

Planning Accessible and Inclusive Organizing Trainings: Strategies for Decreasing Barriers to Participation for People with I/DD

Introduction

Intellectual and developmental disabilities are disabilities which impact someone’s ability to learn, process information, and adapt to their environment. Some examples of intellectual and developmental disabilities include Down Syndrome, autism, and fetal alcohol syndrome. People with intellectual and developmental disabilities learn, think, make decisions, and are powerful advocates when given the right tools. In this paper, we will use “intellectual disabilities” when talking about people whose disabilities affect their adaptive skills and measured IQ, “autism” when talking about autism specifically, and “intellectual and developmental disabilities” or “I/DD” when talking broadly about people with these kinds of disabilities.

Historically, people with I/DD have been warehoused in institutions, and there is often a false assumption that we cannot speak for ourselves or be involved in advocacy and community organizing. The idea that we aren’t able to make decisions about our own lives, such as where to live, contributed to this systemic institutionalization. This is why self-advocacy, the ability of people with disabilities to speak for ourselves in order to have control over our own lives, is such an important skill in the disability community. One way that self-advocacy is taught is through leadership and community organizing trainings, where individuals can learn about the societal problems facing their communities and gain strategies on how to address these systemic issues. This paper is intended to address some of the common barriers to our participation in these trainings, and change the way organizers think about people with I/DD.

The Autistic Self Advocacy Network (ASAN) is a 501(c)(3) nonprofit organization run by and for autistic people. ASAN was created to serve as a national grassroots disability rights organization for the autistic community, advocating for systems change and ensuring that the voices of autistic people are heard in policy debates and the halls of power. We work to empower autistic people across the world to take control of our own lives and the future of our common community. Our activities include public policy advocacy, the development of Autistic cultural activities, and leadership trainings for autistic self-advocates. We provide information about autism, disability rights, and systems change to the public through a number of different educational, cultural, and advocacy related projects.

A major component of ASAN’s work is developing the leadership and advocacy skills of individuals with I/DD. For the past 6 years, we have organized the Autism Campus Inclusion (ACI) Summer Leadership Academy, a weeklong training in Washington, DC for autistic college students who are interested in making their campuses and communities more accessible and inclusive to disabled people. Participants build their skills and expertise in disability history and policy, coalition-building, and community and campus organizing. Following their Leadership Academy experience, ACI alumni are provided with extensive mentoring and technical assistance in support of their work to advocate for systems change on their campuses and to address barriers to community inclusion in higher education faced by autistic students.



The Autistic Self Advocacy Network seeks to advance the principles of the disability rights movement with regard to autism. ASAN believes that the goal of autism advocacy should be a world in which autistic people enjoy equal access, rights, and opportunities. We work to empower autistic people across the world to take control of our own lives and the future of our common community, and seek to organize the autistic community to ensure our voices are heard in the national conversation about us. Nothing About Us, Without Us!

Generously funded by Mitsubishi
Electric America Foundation



In addition to ACI, ASAN has conducted state-based leadership trainings for adults with I/DD. As a part of the Pacific Alliance on Disability Self Advocacy (PADSA) project, ASAN organized the Pacific Leadership Academy from 2014 to 2016 for self-advocates in California, Oregon, Montana, and Washington. These academies helped participants connect with others from their state, develop advocacy skills such as fundraising and conducting meetings, and develop an action plan to meet relevant goals for the disability community in their state. An additional academy which took place in 2014 and 2015, the Tennessee Employment First academy, prepared self-advocates to advocate for Employment First and for home and community-based services (HCBS) in the state of Tennessee.

We know from history that people with I/DD can be powerful organizers when given the right tools. The self-advocacy movement of the 80's and 90's made significant progress in advancing the rights of people with intellectual disabilities. During this time period, people with disabilities played a critical role in shutting down many institutions that held people with I/DD in deplorable conditions. Disabled self-advocates helped shape the language people use to refer to people with intellectual disabilities to be more inclusive; we also helped increase the lifespan of people with I/DD by placing more focus on our health care needs, and through deinstitutionalization itself. With the right supports, people with intellectual and developmental disabilities have changed our own lives—and the world.

Our own experience creating trainings of this nature shows the positive effects they have on participants and their communities. Alumni of our programs have begun campus disability rights organizations, served in student government, helped to found disability cultural centers, worked in disability policy, and played a role in expanding accessibility and opportunity for people with disabilities. In addition, participants spoke to the valuable skills they have developed which can be brought to higher education, employment, and other opportunities. As one ACI participant said, “A lot of the things I wanted to accomplish felt too big for me, but now they feel more manageable.” Overall, participants of all of our academies demonstrated an increase in their confidence for managing their own supports, holding paid employment, and affecting public policies as a result of the training.

ASAN believes that more trainings like this are necessary to give disabled people the skills we need to advocate for accessibility and inclusivity in our communities. Historically, movements to improve societal conditions for people with I/DD have been led by non-disabled facilitators. While having non-disabled allies can be beneficial to the strength of the disability rights movement, there are also notable pitfalls to relying on these facilitators. One important consideration is that when a non-disabled person is leading a community organizing group comprised mostly of disabled people, the non-disabled facilitator can control the goals and actions of the group as a whole. This can leave disabled participants feeling as if they cannot advocate for the issues they care about, and can lead to disengagement from advocacy. This issue has led to the stagnation of many disability advocacy organizations over the years, and the need for self-advocates to be supported to organize ourselves is more important than ever.

From education, to employment, to healthcare, there are a multitude of societal issues facing people with disabilities, and our voices are important to the wider conversation on how to address these issues. In addition to creating more trainings that focus specifically on disability, it is imperative that current community organizing trainings, events, and conferences more broadly are made accessible to people with intellectual and developmental disabilities. When disabled people are not included in community organizing opportunities such as these, non-disabled people don't get the chance to learn from the critical perspectives and unique lived experiences of the disabled community, and disabled people don't receive the tools that we need to turn that experience into effective organizing. The purpose of this white paper is to share the insights we have learned through organizing leadership and community organizing programming for the intellectual and developmentally disabled community in order to encourage the adoption of these techniques for other organization's similar efforts, whether specific to the disability community or not.

Barriers of inaccessible trainings

Accessibility means that people with disabilities can attend and fully participate in a given opportunity. When places and spaces are inaccessible, disabled people are unable to take advantage of the same opportunities as non-disabled people. For example, if an event takes place on the third floor of a building without an elevator, people with certain physical disabilities would not be able to get up the stairs to attend.

Many accessibility issues go unaddressed because of ableism, which is systemic discrimination or prejudice against disabled people. While individuals may be unaware of their own ableist behavior, these attitudes lead to structural oppression against people with disabilities. For example, a common ableist belief is that if an individual needs an accommodation in order to succeed in a given setting (such as needing extra time on an exam at college), then this person is getting an unfair advantage over other individuals. On a systemic level, these attitudes can lead to lack of accommodations in educational and occupational settings, leaving disabled people with less opportunities for education and employment.

While this paper will focus specifically on barriers to leadership programming for people with intellectual and developmental disabilities, there are also more general barriers that can affect the participation of all people with disabilities in a variety of community organizing contexts. In order to ensure your program is accessible and inclusive, you must address these barriers as well. For more information about these barriers, please read the resource on accessible event planning located at <https://pacific-alliance.org/wp-content/uploads/2016/02/Accessible-Event-Planning.pdf>

It may also help you to familiarize yourself with the common characteristics of autistic people, as well as people with I/DD. You can find out more about autism by going to <http://autisticadvocacy.org/about-asan/about-autism/>, and more about I/DD at <http://www.thearc.org/learn-about/intellectual-disability>. To learn more about these disabilities, consider also reaching out to local disability organizations such as:

- Your state's Developmental Disabilities Council
- Your state's Protection and Advocacy agency (often known as Disability Rights [State])
- Local chapters of self-advocacy organizations such as People First and family organizations such as The Arc.

There are many roadblocks that make traditional leadership programming inaccessible or non-inclusive of people with intellectual and developmental disabilities. These barriers are important to address regardless of the skill level of the training. Disabled people are much less likely to be included in more advanced trainings because introductory-level trainings are inaccessible to us. However, disabled people have the same access needs even if we do make it to an advanced-level training, because the skill level of a program does not correlate to the amount of accommodation needed.

To illustrate the barriers of inaccessible trainings, it is important to understand what circumstances people with I/DD may have trouble with. Some of these difficulties apply specifically to autistic people, while others can apply more broadly to most individuals with I/DD. Every person with a disability is different; not every person with I/DD will have difficulty with all of these things, and for some individuals, we may actually have strengths in some of these areas. Still, using these indicators, we can go into greater detail about aspects of community organizing trainings that may be inaccessible.

- Loud or unpredictable noise, motion, and other stimuli
 - Autistic people can be sensitive to a variety of external stimuli, such as noises, certain sights/brightness, smells, and sudden movements. It can be difficult for us to process these stimuli. Some common stimuli that can cause access issues at events such as leadership trainings are microphone feedback; bright, fluorescent, or flashing lights; perfume/body sprays; the sound of people eating; sirens/alarms; and loud music. If an autistic person encounters one of these situations, it could cause sensory overload, leaving us unable to participate in the rest of an event.
- Unpredictable events
 - Many people with I/DD work best with an established routine or structure to our day. Having a routine enables us to understand what is going on and process new information, and it can be distressing and confusing if we do not know what will happen next. This can make events that do not have a set schedule, or events that change their schedule at short notice, inaccessible.
- Abstract or overly-complex language
 - Autistic people tend to take things literally, and may have trouble with abstract language, such as sarcasm and metaphor. In addition, people with intellectual disabilities may not understand language that is too

technical or complex. Presentations or leadership academy applications/materials that use jargon or vague ideas to present information can be difficult to understand.

- Speaking spontaneously
 - People with I/DD may need time to plan out what we are going to say when given a verbal prompt. It can take some time to process what is being said to us, as well as to verbally formulate a response. Activities that put a person “on the spot” by calling them out to respond can be overwhelming for an autistic person, who may be unable to respond at all. In addition, some autistic people use technology to communicate instead of speech; some of these technologies can take a long time to put together sentences.
- Motor planning
 - People with I/DD may have trouble initiating movement if not given time to plan in advance, and can have difficulty with coordination. Even something like getting up out of a chair can be difficult at times. Activities that require an autistic person to move (such as exercise), or that don’t give an autistic person time to plan out their movement (such as a sudden shift to another room/area for an activity) can be inaccessible.
- Interpreting body language, making eye contact, and other types of nonverbal communication
 - Autistic people can have difficulty interpreting nonverbal cues. This can make it difficult to follow directions that aren’t explicitly stated, or to connect with other participants in a leadership program. Eye contact can also be distressing or confusing to an autistic person. When community organizing programs don’t communicate that these differences are acceptable and should be celebrated as a form of diversity, it can be easy for autistic participants to feel disconnected from the rest of the group or ashamed for not “getting with the program”.
- Touching other people or being touched
 - Touching others can be painful or distressing for some autistic people, especially if we are touched unprompted. Activities that require participants to touch others (such as holding or shaking hands), or touching an autistic person without our consent (such as tapping a shoulder or hugging), can be inaccessible to autistic people.
- Identifying and interpreting bodily sensations and emotional reactions
 - Autistic people can have trouble figuring out how we are feeling at any given time, so being asked to do so can be stressful, especially “in the moment”. “Mindfulness” activities that require participants to verbally or internally identify how they are feeling are not inclusive of autistic people.
- Forming relationships with other people on command or in a pre-specified way
 - Autistic people do form relationships, but we may not do it the way others expect or on the same timeline as others. “Relationship-building” activities that require sharing personal information or emotions with others are inaccessible for autistic people.
- Engaging in any activity for a prolonged period of time
 - Intellectually and developmentally disabled people need frequent breaks from scheduled programming to decompress and process what is going on. Trainings that are “intensive” (go for hours without breaks, or do not allow breaks), or trainings that last for multiple days/weeks without scheduled time off, can keep these populations from attending.

Sometimes, you may encounter situations where people have conflicting access needs relating to their disability. For example, one autistic person may be sensitive to loud noises, while another may speak loudly and have difficulty controlling the volume of their voice. Or there may be one disabled person who doesn’t work well in small groups, while another doesn’t work well in large groups. Being flexible and individualizing your approach to accessibility is crucial to address the needs of all participants.

As you can see, it can be very easy for many community organizing and leadership development programs to fall into patterns that keep people with I/DD from participating, or from fully engaging with a program even if they do

participate. However, this does not have to be the case. There are many modifications that can be made to ensure full accessibility and inclusion, as we will discuss below.

How to do an accessible training

The logistical considerations that go into any community-organizing event are vast; for ease of use, we have separated this section into common components of these events.

Establishing goals

Before you even start organizing the logistics of your training, it is important to think about the goals for the training. What skills or knowledge do you want participants to leave with? There may be instances where you have planned an activity that may be inaccessible to people with intellectual or developmental disabilities, but thinking of the goal of each activity can help you restructure the activity to become more accessible.

For example, one early goal of the training may be for your participants to get to know each other better. Many conferences use icebreaker exercises to do this, but some of these exercises may be difficult for people with intellectual and developmental disabilities who have trouble coming up with verbal language spontaneously. A more accessible option may be to give participants a list of questions beforehand (such as “What is your name, where are you from, and what do you hope to learn from this training?”), so that participants can still learn about each other, but the participants that need time to process their answer can still fully participate.

Application/interview process

Consider the selection process that you use to determine participants in your program. Are participants selected through nomination, or do they fill out an application? Is there an interview component to the selection process? How do you do outreach to find potential participants?

The recruitment process for participants can often inadvertently exclude people with intellectual and developmental disabilities. For example, someone organizing an event focused on racial justice may not think to reach out to disability organizations, but doing so might help them recruit disabled people of color who would want to participate and wouldn't otherwise find out about the event. In addition, recruitment materials that contain jargon may discourage disabled potential applicants from applying, as they may not understand the goals of the event and how it pertains to their own goals.

Consider reaching out to local and national disability advocacy organizations to advertise your opportunities, including (but not limited to):

- Your state's Developmental Disabilities Council and Protection and Advocacy agency (if your event is state-based)
- Local Centers for Independent Living (CILs)
- Local chapters of self-advocacy organizations such as People First and family organizations such as The Arc.

Financial Considerations

Even if your application and interview process leads to more individuals with I/DD being admitted into your program, financial barriers may keep these individuals from attending your program. People with disabilities are more likely to live in poverty, and may have additional concerns related to how receiving financial assistance to attend leadership programming may affect our disability benefits. These circumstances need to be taken into account in order to ensure that all the individuals admitted into your program get the chance to participate.

If possible, all costs of a training should be covered for all participants. This includes travel, housing, meals, all costs of support person's attendance/other accommodations, and any other applicable mandatory costs. If this is not possible, another option is to offer scholarships for participants in financial need in order to cover these costs. It should be made

clear in all application materials that these scholarships are available, or that the opportunity is all-expenses paid, in order to encourage applicants who may have refrained from applying due to financial stressors.

Whenever possible, costs associated with a training should be paid to participants up-front instead of through reimbursement. For example, participants should receive a stipend for meals at the beginning of the program, instead of paying for their own meals and being paid back afterwards. Participants with I/DD may not have money readily available for these expenses, or may need this money for other costs associated with their disability, so they may be unable to wait for a reimbursement.

Upon Acceptance

Once accepted into your program, there are two important documents that should be made available to participants. An orientation or “welcome” packet is necessary to help participants know what to expect from the training. This packet should contain the following information:

- A schedule of events for the program (including the date and time for each event)
- Information about the venue, including a map of the premises, accessibility info (where accessible bathrooms & entrances/exits are) and where gender-neutral bathrooms are (if not all bathrooms are gender neutral)
- Information about dining options (if participants are responsible for their own meals)
- Any rules or guidelines participants are expected to follow during the event
- A list of materials participants should pack for the event

At the same time as you distribute orientation materials, it is also imperative that you obtain information about disability accommodations needed by each participant. This gives you ample time to arrange any accommodations. The most efficient way to collect this information is through having each participant fill out an accommodations packet. This can also serve as a method of collecting other important information about a participant. Here are common questions for an accommodations packet to ask:

- Legal name and address of participants
- Preferred name and pronouns of participant
- Roommate preferences (if staying overnight with other people - can include information about preferred noise level, gender of roommate, etc.)
- Accommodation info: it can be helpful to list common accommodations that participants can check off if necessary, as well as leaving a blank space for any other accommodations. Common accommodations include:
 - Braille
 - Large print
 - Sign language interpreter
 - A note taker
 - Access to a break room
 - Bringing a support person
 - Learning and speech disability accommodations (written instructions; having someone read documents out loud; using personal computers and tablets; using speech recognition software, etc.)
- A space to indicate if a participant uses a wheelchair or other mobility device, or if they have difficulty walking long distances. It may also be important to note the make/model of a wheelchair if the venue or travel service needs this information.
- Support person information (if applicable)
- Emergency contact information

- Medical information (health conditions, current medications, etc.)
- Allergies and dietary restrictions

Providing this list demonstrates that you take accommodations seriously and are willing to provide them. If you do not provide these materials beforehand, participants may not indicate that they need accommodations to fully participate in your training, which will result in inadvertent inaccessibility.

Schedule

As mentioned previously, how the schedule of a program is structured can affect the participation of people with disabilities. One of the first considerations of a programming schedule is transportation of students to and from the venue. For trainings that take place over multiple days that require participants to stay overnight, or otherwise require participants to travel a long distance to the venue, it is important to build a “cushion” into the schedule to account for travel time; that is, there should be little to no scheduled programming on the arrival and departure days of the training. One reason for this is that if there are any unexpected delays or cancellations of travel arrangements, participants do not miss out on any programming. The other reason is that travelling can be very exhausting for people with disabilities, who are often dealing with unfamiliar, overwhelming and inaccessible environments. At the same time, once we arrive at the venue, we need to take some time to orient to our new surroundings. Providing this extra time can help ensure that people with I/DD have the space we need to avoid sensory overload and fully participate in the training.

For trainings that require participants to travel out-of-state (by plane, train, or bus), organizers should help participants arrange their travel (including the travel of their support person, if applicable). This should be done well in advance of the training (no later than 1 month before). Some participants with I/DD may not have traveled using public transportation before, so having someone to facilitate that process makes it more accessible. In addition, participants who travel with a support person often need more lead time in order to coordinate their support person’s schedule. Organizers should create a document for each participant with the following information:

- Location of the airport or bus/train station where the participant will be leaving from.
- Departure time of the train/plane/bus, along with any confirmation number or terminal/gate number.
- Name of the airport or bus/train station where the participant will arrive.
- Directions on how to get to the event venue from the arrival location (is there a shuttle to the venue? If so, attach directions on how to get to the shuttle. Will a representative from your organization be there to pick the participant up? If so, attaching a photo of the member of your organization could help the participant find them.)

For participants for whom this information would be helpful, there are also Social Stories available online for the process of traveling by plane or train. Social Stories are a tool that autistic people can use so they know what to expect from a new experience. These tools can be useful for alleviating anxiety that autistic people might experience from being in an unpredictable situation.

The other important consideration relating to event scheduling is the length of each programming day or activity. Having a day or presentation that is too long can lead to burnout for people with intellectual or developmental disabilities. To ensure full engagement of all participants, we recommend having no more than 6 hours of programming per day. In addition, regularly scheduled breaks are important for giving disabled participants time to process the material and decompress. We have found a structure of 10 minutes of break time per 1 hour of programming to be effective in keeping participants engaged and able to participate fully (6 hours of programming, 1 hour of breaks, plus a 1-hour lunch break makes a full programming day of 8 hours).

It is also important to note that lunch or dinner sessions that involve having discussions or special guests do not count as a “break”. Even if there is food being served, being required to stay in a specific space and continue engaging with others can take the same amount of energy from a disabled person as a traditional programming session. If you do need to have a lunch/dinner session, treat this time as part of your general programming schedule, and build in additional breaks to the day as needed.

Schedules such as the ones we have outlined that include frequent breaks and shorter programming periods can seem unnecessary to people without disabilities, or even a sign that the person with a disability isn't motivated to engage in the training. We want to be absolutely clear that modified schedules are not luxuries; they are necessary accommodations for people with disabilities to participate in trainings, and are every bit as critical as ASL interpretation for Deaf participants or braille materials for Blind participants. People with intellectual and developmental disabilities have the same right as all other participants to participate fully in all aspects of trainings, and we cannot participate fully if we are asked to work at the same pace as non-disabled people.

Lastly, consider how many days of programming you need to meet the goals of your training. If you need more than one week, it may be helpful to break up your programming into smaller chunks, as having many days of programming in a row can also cause burnout in disabled people. One model that has been successful is to have programming on weekends over the course of a month or two months. This can also allow participants to get concrete, hands-on practice with the concepts they are learning in real life, which is an important part of learning for people with I/DD. If a program takes place over 2 weeks or more, there should be at least one scheduled day off from programming at the end of each week.

Materials

Any written materials distributed to your participants should be available in plain language. Writing in plain language keeps your information understandable for people with intellectual disabilities. Generally, plain language is written between a 5th and 8th grade reading level. You can use websites like <https://readability-score.com/text/> and <http://www.hemingwayapp.com/> to tell you the grade level of your writing. When writing in plain language, you should avoid:

- Inaccessible words (such as jargon, sarcasm, and metaphor)
- Long sentences/paragraphs. Try to write paragraphs of no more than 5 to 7 sentences and sentences of 10-20 words. When writing lists, use bullet points instead of commas.
- Using words like “this,” “they,” or “it” when it might not be clear what you're referring to.
- Passive voice - using language that denotes a subject receiving an action being done by someone or something else. This can cause confusion about the subject of a sentence. For example:
 - Active voice: You want to avoid using passive voice in your writing.
 - Passive voice: When writing, passive voice should be avoided.
- Non-logical writing flow - All writing should follow a clear outline that makes it easy for readers to understand how one sentence or paragraph leads to the next one. Each paragraph should have one main idea that each sentence supports.
- Unnecessary information - Think about your writing from the reader's point of view. Make sure that your writing either doesn't contain information that isn't relevant to the reader.

Once your program has begun, there are a number of materials that participants should receive upon their arrival. A copy of all presentation materials (powerpoints, handouts, etc) should be compiled in a booklet so that participants can follow along, as well as review these materials before each presentation if this will be helpful to them. This booklet also gives space for participants to take notes. You should also provide an additional copy of the orientation packet at this time, which should contain the finalized event schedule. These materials should be made available in both physical and electronic formats (and the electronic format should be accessible for screen-reading software).

In addition to these materials, participants should receive name tags (which include their preferred gender pronouns) and color communication badges. Name tags are important since some disabled people can have trouble remembering names and pronouns, or recognizing faces. Participants should be instructed to wear their name tags at all times.

Color Communication Badges are a system which were first developed in Autistic spaces and conferences, and usually come in the form of a name tag holder that can pin or clip onto clothing. In the name tag holder there are three cards: one green card that says “GREEN”, one yellow card that says “YELLOW”, and one red card that says “RED.” The card that is currently visible is the active card; the other two are hidden behind the first one, accessible to the person if they should need them.

Showing a green badge means that the person is actively seeking communication; they have trouble initiating conversations, but want to be approached by people who are interested in talking. Showing a yellow badge means that the person only wants to talk to people they recognize and have established beforehand can talk to them while they are “on yellow”. Showing a red badge means that the person does not want to talk to anyone, and should not be talked to unless there is an emergency. For more information about how color communication badges work, please visit <http://autisticadvocacy.org/2014/02/color-communication-badges/>

Color communication badges aid individuals because they allow people to express their current communication preference quickly, nonverbally, and simply - they can change what card is showing if their preference changes. They are a good way to prevent circumstances where someone is caught in a social situation they do not want to be in, or situations where someone wants to talk but can't initiate. In addition, communication badges can serve as an important access tool as they allow participants to regulate the amount of social interaction they engage in. For autistic people, for whom social interactions can require a lot of energy, they can save this energy to be used for other necessary activities, like engaging in presentations they may have had to miss out on otherwise.

Participants should not be required to wear color communication badges, but they can be a helpful tool for some participants and should be made available to everyone. You can explain the purpose of these badges to each participant as they receive them, or do so during any general orientation session.

Presentations

As mentioned previously, all presentations should be made using plain language. It is also helpful to create a glossary with definitions of any key terms used throughout each presentation, if participants are expected to learn new vocabulary. One other important accommodation for disabled participants is access to a note-taker, who can keep track of the details of a presentation. The most effective way we have found to organize note-taking is to assign a staff member as a designated note-taker for each session, and then have this staff member email all participants with a copy of the notes at the end of the presentation. Make sure that your assigned note-taker is able to take notes in plain language.

The way a presentation is conducted can make all the difference in whether or not participants with an intellectual or developmental disability feels included. While having interactive components to a presentation is important to keeping participants engaged, presentations that force participants to move around, make eye contact with or touch others, or spontaneously talk or share how they are feeling can be inaccessible to us. However, there are ways to work around these barriers to make sure your presentations are accessible while achieving the same goals.

The best way to make a presentation accessible and interactive is to focus on skill-building. Presenting information and reinforcing it with a group discussion, small group exercises, or role-playing scenario can help all participants put their learning into practice. There are simple techniques for each of these methods to help include people with I/DD. Most importantly, any activity or role-play scenario should be outlined within the presentation booklet given out at the start of the academy, so that participants know to expect these activities during each presentation.

For all forms of presentations, it is important that the presenter does not spontaneously “call out” any participant to share an answer or opinion, as this can be inaccessible for people who have difficulty with spontaneous verbal speech. However, you can leave space for these participants to share by doing “round robin” exercises, where every participant gets the chance to share, but also has the option to pass their turn. This can be a useful tool for group discussions. You can also present a discussion or role-play topic as a written exercise so that participants have the chance to write down their responses, and give the option to participants to have someone else read their response.

Another option is to have participants to break up into partners or small groups to perform an exercise, and then have each group share their perspectives. This may help participants who feel overwhelmed in larger groups get a chance to share, and also allow a partner to present information to the whole group if the individual is unable to speak to the whole group. However, it is important to keep in mind that autistic people can have trouble filtering out noise, so many groups or pairs talking in one room can be overwhelming. Make sure that each group has their own individual quiet space so that all participants can process what is going on.

Disabled participants who have trouble with verbal speech or anxiety in social situations may be hesitant to ask questions during a presentation. You can work around this by giving participants the option of writing down questions and putting them in a “question box” that will be read at the end of the session. You should also give participants the email address of each presenter in case they need time to process the presentation information and would like to email their questions at a later date.

Some autistic people used methods other than their voice to speak, which are called Augmentative and Alternative Communication (AAC). An example of AAC is a text-to-speech device, like an iPad. These methods take more time to compose sentences than verbal speech. ASAN has prepared a short guide on how to fully include individuals who use AAC in your programming, which can be accessed at <https://pacific-alliance.org/wp-content/uploads/2016/11/PADSA-best-practices-for-inclusion-of-AAC-users.pdf>

Autistic people may engage in “stimming” behaviors such as rocking, flapping, playing with a toy, doodling, or moving around the room during a presentation. This does not mean we are not paying attention - in fact, engaging in these activities can help autistic people better focus on what is going on around them. The autistic community has a saying-- we can either look like we’re paying attention to you, or we can *actually* be paying attention to you. Behavior that looks inattentive is in fact crucial to ensuring that autistic people are able to access and participate in the conversation. It should be made clear to presenters and staff that this behavior is acceptable and celebrated.

Support people (expectations)

Some participants with intellectual and developmental disabilities may require a support person in order to participate fully in an event. Support people can help the participant with a variety of tasks, such as with activities of daily living (eating, getting from place to place, administering medications, etc.), helping facilitate communication through a speech device, or by aiding the participant in following along with an activity. A disabled person who needs this support will usually find and bring their own support staff, so event organizers don’t need to be involved in arranging this. It is important that a request for a support person is treated in the same way as any other accommodation request - that is, if a participant is given funding to attend an event, that funding should extend to their support person. This makes sure that people who need these accommodations are able to attend.

It is important to note that support people are **not** participants in your event, and are not there to participate on behalf of the attendee who needs them. Having a support person take up space meant for the participant may make both the participant and others feel uncomfortable sharing, especially if the support person is sharing opinions that are at odds with the rest of the group. For this reason, it is recommended to have support people sign a code of conduct agreement form prior to the event. This form should indicate that support people must not:

- Speak on behalf of a participant without explicit approval from the self-advocate or share personal opinions about the content discussed in training and group sessions
- Try to influence the questions, thoughts, and opinions participants share with fellow self-advocates
- Remove a participant from a training session because the support person is displeased with the content of the sessions
- Interfere with or remove a participant’s assistive technology

If you find a support person overstepping these bounds, you can take them aside and go over the agreement form with them again, and if they continue to break these rules, it is grounds for their removal from your training.

We also recommend that participants bring support people who are not their immediate family members. In many cases, family members are used to advocating on behalf of the participant, which can lead to more conflict with complying with the support person code of conduct. If there is no other support person who can attend besides a family member, it may be helpful to have a conversation with the family member beforehand about these expectations in addition to having them sign the agreement form.

Venue/food

The first priority when choosing a venue should always be physical accessibility. The best way to ensure this is by visiting the venue site itself and going through each room you will be using (lodging, presentation rooms, dining areas, bathrooms, etc). It is also important to note the general amount of people and noise in the vicinity. If the venue is constantly crowded and boisterous, there may be better options for your training. You should do this far in advance of your training, and discuss with the venue any accommodation needs that they should take note of (for example, if a student with certain dietary needs has to have access to a refrigerator, or if you need multiple quiet areas for small group activities).

A break room should be available at all times during the event for participants who need a space to decompress. There should be no other programming occurring in this room, and the room should be clearly labeled as the “Break Room”. At the beginning of your event, you should explain the purpose of the break room, and emphasize that it is available for use at any time, even in the middle of presentations. Make sure that this room is not used for listening to music, taking phone calls, etc., as this negates the low-stimuli environment that is the purpose of the room.

If the rooms at your venue do not have labels, it is important that you label each room based on what activities you will be doing there (Presentation Room, Group Discussion Room, etc). You should also note on your schedules the location of each activity, either by the name or number of the room (if the rooms are named/numbered), or by the general location (first floor to the right, etc). Providing a map of the venue with important locations indicated on it can also help participants get oriented to the space. For larger venues, you can offer an optional tour of the premises on the date that participants arrive to help speed up the acclimation process.

If participants will be staying overnight at a venue, a staff member should be present during the check-in/check-out process. This is a good time to hand out orientation materials and show participants to their rooms if they are disoriented from traveling. This also helps make sure all venue keys are accounted for at the end of the training, and that all participants get home safely.

As mentioned previously, participants should note their dietary needs in the accommodations packet prior to your training. If all or some meals will be provided for participants, this should be noted on their schedules. If you know what food will be provided for each meal, it is also helpful to list this information. Even if you make your best effort, there may be times where a participant is unable to eat any food that is provided during a meal due to dietary sensitivities, so knowing what food will be there in advance can let these participants make alternate arrangements. If you will not be providing meals during your program, it is important to choose a venue within walking distance to different restaurants or supermarkets, or that has multiple food delivery options. Having access to a kitchen for multiple-day programs is also important in this case.

After the training (follow-up, technical assistance)

At the close of the training, debriefing and getting feedback from participants is necessary to find out what worked well and what didn't, so that this critique can be incorporated into future programming. As with other programming, it is helpful to provide any feedback questions before the debriefing session so that participants have time to think about their responses. Asking participants to submit further feedback a week or two after your event ends is also advisable, as some participants with intellectual and developmental disabilities may take longer to process their feelings about the event.

Reinforcing the lessons learned during a training is crucial to the continued success of participants in their community organizing efforts. These follow-up activities are especially important for people with I/DD, who may need additional support to plan and execute their advocacy goals. One way for participants in a program to support each other is through the creation of an alumni group on social media. This space can be a great opportunity for participants to share advocacy strategies and keep each other accountable for meeting their advocacy goals.

Another method that we have found effective for facilitating the success of participants is by providing direct technical assistance through regular check-ins. These check-ins serve as a method for helping participants talk through their goals and action plans for upcoming advocacy activities, as well as a chance for them to ask questions and receive resources

from your organization. As with the application and interview portion of your training, participants should have the option to perform these check-ins through whichever communication method works best for them (phone, skype, etc).

Conclusion

It is important to note that creating leadership and community organizing trainings which are accessible and inclusive for disabled self-advocates is still a work in progress. Each year we conduct leadership academies, we run into different access barriers, and incorporate the experiences of our participants into our accessibility plans for future years. It is crucial that you take an adaptive approach to the planning and implementation of your programming; every disabled person has different access needs, and you may have to approach a problem from multiple angles to find a solution that works best for everyone involved. However, the general accessibility and inclusivity strategies we have shared throughout this paper are safe guidelines to follow to show the disabled community that you are working to include us in your activities.

Without trainings that are accessible and inclusive to people with disabilities, the disability rights movement is weaker due to a lack of access to organizing tools. In turn, this makes all other movements weaker for lacking the perspectives of the disability community. We hope we can work together to address these barriers for the benefit of community organizing efforts everywhere.