include public policy advocacy, community engagement to encourage inclusion and respect for neurodiversity, quality of life oriented research, and the development of Autistic cultural activities. We provide information about autism to the public through a number of different educational, outreach, and systems change related projects.

Our contributions to this project include essays (and an interview) on Autistic perspectives, neurodiversity, self advocacy, contacting state representatives, meeting accommodations for Autistic people, and Identity-first language.

We'd love to sit down and have a chat with each reader who stumbles upon this project, but we can't teleport, and some of us are a bit shy when it comes to meeting new people. That noted, please stop by our website with a cup of coffee, tea, or your favorite drink, and check us out if you like what we have shared.

ASAN is proud to have partnered with National Youth Leadership Network (NYLN), Self Advocates Becoming Empowered (SABE), and Sibling Leadership Network (SLN) on this fascinating project. Thank you for taking the time to explore it!

NATIONAL YOUTH LEADERSHIP NETWORK (NYLN)

In self advocacy communities, we talk a lot about how to change policy, but not about how to change our relationships. For so long, people with disabilities were forced to be with each other in segregated schools, institutions, segregated camps, and day programs...and in a lot of ways, we still are. However, in the last 20 years, many people with disabilities have gone into mainstream schools and environments. This is great news for our community, but has also meant that when we come together, we don't always know how to be with each other. There is a learning curve to learning about each other and it can take time to be comfortable.

At the National Youth Leadership Network, we prioritize people with disabilities coming together. Our mission statement says: NYLN is dedicated to breaking isolation and building community through supporting youth with disabilities to reach their full potential. It is our dream that others will also do this work.

Our section is designed to inform you about things we think you need to know to bring people together. We focused on topics like challenging ableism and tokenism. We also focused on facilitation and mentorship. We hope it is helpful to you.



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SELF ADVOCATES BECOMING EMPOWERED (SABE)

Self Advocates Becoming Empowered (SABE) was founded in 1990. Since then, we have been working hard for the full inclusion of people with intellectual and developmental disabilities in the community throughout the 50 states and the world for 22 years. Our non-profit advocacy organization is run by a board of self-advocates representing 9 regions of the country.

We are just not any organization; we have a purpose. SABE's contribution to this curriculum is dedicated to the over 1,200 local and state self-advocacy groups who make up the SABE network. The purpose of self-advocacy is to strengthen our peer connections. Local groups are key because it is important for the information to come from us. You get the honest truth from your peers. You are hearing it through the experience of peers directly. It is important to have a peer-to-peer connection because you learn how much you have in common. The strength of your self-advocacy increases. When you get involved, you realize you are not alone when facing tough times.

We need to hammer home to everyone that self-advocacy is a civil rights movement. Like any other civil rights movement, we are the ones who decide the agenda. Like any other civil rights movement, we pick our own leaders. And.... like any other civil rights movement, we need true allies. So allies, think about how people that are white supported the African American civil rights movement. Also, think about how people who are straight support the GLBT (Gay, Lesbian, Bi-sexual and Transgender) movement. We need good allies, but we need to take charge!"

Major contributions to the writing of this section were made by Max Barrows, Nicole LeBlanc and Karen Topper. Additional contributions were made by Tracy Thresher, Kyle Moriarty, Chester Finn and Betty Williams. We are grateful for the stimulating discussions, comments and support from our peers and allies from Autistic Self-Advocacy Network, National Youth Leadership Network and Sibling Leadership Network.



Self Advocates Becoming Empowered

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SIBLING LEADERSHIP NETWORK (SLN)

The Sibling Leadership Network (SLN) promotes a broad network of siblings who share the experience of disability and people concerned with sibling issues. Our organization provides siblings of individuals with disabilities the information, support and tools they need across the lifespan. We work hard every day to enable siblings to be effective advocates with their brother and sister and to serve as change agents for themselves and their families. When Autism NOW approached us with an opportunity to be a part of the Curriculum project, we saw it as a chance to meaningfully collaborate with self-advocates on a project that matters. We are honored to be a part of this project. We send our deepest respect and gratitude to all readers who stumble upon this handbook. If you are a self-advocate reading this, we hope it's helpful and that you share this with your sibling(s)!

— John Kramer, Chair, and Katie Arnold, Executive Director



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A short history of self-advocacy

by Self-Advocates Becoming Empowered



The seeds of the self-advocacy movement can be traced back as far as 1968, when a Swedish parents' organization held a meeting for people with developmental disabilities. The people at the meeting spoke out about the changes they wanted in the programs that were run by their parents.

During the next 5 years similar meetings took place in England and in Canada. A small group of people from Oregon went to one of those conferences, but they felt that it was dominated by professionals. They started planning to have a conference in Oregon that would be run by people with disabilities.



The People First movement began in Oregon on January 8, 1974, at a conference planning meeting. At the meeting, one man talked about being labeled “mentally retarded” and said, “I want to be known as a person first!” “People First” was chosen as the name for the convention, which was held in October, 1974.



Self-advocacy groups sprang up all over the United States, Canada, England, Australia, New Zealand, and Sweden, during the next ten years. In 1984, the first International Self-Advocacy Leadership

Conference was held in Tacoma, Washington. Since then, international conferences have been held in London (1988), Toronto (1993), Anchorage (1998), and England (2001).



In the U.S., the self-advocacy movement continues to grow. In many states, local groups have come together and formed statewide organizations that have boards of directors (most or all of whom have disabilities) and employees (who may or may not have disabilities) that carry out the goals of the self-advocates who are the members. Some of the state organizations are called People First, and some have other names, like Speaking for Ourselves, Self-Advocacy Association, Advocates in Action, and other names.



In 1991 members of many different state and local groups came together in Nashville, Tennessee, to form a national organization. They elected a Steering Committee that later became the Board of Directors of Self-Advocates Becoming Empowered.



Today there are many self-advocacy organizations. These groups build connections between people with intellectual and developmental disabilities that is like a family. This family is like a strong tree growing from the grassroots that branch out from the community across the state and nation.



If it weren't for individual self-advocates in local groups combining their energy and ideas to change their own communities, there would be no roots or branches to support national organizations. **What you do, and who you are, really counts. That is why this is your organization.**

Neurodiversity and autistic people

by Autistic Self Advocacy Network

Neurological diversity (or neurodiversity) is the idea that we are all neurologically different—that individuals on the autism spectrum do not have a disease but rather a difference to be recognized. Autistic people have a unique set of characteristics, which can manifest as difference, disability, or gifts/skills, from person to person and within the same person. These differences provide Autistics with many rewards and challenges, not unlike our non-Autistic peers. The neurodiversity movement works toward equal rights for those of all neurological configurations—the rights to accommodations and support services so that we all might lead fulfilling and productive lives.

The concept of neurodiversity does not support one neurological type over another. ASAN believes in the same human rights for all people regardless of neurology. We consider non-Autistics to be neither superior nor inferior to Autistic people. Likewise, we do not consider “high-functioning” autistics (including people labeled with Asperger’s Syndrome) to be either superior or inferior to “low-functioning” autistics. We are generally against the use of functioning labels, which lead to the false idea that people function at the same level across all areas. In reality, each person (on and off the autism spectrum) has a unique set of skills and challenges. Functioning labels significantly downplay the uniqueness of each individual, and lead to artificial and inaccurate categorization.

Neurodiversity is not against the idea of therapy and education for autism-related difficulties, as long as this therapy is geared toward improving quality of life and not toward eliminating non-normative differences. (Cure-based approaches seek to eradicate non-normative differences.) Moreover, the therapy and education must be appropriate for the individual’s needs and must not involve practices that are considered extreme among the general population.

Neurodiversity supports the right for all people to live as independently as possible. We are against forced institutionalization and are for community choice. In other words, no person should be forced into an inappropriate living situation, just as no person should be forced to endure inappropriate treatment. Moreover, neurodiversity focuses on providing everyone with the skills needed to live independently. These skills include self-care, education, employment skills, transition, and self-advocacy.

Presuming competence

by Self-Advocates Becoming Empowered



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 Facilitated or Augmentative Communication, 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.

Keep this in mind when you interact with persons with disabilities. When it comes to being intelligent, everybody is in their own way. One reason kids with disabilities are not



included is because people make false assumptions about their abilities to learn and grow. Doug Biklen said, “The question is no longer who can be included or who can learn, but how can we achieve inclusive education. We begin by presuming competence.”

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 their intelligence. My friend, Tracy Thresher, says 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

1. Always ask before giving assistance and let the person tell you what you may do to be helpful.
2. Treat adults as adults. Use a typical tone of voice, just as if speaking with a friend or co-worker.
3. In general do not assume a person can't read, but also don't assume they can.
4. Speak to the person directly, not the support person or companion.
5. 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.
6. 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.
7. 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.
8. You might not be able to see someone's disability. There are many disabilities that are hidden within a person.
9. 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.
10. Offer compliments but avoid giving a lot of praise when people with disabilities do typical things.
11. Most people with disabilities want to help others, as well as be supported, and enjoy making a difference in someone's life.
12. Look for something that indicates a person understands. Respond to any attempt the person makes to communicate.
13. 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.

14. 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.
15. Have your support of the person be low-key, almost "invisible" to others. Don't "over-support."
16. 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.
17. Focus on what a person can do. All people want a chance to live a typical life, just like everyone else.
18. Find ways to include a person in a conversation. Do not talk about the person to others as if they're not there.

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

–Douglas Biklen

Ableism

by Stacey Milbern

Society has a lot of ideas about disability. A lot of the ideas are negative. For example, people with psychiatric disabilities are always the villains in society's imagination. We see this with movies and the way that the media talks about mental health. In the 1900s, many important people (scientists, politicians, philanthropists, etc) supported eugenics. Eugenics was an effort to "better" the human race by eradicating people who were considered "unfit". People considered unfit were usually people of color, poor, and with disabilities. In an ideal eugenic world, everyone would be white and able-bodied. To try and create this world, doctors would sterilize women [stop them from having children] during surgeries, without telling them. The government would test children in schools to see who had low IQs and keep record of it. Over 60,000 Americans were sterilized. The Supreme Court even supported eugenics. In a case about eugenics, Justice Oliver Wendell Holmes Jr wrote the Courts' opinion. He said: "It is better for all the world, if instead of waiting to execute degenerate offspring for crime or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough." Some state governments are starting to apologize for practicing eugenics. However, there are traces of eugenics still left.

Ableism is the favoring of able-bodied people at the expense of people with disabilities. It is like racism and sexism, but different in many ways, too. Racism, sexism, and ableism are all systems of power. This means that ableism is a system, not just an individual person's belief. A lot of times when society talks about things like racism, people just focus on prejudice [one person not liking another person]. However, it is important to talk about institutional power, too. The thing that makes ableism and racism so bad is that the systems people live in are prejudiced in a lot of ways. Systems have the ability to give or take away resources. They also can exercise control over others. Eugenics was practiced on the systemic level.

Ableism is not personal... everyone has ableist beliefs and everyone is part of an ableist society. For example, a lot of individual policymakers are trying to create more employment opportunities for people with disabilities. However, a lot of government policies don't actually support people with disabilities working. It isn't enough to talk about individual policymakers. It is important to talk about what keeps institutional beliefs in place.

Systems of power have three levels:

- **Institutional level:** This is where ableism is practiced on the level of the government, media, and corporations. (For example: housing policy or media messaging around disability).
- **Interpersonal [between people] level:** This is where ableism is practiced between individual people (for example: two people calling each other the r-word).
- **Personal level:** This is where ableism takes place in people's minds. (For example: a blind person thinking he is ugly).

Ableism shapes everyone's decisions and actions. The best way to challenge ableism is to educate yourself.

A few resources on ableism:

- **disabledfeminists.com** (feminism and disability)
- **stopableism.org** (stopping hurtful attitudes toward disabled people)
- **ableism.wordpress.com** (stopping hurtful attitudes toward disabled people)
- **eliclare.com** (about disability, sexuality, race, class, and gender)

Tokenism

by Stacey Milbern

Often times, when people who are from a marginalized community participate in something new, they face a lot of challenges. One of these challenges can be tokenism. Tokenism is a practice where a group wants to seem inclusive, but is not doing what they need to include marginalized members in a real way.

A few examples of tokenism

Jerry is a new city employee. His boss asked him to join a commission on urban street safety. Jerry isn't sure why he was appointed since he works in finance. His job has nothing to do with improving street safety. He is the only African American on the board. Every time anyone in the group says something about race, they look to Jerry. It's almost like they expect him to speak for all people of color. Jerry doesn't know much about city living — in fact he grew up in the suburbs. No one really bothered to ask. They're just happy to have an African American on the board.

Cindy is a new director of an environmental rights organization. There is a coalition for directors like Cindy. She is thankful to join it so she can meet people doing the same work. Cindy is 20 years younger than all the other directors. They tell her that she is the “future” and that they're “proud” she's carrying the environmental movement forward. They also tell her to give them a call if she ever needs support. One day, one of the directors proposes that the coalition should take a donation from a toxic waste plant. She challenges that idea. At first, everyone ignores her. She says her point again, this time more directly. Everyone shuns her. They treat her like she doesn't know anything. She realizes that when the older directors told her that they would support her, it was just talk. They do not want her to be a leader unless she agrees with their agenda.

Jamie and Louie are two Deaf comic book fans. All the comic book fans love spending time with them because they're a lot of fun. Every time they go to comic conventions, the convention organizers start asking them about disability accessibility. Jamie and Louie are frustrated. They aren't there to talk about access. They just want to enjoy the conventions. Everyone keeps inviting them to speak on disability. When they meet a wheelchair using comic fan, the three compare notes and notice the same thing happens to the wheelchair user.

A few results of tokenism

- People feel disempowered and devalued.
- When people are actually chosen for their talent, everyone thinks they didn't earn it.
- It keeps unfair power dynamics in place.
- People feel like they are just filling a quota.
- The group stays irrelevant and out of touch with a lot of communities.
- The group does not know the needs of communities.

A few ways to combat tokenism

- Create a group agreement on the importance of inclusion and diversity. Have conversations about how the group can support inclusion.
- Never have just one person from a certain community present. It almost always leads to tokenism. Having only two people from a community also often leads to tokenism, but it is a start.
- Notice power dynamics within a group and find a time to say them aloud.
- Participate in trainings to become more inclusive.
- Think about what it would take for someone to have a leadership position in a group. Also think about what support the group could give to support that person.

An example of someone combating tokenism

John notices that Cindy is not being taken seriously because of she is younger than everyone else. He is a director, too. He invites Cindy to coffee to talk about her interests and vision for the group. Afterwards, he connects Cindy to different people in the group. Cindy trusts John, so she feels like she can go to him with questions she has. John nominates Cindy to a higher position. A few months later, Cindy is just as included as everyone else.

All groups can fight tokenism. Talk with other people about what you can do to make sure everyone can be included.

Mentorship

by Stacey Milbern

“In learning you will teach, and in teaching you will learn.”

– Phil Collins, singer

A mentorship relationship can be the most important, life-changing relationship in two peoples' lives. Mentorship can happen in smaller ways, like helping someone learn the ropes of a job. It can also happen in large ways, like helping someone realize that they can do something they never imagined for themselves. Mentorship can happen between anyone. It is common to see mentorship happening between someone who is more established in something (the “mentor”) and someone who is less experienced in that area (the “mentee”).

A few examples of mentorship relationships

- A teacher who takes time after class to meet with a student and introduces that student to new ideas
- A 26 year old girl and her 18 year old cousin talking about how to date safely
- A studio producer showing a new artist how the music industry works
- A community organizer inspiring someone to be an activist

Mentorship is often a relationship where one person gives and the other takes. In this kind of mentorship relationship, both people agree to this dynamic so it's okay for one person to give and one person to take.

There are many scholars who study mentorship. One new idea these scholars are talking about is co-mentorship. Co-mentorship is a relationship where both people benefit equally from the relationship.

An example of co-mentorship

Jen and Irene met at church. Jen is 20 years old and Irene is 75 years old. Irene loves the spunk Jen has. Jen appreciates Irene's perspective on life. Jen and Irene start having lunch every week because they enjoy each other's company. Jen inspires Irene to try new things. Irene gives Jen advice on how to deal with issues in her family. They would never call each other a mentor, but they learn a lot from each other. Both people benefit.

Some common features of a co-mentorship relationship

- Both people give and take equally.
- Both share power.
- Conversation is not just about one topic, but it is holistic [whole].
- People take more risk sharing their feelings. They are more vulnerable with each other.
- People don't take on official language. (This means, they rarely call each other "mentor" or "mentee").

Everyone can be a mentor, just like anyone can be a co-mentor. We all have things to offer each other. Look around you. Who could be your mentor? What could you offer to another person? How could mentorship make your life better? How can mentorship make the community better?

Identity-first language

by ASAN intern Lydia Brown

Originally published on Lydia's blog: Autistic Hoya, under the title
The Significance of Semantics: Person-First Language: Why It Matters.

At an Adult Services Subcommittee meeting, much to-do was made about semantic disagreements — “ASD individual” versus “individual with ASD,” and of course, the dreaded “person with autism” or “person who has autism” versus “autistic person.” These issues of semantics are hot button issues, and rightfully so.

Words and language are powerful tools by which an individual can express ideas, whether abstract, actionable, or concrete. As a writer and editor, I know firsthand that language and the meanings we attach to words very much impact, influence, develop, and change the attitudes that we have toward the subjects of discussion. That is why people are easily insulted or upset by word choices. Changing a phrase — even if it holds the same literal meaning — alters the subtle connotations and nuances of the speech, and communicates a different meaning and context than the original phrasing.

In the autism community, many self-advocates and their allies prefer terminology such as “Autistic,” “Autistic person,” or “Autistic individual” because we understand autism as an inherent part of an individual's identity — the same way one refers to “Muslims,” “African-Americans,” “Lesbian/Gay/Bisexual/Transgender/Queer,” “Chinese,” “gifted,” “athletic,” or “Jewish.” On the other hand, many parents of Autistic people and professionals who work with Autistic people prefer terminology such as “person with autism,” “people with autism,” or “individual with ASD” because they do not consider autism to be part of an individual's identity and do not want their children to be identified or referred to as “Autistic.” They want “person-first language,” that puts

“person” before any identifier such as “autism,” in order to emphasize the humanity of their children.

Yet, while I have been familiar with this rift among the autism community over the use of “person with autism” as opposed to “Autistic person,” I hadn’t fully explored the diversity of perspectives on the topic until now.

During last Wednesday’s meeting, one subcommittee member, who I believe is the parent of an Autistic child, and an Autistic self-advocate expressed disagreement over the terms. Feedback from one of our members suggested changing “ASD individual” in our report to “individual with ASD.” The Autistic self-advocate sitting beside me, who also has an Autistic brother, voiced her objection to use of the term. “I disagree,” she said as the suggestion was read aloud. “I’m not a person with autism; I am Autistic.”

Immediately, a mother sitting next to her responded, “I come from a time where that word, ‘autistic,’ had — still has — a negative meaning. It’s offensive. When someone refers to my son as ‘the autistic,’ I cringe at that word; I get ready to defend him.”

After our meeting, I took the time to explore a wealth of opinions online about the use of person-first language — from those who support it and those who oppose it. The theory behind person-first language is that it puts the person before the disability or the condition, and emphasizes the value and worth of the individual by recognizing them as a person instead of a condition. And that’s a great idea. In fact, when discussing specific people, I have never once heard anyone — self-advocate, parent, teacher, or otherwise — refer to a person as anything except by his or her name. I can’t think of any teacher — at least any decent one — who would refer to a student as “that Autistic kid,” or “that kid with autism.” And I certainly can’t think of any parent who wouldn’t refer to his or her child by name.

But why are we self-advocates so opposed to this terminology? Aren’t we all about de-emphasizing and correcting inaccurate, misleading, and harmful stereotypes and

attitudes? Right? From that other perspective, you would think we would support the use of person-first language, because we want to be seen as people with equal rights, value, and worth to non-Autistic people. But we don't. Because when people say "person with autism," it does have an attitudinal nuance. It suggests that the person can be separated from autism, which simply isn't true. It is impossible to separate a person from autism, just as it is impossible to separate a person from the color of his or her skin.

One argument I encountered in one of the more cogently-written papers in favor of person-first language expostulates that because cancer patients are referred to as "people with cancer" or "people who have cancer," as opposed to "cancerous people," the same principle should be used with autism. There are some fundamental flaws with this analogy, however.

Cancer is a disease that ultimately kills if not treated or put into long-term remission. There is absolutely nothing positive, edifying, or meaningful about cancer. Cancer is not a part of a person's identity or the way in which an individual experiences and understands the world around him or her. It is not all-pervasive.

Autism, however, is not a disease. It is a neurological, developmental condition; it is considered a disorder, and it is disabling in many and varied ways. It is lifelong. It does not harm or kill of its own accord. It is an edifying and meaningful component of a person's identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all-pervasive.

What I found most interesting in reading this selection of articles and blog posts is that many of the same arguments are used for both positions, but with separate sides, naturally, coming to very divergent and contradictory conclusions.

Firstly, I saw in at least two articles in favor of using "person with autism" that the authors strongly oppose language referring to disabilities like "suffers from," (i.e. "Alan suffers from Asperger's syndrome;" "Joey, an autism sufferer;" etc.) which has

traditionally been a talking point of self-advocates as well. I do understand that not everyone who supports the use of terminology “person with autism” would disagree with language like “suffers from,” but it is still interesting that there are those who do. It suggests a fundamental shared value — that people with different neurological conditions are not “suffering” because of their difference or disability.

Secondly, as alluded earlier, those on both sides want to emphasize the value and worth of the person. Person-first language advocates believe the best way to do this is through literally putting the noun identifying “person” before any other identifiers. (As noted in one of the other articles opposing person-first language, however, English is a language that puts adjectives before nouns, whereas there are multiple languages that always place adjectives after nouns. In Spanish, for example, “person with autism” is “persona con autismo,” while “Autistic person” becomes “persona autística.” In both cases, autism/Autistic follows the noun.) Person-first language opponents believe the best way to do this is by recognizing and edifying the person’s identity as an Autistic person as opposed to shunting an essential part of the person’s identity to the side in favor of political correctness.

It is impossible to affirm the value and worth of an Autistic person without recognizing his or her identity as an Autistic person. Referring to me as “a person with autism,” or “an individual with ASD” demeans who I am because it denies who I am.

Lastly, what is most interesting indeed is the shared expressed sentiments that using or not using person-first language is necessary to change and shift societal attitudes toward Autistic people. Returning to the premise of this article, this is the sole reason why this debate continues to be argued and why many people on both sides regularly emerge upset and feel personally attacked.

Language does play a large role in shaping societal attitudes.

But let’s think about what we are doing when we use these terms. When we say “person with autism,” we say that it is unfortunate and an accident that a person is

Autistic. We affirm that the person has value and worth, and that autism is entirely separate from what gives him or her value and worth. In fact, we are saying that autism is detrimental to value and worth as a person, which is why we separate the condition with the word “with” or “has.” Ultimately, what we are saying when we say “person with autism” is that the person would be better off if not Autistic, and that it would have been better if he or she had been born typical. We suppress the individual’s identity as an Autistic person because we are saying that autism is something inherently bad like a disease.

Yet, when we say “Autistic person,” we recognize, affirm, and validate an individual’s identity as an Autistic person. We recognize the value and worth of that individual as an Autistic person — that being Autistic is not a condition absolutely irreconcilable with regarding people as inherently valuable and worth something. We affirm the individual’s potential to grow and mature, to overcome challenges and disability, and to live a meaningful life as an Autistic. Ultimately, we are accepting that the individual is different from non-Autistic people—and that that’s not a tragedy, and we are showing that we are not afraid or ashamed to recognize that difference.

That’s why, when I read a few articles scoffing entirely at the debate, and dismissing it as ultimately irrelevant (insisting that each person should use the terminology he or she prefers and to ignore what other people say or write), I was concerned. The question of person-first language is definitely important and cannot be disregarded. The way we use language affects those around us — in our immediate communities and in society at large. Trends of language have the power to transform ideas and attitudes. To dismiss this as “a silly semantics argument” denies the power of language.

What does, however, disturb me is the vitriol during debates about this (and similar) topics in the autism community. While it is, as repeatedly emphasized, an important debate with huge ramifications both short-term and long-term, hurling ad hominem insults, making baseless accusations, and shouting over tables (or computer

screens) at the people on the other side ultimately demeans both you and them. It shows great immaturity, inability to civilly and peaceably discuss important topics, and insensitivity to the personal experiences vested in each of us with a stake in this debate. Having strong opinions on a topic and being able to have a respectful discussion with someone else are not mutually exclusive.

So what can we do moving forward? Or, more importantly, what should we do? To those of you who use “person with autism,” I will always respect your Constitutional right to express yourself however you like, but I urge you to reconsider the consequences of using such language. To those of you who use “Autistic person,” I urge you to consistently use such phrasing everywhere possible, whenever discussing autism and issues that affect Autistic people, and to develop coherent, rational explanations for why you prefer this terminology, so that you can engage in such mutually respectful and civil exchanges with others.

That, actually, goes for everyone. If we ever want to accomplish anything as a community, as a movement, or as advocates, we cannot allow ourselves to be constantly divided by infighting and vicious bullying — and yes, that occurs from all sides of these debates, not just one. It is imperative that we learn to engage critically and respectfully with one another, and to value each individual’s voice and feelings as equally important. Otherwise, we’ll become even more dysfunctional than my subcommittee has been in recent months.

Neurodiversity & Self-Advocacy: A Personal and Internet History

By Leah Jane Grantham

“This is my voice. There are many like it, but this one is mine”

– Shane Koyczan

The history of self-advocacy is a story of pioneering and revolution. It’s an ongoing story to this day, which I am proud to participate in as an autistic self-advocate, and nothing is quite as exciting to me as watching this movement expand and transform as I participate in it. The ultimate force in shaping neurodiversity and self-advocacy in my life can be illustrated by various small acts of self-advocacy in my life, and keeping the “Iceberg Effect” in mind.

What do I mean by the “Iceberg Effect”? It’s simple: it refers to the fact that appearances can be deceiving. When you look at an iceberg out floating on the water, your eyes can deceive you into thinking that’s all there is to the iceberg. Nothing could be further from the truth. That’s only a small portion breaking through the water. Underneath the water, icebergs can be jaw-droppingly massive and have the power to sink ships, among other things.

This relates to the neurodiversity movement each time we do an in-person protest, such as the recent protests against the Judge Rotenberg Center at the Massachusetts State Legislature. There were many luminaries and supporters of the neurodiversity community there, holding up signs, protesting, encouraging local politicians to stand up for human rights and shut down the Center once and for all. But the photographs of the event couldn’t tell the whole story – couldn’t show the hundreds of people like me, who couldn’t physically show up at the Massachusetts Legislature to protest, but offered our support and solidarity with the protesters on Facebook, Twitter, Tumblr, and our blogs.

We constitute the invisible part of the iceberg that makes up the majority of the neurodiversity movement. Online activists may not have the time, health, money, and resources necessary to travel to various protests, but our spirit and our dedication to the cause help petitions get signed, news stories released, and statements made. The Internet has played an essential role in the development and flourishing of the self-advocacy/neurodiversity movement. The Internet offers unique opportunities for disabled people to organize and advocate. Many disabled people can be limited from participating in real-life rallies and protests, either because the events are not accessible, they lack the “spoons” (the ability) to go out unless absolutely necessary, they may not have the money, time or resources to protest; they may not be able to make it if it requires transportation, or because they fear that their way of communicating will be lost in a large crowd.

With the advent of online activism, many of these fears became a non-issue. It requires far less energy and resources to write a blog post or participate in online discussions compared to arranging the free time and transportation necessary to attend a protest. Adaptive technology and accommodations, such as captions, voice-to-text adapters, transcripts, and other methods, makes the Internet more accessible for those who have different ways of communicating. The anonymity of the Internet makes it safer to protest for those who may worry about the reactions of controlling/abusive caretakers and family. The Internet has a wider pool of people to associate with, so if you have personal or ideological disagreements in your local disability community, the Internet poses an alternative.

Apart from connecting people across large spans of distance, the Internet also strengthened the self-advocacy/neurodiversity movement by giving people who would otherwise be ignored or marginalized the chance to tell their stories with creativity and honesty. One example of this in neurodiversity history is Amanda Baggs’ video, *In My Language*, which she uploaded to Youtube in 2007. Amanda’s video played around with the previously mentioned Iceberg Effect, challenging people to look past their

presumptions about nonverbal people to see her form of communication as a valid form worth respecting.

The history of self-advocacy before the Internet is important to understand, if one wants to grasp how it was a “game changer” in the lives of self-advocates and the power of self-advocacy organizations. In North America, self-advocacy of the disabled entered the public eye in 1854, when the New England Gallaudet Association of the Deaf was formed. Later, in 1880, the National Association of the Deaf followed it. The Museum of Disability attributes this quote to the National Association of the Deaf, a precursor to the modern motto of “Nothing about us without us”: “We have interests particular to ourselves which can be taken care of by ourselves”.

But it was the 20th century that really saw the kick-start of self-advocacy. Helen Keller, probably the most internationally, historically famous self-advocate, raised funds for The American Foundation for the Blind, and advocated for the rights of workers who were injured and disabled on the job. It wasn’t until the 1970s, however, that self-advocacy would become a united movement that included people with cognitive and intellectual disabilities as well as those with physical disabilities. Now, in the 21st century, with the advent of Internet organization, skype, webinars, and other means of user-friendly online communication across the world, this has allowed greater participation for people with all types of disabilities interact with the disability rights community and advocate for themselves and with others.

I entered the world of Internet self-advocacy and disability community through websites like Aspies for Freedom, WrongPlanet, and various disability-oriented blogs. Up until that point in my life, the only resources on disability that I’d been made aware of were primarily books directed towards parents, given to my mother to understand me, but nothing to help me understand myself and my own condition. The books my mother read were inscrutable and depressing. I didn’t recognize myself in the examples given of autistic children, who were almost uniformly male, and painted with words of pity, isolation, and hopelessness. This was not my reality, and I needed to

seek out ones fit mine better. These websites and forums filled that void in my life with much more personal, uncensored stories from the minds and blogs of autistic people, in their own words. It was a profound experience that changed the way I saw my disability and myself.

Eventually, I started my own blog, hoping to join the conversations and offer yet another perspective, because my time on autism forums taught me that there was no one universal experience with autism, and that all of them were valuable and worth listening to, not just the stories of the pitied or the ones who “overcame” their autism. Blogging helped me connect with other autistic self-advocates, and I’ve found great happiness and satisfaction in collaboration and advocacy, all of which I am capable of because I can connect with other self-advocates through blogging and social networking.

The original credo of the disability community is simple and powerful: Nothing about us without us. The Internet has played an integral role in allowing everyone, regardless of the presence of disability, to participate in self-advocacy.

How do I get involved?

Getting involved in self-advocacy is easier than ever, but it’s always nice to know where to begin. The first step is to have a look around the Internet, and see what kind of self-advocacy appeals to you. Go onto a search engine, like Google, and type in “neurodiversity”, “autism positive” or “autism self-advocacy”, and see what comes up. Look for websites written by autistic people, or which have a focus on the contributions and involvement of autistic people. You’ll probably feel more welcomed there than you would at a parents/researcher-centric website.

When you’re searching the Internet, keep in mind that there’s no filter for the quality and truthfulness of the content. There are a lot of websites out there which post lies about autism, or which post hateful, inflammatory, or violent ideas and words. It’s up

to you to filter out which ones are the truthful sites and which ones are not, but there are a few ways you can take mental “shortcuts” to tell which ones are deceiving you and which ones are genuine. One way to do so is to observe the attitude of the author towards autism. Are they an autistic person themselves? If they’re autistic, what’s their outlook on their autism? Do they see it as a burden, or do they think their autism gets in the way of them doing “normal” activities, like socializing, dating, having sex, or having a job? If it’s all negative coverage of autism, that should arouse suspicion. Autism has its ups and downs like any other disability, but a constant focus on how it holds you back is not a neurodiversity-positive attitude. Blaming autism, rather than the ableism and barriers of society and discussing how those could be improved upon or eliminated, is another alarming sign that the website isn’t neurodiversity-positive. Another red flag is language use: Does the person compare autism to a debilitating or fatal disease, like cancer or AIDS? Do they compare autism to something malignant or evil, like a tumour or a plague, which needs curing? These are clear signs to stay away.

There are positive indicators you can look for though! Does the blog/website cover a diverse variety of experiences related to autism? Does the blogger/website talk about autism with the language of neurodiversity and the social model of disability? If so, you can probably gain a lot from what they have to offer, and are definitely worth subscribing to.

Once you have a good blogroll of a variety of autistic experiences, you can get involved with your own social network or blog. On Twitter, keep an eye out for autism-related hashtags. Random trends can often be pleasant surprises, such as the autism positivity flash mob, or they can be chances to advocate: see, for example, the autism twitter campaign against TV programs which talk about autism without including any autistic people. On Tumblr, there’s the #actuallyautistic and #autism tags, along with #neurodiversity and #autismpositivity (Tumblr uses the # symbol to identify tags, or searchable topics). It’s out there, if you know where to look. Keeping an eye out on the trends can help you advocate along with other autistic advocates. Don’t forget to write about whatever strikes your fancy or you think needs attention though! The world

needs as many unique autistic outlooks as it can get, and don't let what everyone else is writing about hold you back from offering your own perspective on new and different topics.

For me, autism blogging and self-advocacy means that not only do I get to share my own viewpoint with the world, but I also get to be part of something far larger than myself, composed of many who are, like me, offering their voices and their advocacy out to the world. If I've seen further than some, it's only because I've stood on the shoulders of giants.

Including members who use augmentative and alternative ways to communicate

by Self-Advocates Becoming Empowered



All of us have a voice. But for some, it is not always the voice we are used to hearing. When people assume you can't communicate, they often make decisions for you. But, you don't have to have a voice box in your throat to get your message across. There are many devices to help people communicate and there are ways to make sure their voice is heard loud and clear. Let's learn to listen to each other, and open up doors for everyone.

Story by Tracy Thresher wretchesandjabberers.org



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.

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. A person may be too upset, timid or shy 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.



Tips On How To Include Members Who Use Computers Or Other Ways To Communicate:

Before a Meeting

- ☆ Let members know what is on the agenda. If members know ahead of time, they can bring a picture or an object to help describe what they want to communicate. They can also write what they want to say ahead of time.

During a Meeting

- ☆ Avoid making a person feel like they are taking too long:
 - ❖ Give enough time to think about a topic.
 - ❖ Give enough time to answer.
 - ❖ Don't talk right over us or change the subject when somebody is still typing.
- ☆ People should see and hear what we are typing. Successful meetings are when we have a projector so people see what we are typing.
- ☆ Once you see somebody typing, don't go on to the next topic until they get to share. The thing that people do not understand is we cannot be spontaneous and that it is work to put verbal words on paper.
- ☆ In general it is good to cue the group when they should slow down and wait for someone to finish a thought or ask a question.
- ☆ Take a break and debrief before a decision is made or a vote is taken. We need to make sure that everybody is heard.

- ☆ Don't be so quick to judge and say that someone is saying something off topic. Give the person a chance and eventually they will come around to make their point.
- ☆ Communication is everything. Give me opportunities to communicate throughout the activity or meeting.



What Can Communication Partners Do? Adapted from Vermont Communication Task Force <http://goo.gl/ZklHi>

- ☐ Believe that I am intelligent and have things to say.
- ☐ Support people to get equipment that helps them communicate.
- ☐ Let me answer for myself when people ask me questions. Don't answer for me.
- ☐ Give me chances to have casual conversations with other people during the activity or meeting.
- ☐ Remember that all people use body language to communicate.
- ☐ Don't always ask me yes/no questions. Ask me "what, where, when, why and how" questions.
- ☐ Tell others to talk to me directly to me, not my support person or companion.
- ☐ Do not finish my sentences. Listen until I have finished typing, even if you think you know what I might say.
- ☐ You need to be patient with FC users who find it hard to respond during a meeting. Support them to communicate their thoughts afterwards to the meeting participants.

How to start and run your own local self-advocacy group

By Self-Advocates Becoming Empowered



The term self-advocacy means persons with disabilities taking charge of their personal lives. It is a movement where we strongly encourage our peers to speak up. Self-advocacy groups can be an amazing and empowering experience. Belonging to a self-advocacy group gives power to individual members and to the group together. It is one of the best ways to discover the different stages of self-advocacy:

1. **Standing Up For Yourself** - This is when people find their voice and start to use it.
2. **Standing Up For A Friend** - After a person is feeling comfortable speaking up for themselves, you may see that they start advocating for others.
3. **Standing Together As A Group** – “I belong to Becoming Empowered of Rutland.”
We have a stronger voice when we work and speak up together.

In 2012, there were over 1,200 local self-advocacy groups across the nation. They are our grassroots. You can't have self-advocacy without supporting a network of local self-advocacy groups!



We are just not any organization; we have a purpose. The purpose of self-advocacy is to strengthen our peer connections. A peer connection is when you connect with somebody that may have been through the same challenges as you. A peer is not a staff person or an advisor. It is not a

parent or guardian. A peer is another person with an intellectual and developmental disability. It is important to have a peer-to-peer connection because you learn how much you have in common. The strength of your self-advocacy increases. When you get involved, you realize you are not alone when facing tough times.

Local groups are the key because it is important for the information to come from us. You get the honest truth from your peers. You are hearing it through the experience of

peers directly. When information comes from others, it can be sugar coated; the environment can feel too controlling and biased. Self-advocates should start out by running their own group meetings. This is so you can learn to advocate directly about your needs in life.



So you may be curious to know what it looks like to run a meeting effectively? It does **NOT** mean having your advisors in charge. Let them be there to assist you only when needed. Local groups have elected officers: a President, Vice-President, Secretary, and Treasurer. Some groups also have a Sergeant at Arms to help keep meetings on track. The officers set an agenda ahead of time often having a separate meeting or conference call. Common agenda topics include a list of group agreements (“Rules”) that officers help the group put together. A common item could be a prompting question that allows people to discuss how they’re doing. Another common topic is preparation for upcoming events, such as: legislative advocacy, social activities (dances) and educational trainings.



Some groups do well in community outreach. For example, visiting local high schools and universities, and participating in parades. The purpose of this is to get more disability awareness out to the public.

What are the benefits of running your own group? First, it encourages peer to peer connections. Having a self-advocacy group creates an atmosphere where persons with disabilities feel safe and welcome. A lot of self-advocates have been through times of feeling isolated. It’s good when people meet others that have shared the same experiences. You also can develop better skills at being less afraid of speaking up with other people. Being part of a group can also give you more social confidence, to treat people with respect, even if they are not quite like you. So, get out there and get involved! Your self-advocacy group needs you!



Steps To Starting A Successful Self-Advocacy Group

It is important for members of the group to have control right from the beginning so that the group will belong to the members. Starting a group takes time so that everyone will understand what is going on and can feel involved.

1. Make sure that everyone understands what a self-advocacy group does, and why people meet as a group.
2. Decide on the responsibilities for getting the group going: place to meet, transportation, publicity, etc.
3. Find out how other groups work and learn from them. Invite another group to visit and talk about their experiences.
4. Decide on group agreements. It is important that we know how the group is going to work. We want to be sure we have a group that is safe and fair for all. These aren't "rules", these are agreements. We are all agreeing to these ideas.
5. Develop "team spirit" and a good working friendship with members.
6. Decide on goals for the group; start small, then build up to bigger things.
7. Create an action plan: the ways to reach your goals.
8. Develop "connections" with the community.
9. Evaluate the group, then make changes as you go.

Making meetings make sense: Because words can be confusing

By Self-Advocates Becoming Empowered



Attending a meeting with a new group of people can be a confusing experience. Words can be welcoming or make you feel left out. We have found that some groups use mentors to introduce new members to how the group works. A mentor might describe the current members, the roles of group members, group priorities and the organization's background.



We have come up with strategies on how to prepare for and conduct meetings that strive to include people with intellectual disabilities. These guidelines do not address how a room is set up before a meeting or attend to sensory issues. We do not focus on accommodations for people who are deaf, blind, have hearing loss or low vision.



People with intellectual disabilities might need to get necessary support before, during and after 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 opinion, make suggestions and informed decisions. Inclusion is more than just being present; it involves active participation.



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 an agenda that is understandable and doable in the time you have.
- ❑ 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...

- ❑ Create a list of group agreements and read them aloud. This is so a meeting can stay on track.

- ☐ 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 retardation”.
- ☐ Do introductions to remind folks who is there. Introductions make you feel “not left out”.
- ☐ Let folks know where things are, like the restrooms.
- ☐ Speak clearly. Use words that everyone understands, no abbreviations or acronyms.
- ☐ 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. Use patience before responding.
- ☐ Keep confidentiality. What is said in the room stays in the room!
- ☐ 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.
- ☐ Read aloud written information not sent out ahead of time.
- ☐ 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 accommodations will work best for them.

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 intellectual and 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 intellectual and developmental disabilities live and work throughout the United States. An effective approach for recruiting state and local peer leaders is to establish a relationship with a state self-advocacy organization. It is our goal to assist national, state and local organizations as they continue to develop their groups to reflect the philosophy of inclusion and to model active participation.

Accommodations during meetings for autistic individuals

by Elesia Ashkenazy

Autistic Access Needs: Notes on Accessibility

Looking for ways to meet the access needs of Autistic individuals? Do you wish to avoid dropping the ball at your function, get-together, or meeting? The autistic spectrum includes a wide variety of individuals with an equally wide variety of support needs. Planning ahead for your Autistic guests will help establish balanced and fair participation.

Important points to consider

The lists below consist of access needs, and are not conveniences or luxuries.

Misunderstanding and unnecessary obstacles have often limited Autistic participation in the national self-advocacy movement. This causes frustration and discourages Autistic individuals from learning about and engaging in self-advocacy activities—both personally and in larger society. The Autistic community is decades behind the Intellectual Disability community in terms of development of a self-advocacy movement. More enthusiasm and accommodation from others is necessary to support our community's further growth.

Unfortunately, there is widespread critical misunderstanding of the needs and abilities of individuals with developmental disabilities who achieve socially or culturally recognized competency in a publicly visible way.

Common Support Needs

GROUPS

- Large groups can be over-stimulating and overwhelming for Autistic people. For example, large groups can pose difficulty for Autistic people who struggle to time responses or understand other social nuances of large groups.
- Many Autistic people often share that “the right words” do not always come easily. And for some, words can be non-native to their individual mode of thinking. (Some Autistic people describe words as flattened translated inaccurate versions of what they truly wish to express.)
- For Autistic people who struggle with communication issues, and/or sensory overload, small groups can provide a much better option for meaningful participation.
- Separate rooms for small group discussions can help prevent an Autistic person from experiencing undue sensory overload.

AGENDAS

- Providing agendas and materials in advance, in addition to sticking closely to agendas can go a long way in terms of accommodating an Autistic person.
- Changing agendas pre or mid-meeting can throw Autistic people off, as well as cause access issues.

SENSORY NEEDS

- Avoid holding conferences in hotels with large waterfalls or other similar types of background noise.
- Due to Central Auditory Processing Disorder (CAPD), many Autistic people report difficulty understanding auditory information, and especially so when background

noise is present—separating foreground from background noise is taxing (and also poses issues for blind and/or deaf individuals who are Autistic).

- Closing doors (to shut out background noise) can be helpful.
- Designated sensory retreat rooms provide a safe space to manage overload and give people a place to go if they need to retreat from an over-stimulating and/or overwhelming situation.
- Sensory retreat rooms should be easily accessible, but free of outside stimulation (e.g. away from elevators and escalators).
- Offering disposable earplugs is another way to accommodate Autistic people with sensory sensitivities to sound.
- Request that attendees to avoid wearing perfumes or using strongly scented toiletries (e.g. shampoos, lotions, etc.) Doing so can Autistic people avoid sensory overload.
- Use non-fluorescent lighting, or other accommodations for reducing visual stimulus. Natural lighting is best. If unavailable, incandescent lighting would be the next appropriate option as it is much more tolerable. As for compact fluorescent lighting, it can cause severe sensory issues with balance, dizziness, and communication.
- Be mindful that flash photography can cause seizures in Autistic people who have seizures and/or epilepsy.
- Sound systems should also be taken into consideration. Monitor volume levels and feedback. Noisome sounds like feedback have the potential to cause some Autistic people to completely shut down.

SOCIAL ACCOMMODATIONS

Autistic Network International (ANI, <http://www.autreat.com/>) created color-coded interaction signal badges consisting of plastic name badge holders with a piece of red paper on one side, and a piece of yellow paper on the other. People needing to restrict interaction could wear a badge with the red side facing out to signify, “Please do not interact with me,” or with the yellow side facing out to signify, “Only people I already know should interact with me, not strangers.” Another color option could be used to signify, “I am fine with interaction.” These badges have been used for over 10 years at Autreat, the Autistic community’s annual conference.

RESPECTFUL LANGUAGE

- Identify-first language verses person-first language should also be taken into consideration.
- The Autistic community prefers to be referred to as Autistic, in much the same way the Blind and Deaf communities prefer to be referred to as Blind or Deaf. To drive the point home, the terms hearing impaired and visually impaired are often offensive to the Blind and Deaf communities. Referring to an Autistic person as a person with autism is often offensive in the Autistic community.

ACCESSIBLE LANGUAGE + FACILITATION

- Has the meeting facilitator been trained on the needs of Autistic self-advocates?
- Semantic and pragmatic understanding of oral and written language used should be maximized.
- Pre-writing questions that will be asked to the group (and making them large and visible) helps facilitate Autistic communication and participation.
- Ensure Autistic people have enough time to process what is being asked before moving forward.

- Conduct meetings online when possible (via an Instant Message chat service, such as Skype—no phone or video, text only). Phone conversations and/or meetings can pose a problem for Autistics who have Auditory Processing Disorder and who might struggle with voice as opposed to text. IM chats also often provide a workable solution to address social anxiety issues.

Other specific meeting accommodations to consider

- Make it possible for someone else to register and/or pick up registration information for people on the spectrum who are easily overwhelmed by crowds, noise, communication, and massive (usually early morning) overstimulation.
- Provide conference schedule information in advance. This should include information about who is presenting when and about what, which in turn helps in the planning of necessary breaks and downtime, as well as helps make the event more predictable and less stressful.
- Note bathrooms, exits, and retreat rooms in bold.
- Are there power outlets, flat surfaces, or any other items needed to operate necessary assistive technology throughout the duration of the event?
- Provide alternative modes of participation to real-time face-to-face. For example, group conference IM chat via Internet.
- Offer sensory friendly areas. Even though large meeting locations typically come under the strobe-and-buzz of fluorescent lights, there is usually some room or area that can be set aside to be bright light & fluorescent free, and quiet, for people to retreat to as needed. Better yet, use meeting sites that offer incandescent or natural lighting, neutral walls and carpeting, a quiet setting, and otherwise are just sensory friendly in general.

- Slow down! It can be really, really hard or impossible to process the amount of information that is typically thrown out in a conference or workshop. It's better to fully understand a smaller amount of ideas than to not understand any ideas at all.
- Have a clearly stated protocol for how to participate—how will everyone who wants to get a turn to speak communicate during the meeting?
- Give information in more than one way. Don't just present with the blah blah blah—use images, movements, demonstrations, provide written information.

Communication is an active, dynamic process between two or more people. It is not something a single person does or does not do; it is something people do together. Yes, those of us who communicate in non-standard ways should make an effort to make communication easy for others—if only because it in turn will make the exchange easier for us since there will be less confusion and resistance from our communication partners. But also, others need to make that same (and sometimes a bit extra) effort for us. We like things to be easy too. And sometimes it's not even a question of ease—we may need others to make that extra effort to communicate with us on our own terms because otherwise we can't find our way to the common ground where communication can occur at all. Communication is a two way street.

Interview with Jim Sinclair

by Elesia Ashkenazy

Jim Sinclair lives in Syracuse, New York. Xe is an autism rights activist, as well as one of the founders of Autism Network International (ANI). (“Xe” is a gender neutral pronoun.)

What issues are of utmost importance to the Autistic community at this time?

I can think of a bunch of them, but I would say they all basically come down to ignorance about what autism is: There’s more effort, funding, and research being directed at preventing the existence of future autistic people than at supporting and maximizing opportunity for autistic people who already exist.

Many of the “services” that do exist for autistic people are not as helpful as they could be, and often are even counterproductive, because they don’t accommodate the way autistic brains work.

The misconception that any given autistic person has an across-the-board “functioning level” means that people considered “low functioning” are denied opportunities for access and self-determination because it’s presumed that they’re unable to benefit from those opportunities; while people considered “high functioning” are denied supports that would enable them to pursue opportunities, because it’s presumed that they’re able to function without needing those supports.

How can others become involved?

You mean as allies? Become educated about autism—NOT by reading materials by non-autistic people about how terrible autism is, but by getting to know autistic people. And not just by reading books written by anyone at all—autistic or non-autistic. Meet us and spend time with us and relate to us as equals, not as

beneficiaries of special help. Online forums run by autistic people, where most of the participants are autistic, are good places to “meet” autistic people in autistic space where we’re allowed to be ourselves, instead of being expected to appear neurotypical.

Live autistic gatherings, such as Autreat, are even better if someone really wants to become involved. I remember I once told someone that I hoped he would come to Autreat, because I wanted him to be able to see me in an environment where I’m not handicapped. In the environment where he usually saw me, I was very handicapped. At Autreat, I’m just as autistic as I am everywhere else, but I’m not handicapped. If you get to see autistic people functioning in an autistic-friendly environment, you see a whole different picture than the typical tragic images of autism.

Speak up whenever and wherever you see anti-autism propaganda, puzzle logos, etc. Maybe carry around copies of leaflets like the one produced by the Autistic Advocacy Group, to hand out when the occasion arises. Write letters to newspapers, television and radio stations, and Internet news outlets critiquing their autism coverage. If you see that a local business is running an anti-autism campaign, take them to task for it, and urge them to do something to promote autism acceptance instead.

Write to your city school board, state and local legislators, and other officials demanding full access and adequate supports for autistic people to participate in education and community life.

Phil Schwarz has written some good stuff about allies. I think you can find at least one of his articles in the library at the Autism Information Library [<http://archive.autistics.org/library/>].

What are some a) resources and b) etiquette tips that someone new to the Autistic community may find helpful?

a) Of course I'm going to recommend Autism Network International.

Also look at autistics.org, The REAL Voice of Autism, Autistic Self Advocacy Network, and a whole lot of different blogs that you can access through The Autism Acceptance Project. There are a huge number of other resources that you can find if you start exploring those.

b) Be aware of sensory issues, and respect whatever unique sensory needs an autistic individual has. These vary a lot among people, so there are no etiquette rules that work for everyone—other than the #1 rule, which is NEVER ASSUME, ALWAYS ASK. The same thing goes for communication, especially nonverbal communication. Don't try to interpret facial expressions, body language, or tone of voice, because if you don't know this person very well, your interpretations are pretty much guaranteed to be wrong. Don't expect autistic people to be able to pick up on things you don't explicitly spell out for us. We have a whole set of guidelines for Autreat. Feel free to ask if you want to see them.

Etiquette snippets taken from the Autreat orientation guide, which are good to keep in mind around autistic people in any situation:

ASSISTIVE TECHNOLOGY: Many people use assistive technology (AT), such as wheelchairs and communication boards, in order to function. Please do not touch or climb on other people's AT devices without their permission. This applies to service animals too! Do not pet, call, talk to, make noises at, or attempt to feed or play with a service animal, unless the handler gives you permission.

FLASH PHOTOGRAPHY: Flashes of light can hurt people. Before using a camera

with a flash, you should get the permission of everyone in the area who will be affected by the flash, even if they will not be in the picture.

SCENTS: Many people are sensitive to scents. Please do not use scented products at Autreat. If you smoke in designated smoking areas, please be considerate about tobacco odors. If you use products that make it hard for other people to breathe, you may be asked to leave events.

SOUND: Many people at Autreat have auditory sensitivities and can be hurt by noises that are loud, unexpected, or at a frequency that is painful to the hearer. Please try to avoid making unnecessary loud noise. You don't need to go around on tiptoe and whisper all the time. Just try not to shout, bang, stomp, slam, or play music or television at high volume. Activities that are meant to be loud, such as African drumming, will be held in places that can be easily avoided by people who need to avoid them.

TOUCHING: Please do not touch other people without their permission! This includes routine [in non-autistic society] touching such as tapping people on the shoulder to get their attention. Many people at Autreat find it startling or unpleasant to be touched. If you already know a particular person and you know that person is comfortable with certain kinds of touch, fine. But do not touch people unless you know it is okay with them.

The role of allies, advisors and support workers

by Self-Advocates Becoming Empowered

Allies

By Tracy Thresher



There is a need for those “supporting” a person with a disability to slow down 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.

The Role of an Advisor

By Self-Advocates Becoming Empowered

Local Self-Advocacy groups are run by peers themselves, but sometimes it can be a challenge. This is where the role of advisors comes in. An advisors' job is **NOT** to run a group meeting. They are there to assist self-advocates.



Members of a local group are responsible for recruiting advisors to work with the group. It is a good idea for the group members to write a job description clearly saying what they want an advisor to do. The officers of a local group and the advisors work together like a team. Here are some of the possible roles of an advisor:

1. Before a group meeting, officers have meetings ahead of time to put together an agenda. Advisors are there to make sure nothing important slips through the cracks.

2. Advisors can assist with making sure everybody in the group is notified of the time and location of the meetings.
3. Some groups have refreshments during their meetings. Self-advocates usually bring the own, but an advisor can help keep track of who is bringing what.
4. Transportation is also important. Advisors usually don't give rides, but can make sure everybody gets to and from a meeting successfully.



When a meeting is in session, advisors are usually “invisible”, meaning they stay quiet and let the Self-Advocates take command. While going through the agenda, the advisors can support the officers to make sure the meeting stays on track. At anytime, advisors can be asked by the officers to make announcements to the group. Sometimes, officers can look to advisors to assist when somebody is having a difficult time, but it is best if peers support each other. Some groups handle these situations on their own, by electing a sergeant-at-arms. This person reminds everyone of the group agreements. They (or somebody else) could keep track of time, to keep the agenda on schedule.



When a meeting is over, advisors help by making sure everybody has a ride home. Advisors help self-advocates by putting the room back to how it was found. They make sure that everybody knows when and where the next meeting is, and any upcoming events.

Advisors are not there to take control of the meetings. For example, advisors shouldn't tell self-advocates how to run the meetings, or run the

meetings themselves. There are just there to give support. One important role of the advisors is to support the group to make sure everyone understands what is being discussed. Work together as a team so everyone has a chance to participate.

When the meetings are in session, just like everyone else, the advisor should only speak if they raise their hand and are called upon. As an advisor, keep this in mind: “pay no attention to the man behind the curtain”, like is said in the Wizard of Oz! Stay as “invisible” as possible, and let self-advocates be in charge!

What Makes A Good Ally?

By Chester Finn



Allies believe in the same values as us. When it comes to speaking up at the table they make sure we are not tokens. The allies support and help us to prepare things but it is our ideas. There are times when they share the knowledge that they know about a topic but they make their opinions after that. The opinion that they say is a reflection of what they get from us.

Many meetings we attend are not accessible. When meeting organizers do not meet our accommodations we need to use our allies to break down the information for us. If the information is not accessible then how are we going to understand what is going on and make a decision about an issue.

A lot of times people assume we are not smart enough so they don't tell us about changes or educate us on things. Part of what is important about having allies is that they tell us what is going on.



The Advisor's Role: Tips On What To Do

- Give advice to the group when asked.
- Treating people with respect means being open to everybody's ideas.
- Have creative ideas about the group; think outside the box.
- Look at a person's ability, not their disability; focus on their strengths.
- Feel comfortable with people with all different kinds of disabilities.
- Believe that labels hurt us: mental retardation, client, consumer, etc; use respectful language.
- Talk to us like adults, **NOT** children.
- Help us get to and from meetings.
- Show us how to make our own decisions, even if you do not agree.
- Encourage us to speak up for what we want to do.
- Give and take constructive criticism.
- Encourage us to use our own words.
- Go to all the meetings.
- Be our equal not our boss.
- Remind us about group agreements.
- "You have two ears and one mouth; use them accordingly." Please: listen to us.
- Find ways to help everyone get involved.
- Make sure everyone knows when and where the meetings are happening.



PLEASE

- 👉 Don't run the group
- 👉 Don't have a closed mind
- 👉 Don't take over for the leader
- 👉 Don't tell us what we should do
- 👉 Don't make decisions without the members
- 👉 Don't assume that everyone agrees
- 👉 Don't talk too much
- 👉 Don't do too much for us



How your brother or sister can support you in self advocacy

by John Kramer

Sibling relationships (relationships between brother and sister, brother and brother, or sister and sister) are often the longest lasting relationships people experience in life.

The language we use to describe sibling relationships can be tricky. During this essay, we will refer to people with disabilities as people with disabilities and their brothers and sisters as siblings.

What is unique about relationships between people with disabilities and their siblings?

Brother and sister relationships are one of the longest lasting relationships we experience in life. These relationships come in all shapes and sizes and often are one of the most central relationships in our families. People with disabilities are also brothers and sisters. It is important to note that some people refer to family or close friends who are just like sisters or brothers as siblings, and those types of relationships are just as valid and important.

In the 80s and 90s, researchers began to look at the impact of having a sibling with a disability. Many of these studies made assumptions that growing up with a brother or sister with a disability is inherently stressful. Researchers studied issues such as adjustment to loss, depression, behavior problems, worry, anxiety, etc. Their findings in those areas generally suggested that, all in all, sibling relationships are pretty much like any other sibling relationship. For example, people with disabilities and their brothers and sisters experience rivalry, jealousy and all the emotions that siblings often experience. They also experience friendship, closeness, and solidarity and often grow closer later in age. Assumptions that disability presents families with difficulties that most families do not have to experience can be unhealthy.

There are a few issues that seem to be common among siblings of people with disabilities. One example is when brothers or sisters take on too much responsibility – more than what would usually be expected of siblings. Parentification refers to a child taking on parental-type roles prematurely. Some people disagree about the effects of parentification, or even if it is always a bad thing, but many siblings of people with disabilities feel that too much responsibility is expected of them at too early of an age. We don't know as much about the perspectives of people with disabilities about this issue, from a research perspective, but many individuals with Intellectual and/or Developmental Disabilities (I/DD) are more interested in leading self-determined lives and want their brothers and sisters involved just as any other brother or sister would normally be involved.

Some questions for siblings with disabilities to ask themselves

How are my brothers and sisters different than my parents?

Are my siblings and I close? What do we do together? Do we do a lot of things together?

Do my brothers and sisters advise me? Do I help them out when they need me?

Siblings often make different choices than moms and dads about how to provide support.

Parents and siblings don't always agree on how best to support people with disabilities. For example, parents sometimes are protective of their son or daughter with a disability, while brothers and sisters may not feel that same concern, opting more to give the person with a disability the opportunity to take a risk. There is no one approach. Sometimes safety can and should be the first priority, while other times, the person with a disability could learn from taking a risk and failing. It is important for people with disabilities to keep this in mind too. If you want to do something that mom and dad disagree with because it might be too dangerous, sometimes it might help to get a brother or sister who is supportive to talk with you and your parents about it.

An example of where parents and brothers and sisters might have a different approach

While living in a major metropolitan city, a sibling decided to have his brother, who has a disability, fly out to visit. This was the first time the brother with a disability had ever flown by himself. The sibling was going to meet his brother with a disability at the airport, and they were going to head back into the city together.

When the plane landed, the sibling's mother began to call frequently to check up on if the sibling and his brother had found each other at the airport. The sibling was not at all worried about his brother with a disability, but the mother sure was! The sibling had already told his brother before the flight, "If you get into trouble, just talk to someone in a uniform." The sibling chose a more hands off approach, because he had trust in his brother with a disability, but the mother chose to be more actively engaged. Guess what? The sibling and his brother found each other just fine without the help of the parents, and without the help of anyone in a uniform!

Another example of a different approach could be related to getting a competitive job in the community. Whereas parents may be more focused on the longevity and the safety of a job offered by a work group, for example, siblings might be more inclined to connect their brother or sister to a competitive job in the community. In other words, some family members are more concerned with being "safe" than other aspects of employment such as working more hours or working farther away, etc.

An important point to remember is that siblings often see each other as equals, whereas they often do not view their parents as equals. This can translate into brothers and sisters doing different things together with each other than with their parents. Socializing out in the community with others who are comfortable with people with disabilities is a good place to start if siblings and their brothers and/or sisters with disabilities feel disconnected or lonely.

Things for brothers and sisters with disabilities to think about

- When is it better to have a “hands off” approach? When is it better to get more help?
- Oftentimes, a person you feel close to might not share the same thoughts about what you can or would like to accomplish. What vision does your family hold about your future? What possibilities do they see for you? Would you like to change your family’s concerns or opinions about your dreams and abilities?
- How do my brothers and sisters support me in different ways from my parents?
- What might I seek advice about from my parents? How is that different from advice I might seek from my siblings?

Sometimes life changes, and sometimes it stays the same

Brothers and sisters often drift apart so helping them to maintain a relationship, in an accessible way, over distance is a good first step. While many people with I/DD are living more independently than before, most continue to live at home with mom and dad for an extended period after high school. Brothers and sisters, on the other hand, are more likely to go off to college, get a job, and begin families of their own. All of this can sometimes feel like it creates both physical and emotional distance between siblings and their brothers and sisters with disabilities. It’s important to remember that people with disabilities often say they want the same things in life as their brothers and sisters.

As a result of these issues, many siblings find they drifting apart after high school and have a harder time maintaining their relationship. For people with disabilities—who often rely more on their families than their siblings do—this can create challenges. A key issue that many families of people with developmental disabilities have identified is distance. The National Family Caregiver Alliance says that there’s no one right way

to be a caregiver; there are many possibilities. Families of people with disabilities should pay close attention to what they can potentially manage from a distance and what they cannot.

Helpful tips for siblings, brothers and sisters, and their families

- Gather information by telephone or the web on medical conditions, medications, local community resources, support groups, and government programs. This can all go into a Letter of Intent (a document that explains preferences related to the care of a family member with a disability).
- Provide emotional support to relatives who need it, and to others on a care giving team, through regularly scheduled phone calls or e-mails. Also, friendly letters every week about activities and news can also include reminders to purchase medication or remember doctor's appointments.
- Use Internet services online for banking and bill paying, direct deposit or traditional mail.
- Have someone help you arrange and monitor hands-on services that help you.
- Have someone help you with arrangements and plans by using telephone calls, or emails, or even short visits to your home.
- Siblings can act as the primary contact for physicians, care providers, or others in family situations where this would be a good fit for all.

Siblings who need it should seek emotional support about any care giving challenges that arise. Discuss your situation and let your feelings out. Listening to and talking to others can provide some relief and help you to refuel.

How to contact a state or local representative

By Andee Joyce and Elesia Ashkenazy

Let's say you've heard or read about a bill that's coming up for a vote soon in the state legislature that could have an impact on the Autistic community. And you'd like to contact your state senator or local representative to ask them to vote for/against this bill. Maybe you'd even like to get an in-person meeting to discuss the bill.

But maybe these thoughts are crossing your mind:

"That sounds something I'd like to do but wouldn't dare try..."

"I might embarrass myself..."

"Speaking to someone on the phone or meeting with them face to face gives me the heebie-jeebies..."

You could e-mail or tweet your state senator, or mail them a letter. But do you know that live voices are more difficult to ignore and that they are likely to make more of an impact?

What can make contacting my state senator easier for me?

If you don't know who your local representatives are, you can find their names and contact information at: <http://thomas.loc.gov/home/state-legislatures.html>

From there, you will find a map. Click on your state to be taken to a screen where, at the bottom of the page, you will find a link that reads, Contact information and answers to frequently asked questions.

After clicking on it, about halfway down the page under, "Legislator Contact Information," there will be a link that reads, Find Your Legislator (State and Federal).

When you click on it, you will be prompted to enter your address, and then you will receive the contact information you need.

If you don't have Internet access, you can contact your state's Capitol building by phone and get information that way, or ask your local library for assistance.

1. Try a practice call first

It's unlikely that when you call (even during standard business hours), that you'll reach the Senator or Representative on the phone right away. If you get a live voice on the phone, it's likely going to be a receptionist or an assistant. These folks receive a high volume of calls a day. If you have phone anxieties, this can actually work to your advantage, as your phone call could be brief and over with fast!

It might help quell your fears to make a trial-run call at least one day before your official call. For example—without even having to identify yourself—you could call and say to the person who answers:

“Hello, could you tell me what the Senator/Representative's position on [official name of proposed legislation, referred to by number, title, or both] is?”

They'll tell you, and then you can say something like:

“Okay, thank you,” and hang up.

(Sometimes callers are put on hold before getting a chance to talk. Don't be alarmed if you have to wait for a few minutes.)

If you don't know the official name of the legislation you are concerned about, search for the link on the state legislature page (the same page that the “Find Your Legislator” link is on) that will take you to a search engine that can help you find it.

2. Prepare a script

If you think you might get tongue-tied when you make your official call, prepare a script to read from. The goal is to make your point clear and succinct. If you are simply calling to express an opinion about how you think the Senator/Representative should vote, your script can read something like:

“Hello, my name is Elesia, and I’m calling about the upcoming vote on [name of legislation]. As an Autistic self-advocate and member of the local Autistic Self Advocacy Network, I would like to ask [name of elected official] to vote for this legislation, because it would ensure that [reason the legislation is important].”

You can also read from the same script above if your call goes into voicemail. You might be asked to spell out your name and to share contact information; if not, thank them for their time—when you are finished leaving your message—and hang up.

3. Set up an in-person meeting (if you want to)

There may be instances where you want to get into more detail, especially if you know that the Senator or Representative is either undecided on the bill or plans to vote the opposite of how you want him or her to vote. You might like a chance to have an in-person meeting. In this case, your script can read:

“As [an Autistic self-advocate and member of the local Autistic Self Advocacy Network—or however you want to identify yourself], I understand Senator/ Representative [Last name] plans to vote for/against this legislation, and I have some information I think might change his/her mind. What can I do to get an in-person meeting with him/her?”

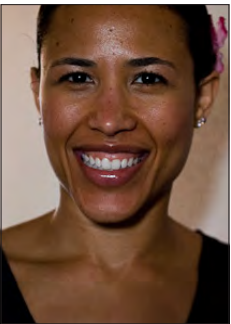
Your success in securing an in-person meeting often depends upon how much time there is between your call and the vote. The more lead time, the better your chance.

If you require ADA accommodations, give at least 72 hours notice, and make your request to the person assisting you on the phone.

Contributors



Katie Arnold is Executive Director of the Sibling Leadership Network (SLN), a national nonprofit whose mission is to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families. Her work is anchored to her experience growing up with her sister with developmental disabilities.



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Lydia Brown is an Autistic woman who interns for the Autistic Self Advocacy Network. She was the 2012 Patricia Morrissey Disability Policy Fellow at the Institute for Educational Leadership, Center for Workforce Development. Lydia is a student at Georgetown University. autistichoya.blogspot.com



Leah Grantham is a twentysomething year old autistic student at the University of Victoria who could minor in advocacy if she so desired and it were offered. In between social justice and studying, she spends her time reading, blogging, and sketching.

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Andee Joyce is the Portland, Oregon Chapter Lead for ASAN. She is a self-advocate representative on the Oregon State Commission on Autism Spectrum Disorders and chair of the Commission's Adult Lifespan subcommittee. She was diagnosed with Asperger Syndrome at the age of 44. She has written several essays about autism scheduled to be published in the near future, and is working on a young adult novel about autism and baseball, two great tastes that taste great together.



John Kramer works with the research team at the Institute for Community Inclusion at the University of Massachusetts at Boston on systems change and employment issues for people with disabilities. He co-founded the Sibling Leadership Network, Massachusetts Sibling Support Network, and Supporting Illinois Brothers and sisters.



Nicole LeBlanc, a person with autism, works for Green Mountain Self-Advocates as Advocacy Coordinator. Nicole has a keen ability and interest in public policy and excels at communicating about the needs of people with developmental disabilities to public officials.

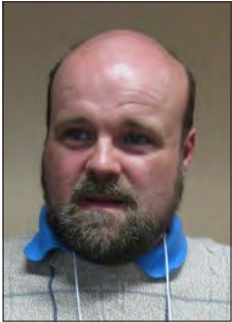


Stacey Milbern is an activist, writer and student in the disability community. She is a proud supporter of the National Youth Leadership Network, a national non-profit organization run by and for youth with disabilities.

www.nyln.org

Jim Sinclair, an autistic person, has a B.A. in Psychology and graduate education in Developmental and Child Psychology and in Rehabilitation Counseling. Jim pioneered the use of service dogs for autistic people in the late 1980's; co-founded Autism Network International in 1992 and has been its coordinator since that time; and produced Autreat, the first annual gathering of its kind designed by and for autistic people, since 1996. Jim's writings have been widely reprinted and translated into many languages.

www.jimsinclair.org, moosepuppy.petfinder.com



Tracy Thresher is an advocate for people with disabilities who lives and works in Vermont. He began typing to communicate in 1990. He has presented at local, statewide, and national workshops and conferences. He has consulted with local schools, is a member of the Vermont Statewide Standing Committee and has worked for the Green Mountain Self-Advocates in Montpelier, Vermont. In Vermont, he mentors teenagers and adults.

www.wretchesandjabberers.org



Karen Topper is the state coordinator for Green Mountain Self-Advocates. In the 70s and 80s she worked to create individualized supports for people moving out of institutions. During the 90s she worked for the Center for Disability and Community Inclusion at the University of Vermont. Topper has worked for and been an ally of the self-determination, disability rights and self-advocacy movements since the late 90s. She has served as a national advisor for SABE.



Betsy Valnes is the founding Executive Director of NYLN. She has contributed to a variety of international and domestic programs in the areas of human rights and full inclusion. Betsy completed her Master's degree at American University in 2010.

Glossary of Terms

Ableism: discrimination against people with disabilities, including the expression of hate for people with disabilities, denial of accessibility, rejection of disabled applicants for housing and jobs, institutionalized discrimination in the form of benefits systems designed to keep people with disabilities in poverty, etc.

Assistive Technology: any assistive, adaptive, and rehabilitation piece of equipment used to help an individual with a disability to maintain or improve their functional capability or communication skills.

Accessibility: the degree to which a product, device, service, or environment is available to as many people as possible. Accessibility can be viewed as the “ability to access” and benefit from some system or entity. Accessibility can be related to entering a building, using assistive and adaptive technology, transportation, housing, adaptations and accommodations, or even the web or the internet.

Accommodation: an adaptation or modification of the environment or materials which make it possible for a person with a disability to fully participate in an activity.

Advisor: a person who assists the self-advocates, with support where needed. They usually stay in the background and let the self-advocate take command and only do things when the self-advocate asks for help.

Allies: people or groups that have come together for mutual benefit or to achieve some common goal. Allies can help support individuals with disabilities by helping them to prepare things and share knowledge about a certain topic.

Augmentative and Alternative Communication (AAC): non-speech methods of communication, including specialized gestures and sign language, charts, and electronic devices that can speak in response to keyboard entry.

Facilitated Communication (FC): a method by which a facilitator supports the hand or arm of an individual while using a keyboard or other devices with the aim at helping individual to develop pointing skills and to communicate.

Identity First Language: a term used in the autism community, that one has autism as their identity first and they are an individual second. Ex. An autistic individual

Inclusion: term used by people with disabilities and other disability rights advocates for the idea that all people should freely, openly, and without pity accommodate any person with a disability without restrictions or limitations of any kind.

Mentor: someone who believes in the capabilities of an individual with a disability without telling them what to do. They guide the individual, give them advice when asked for, and allow the individual to make their own choices and run their own life.

Neurodiversity: originally arising in the context of the autism community, the notion that neurological differences should be viewed as gender and race are viewed, as examples of human variation. According to this perspective, autism should be thought of not as a disorder, but as a different way of being that should be accepted, and perhaps even celebrated; the idea that individuals should be valued, socially accepted, and have access to equal opportunity whether or not their brains are “typically” wired.

People First Language: a term used in the autism community, that one is an individual first, and then they have autism. Ex. An individual with autism or an individual with ASD.

Presuming Competence: assuming all individuals are intellectually complex, desire to have meaningful interactions and opportunities; and have the right to learn rigorous academic content, despite communicating differently or having other support needs.

Self-Advocacy: the awareness, motivation, and ability of an individual to represent and communicate his or her own interests, to exercise personal choice, to exert control over his or her environment and to avoid exploitation and abuse.

Self-Determination: determination of one's own fate or course of action without compulsion, free will. It is also the power or ability to make a decision for oneself without influence from outside.

Support Worker: someone who helps disabled individuals with their daily living skills, takes care of their everyday needs, and supports them emotionally, and physically as well. A personal assistant who comes to your house and drives you to your appointments is a type of support worker.

Tokenism: a policy or practice of making a thoughtless gesture toward the inclusion of individuals with disabilities, minority groups, or women. This token effort is usually intended to create a false appearance of inclusiveness and deflect accusations of discrimination. Typical examples include purposely hiring a person of color in a mainly white occupation or a woman in a traditionally male occupation.

Acknowledgments

Thank you to **Elesia Ashkenazy** for project management and editing.

