

Survivors with Intellectual & Developmental Disabilities:

Providing Appropriate Support and Advocacy



Part 2
March 15, 2023
1:00-2:30 PM PT

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Survivors with Intellectual & Developmental Disabilities:

Providing Appropriate Support and Advocacy

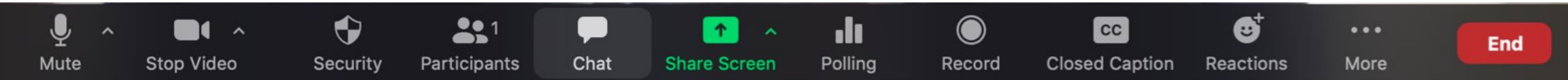
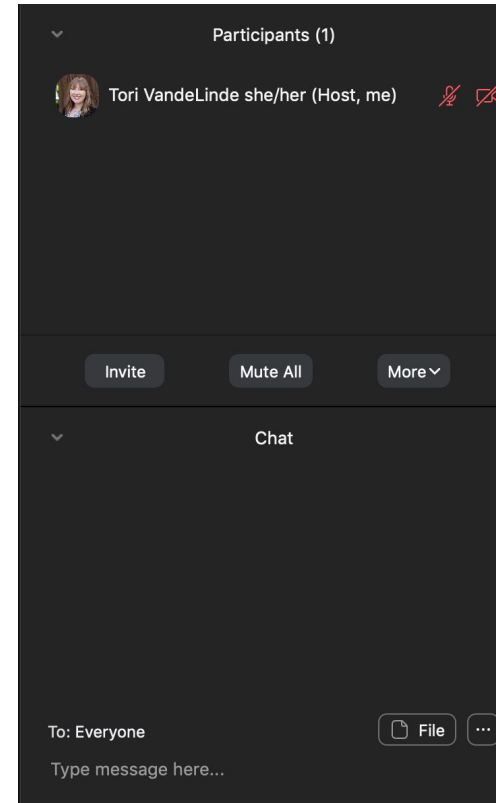
**C.A.
LEADDs**

A ValorUS® and
Arc of California Project

**Part 1
March 13, 2023
1:00-2:30 PM PT**

HOW TO USE ZOOM

- Text chat & breakout rooms
- Phone
- Live captioning
- Recording & slides
- Certificate of participation



Legal Disclaimer & Reminders

- VALOR® & the Arc of California cannot give legal advice
- Persons seeking legal advice should consult an attorney
- Acquaint yourself with your agency's policies and procedures on mandated reporting
- Talk to your supervisor about mandated reporting prior to working with survivors
- Consult with your supervisor if you think you may need to report a situation
- Discuss your duties to report with clients and survivors



Meet Your Hosts



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Meet Your Presenters



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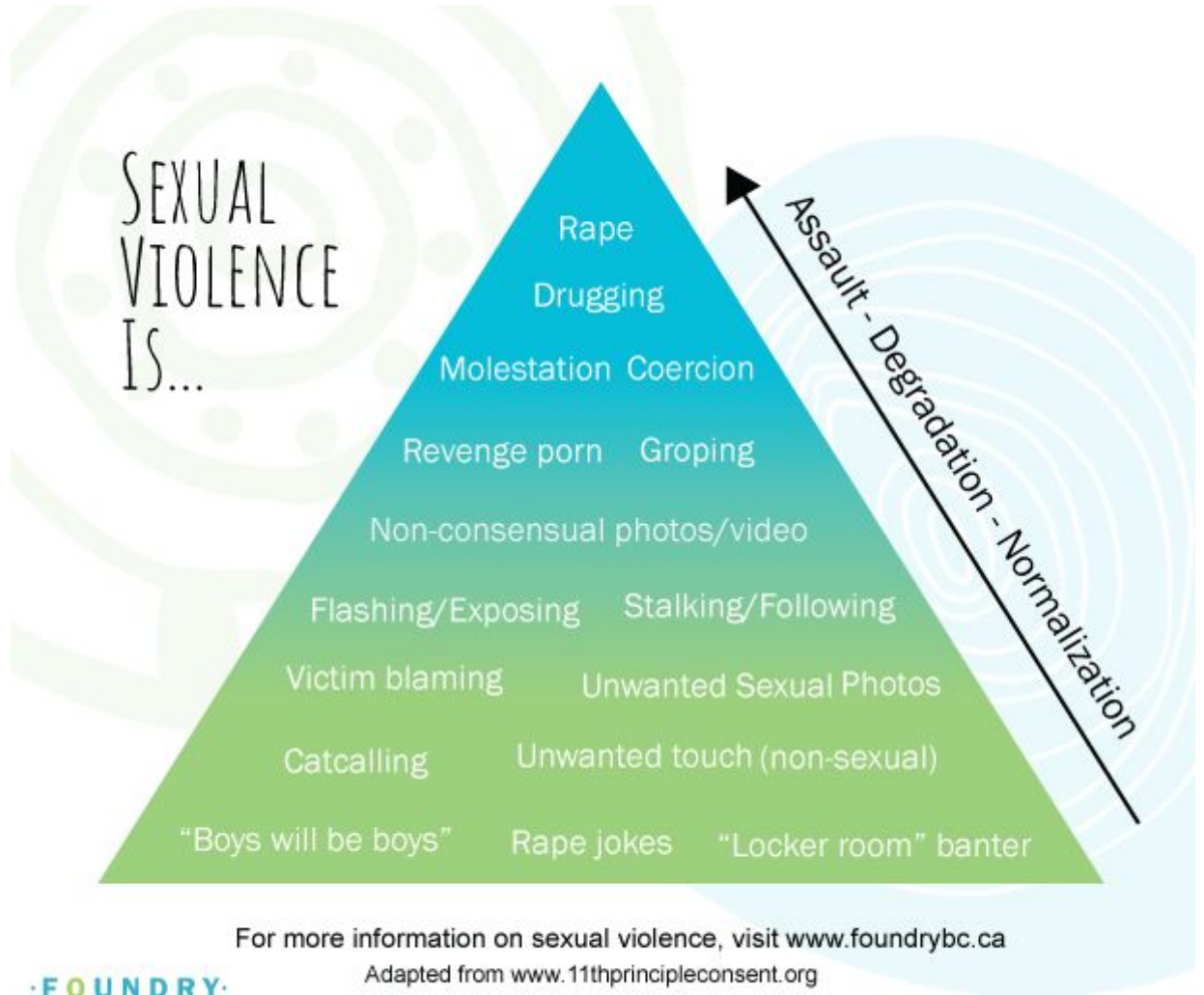
Learning Objectives - Part Two

- Participants will be able to describe the prevalence of sexual violence for people with IDD
- Participants will be able to identify risk factors for experiencing sexual assault and barriers to accessing services
- Participants will examine the impacts of trauma on people with IDD
- Participants will be able to describe person centered services
- Participants will be able to evaluate accommodations & accessibility strengths and weaknesses in their own organizations



Prevalence of Sexual Violence and Abuse of Persons with Disabilities

Sexual Abuse



Statistics

- Rate of violent victimization against persons with disabilities is nearly 4x the rate for persons without disabilities.
- Only 19% of sexual assaults against persons with disabilities were reported to police compared to 36% of sexual assaults against persons without disabilities.

Statistics

- “For each racial and ethnic group measured, persons with disabilities had higher violent victimization rates than persons without disabilities.”
- “For whites, blacks, Hispanics, and persons of other races, the rate of violent victimization for persons with disabilities was at least triple that of persons without disabilities.”

Crime Against Persons with Disabilities, 2009–2019 – Statistical Tables, Bureau of Justice

<https://bjs.ojp.gov/content/pub/pdf/capd0919st.pdf>

Statistics

- Many are abused multiple times, 49% of people with developmental disabilities are assaulted 10 or more times.
- More than 90% of people with developmental disabilities will experience sexual abuse in their lives.

Statistics

- Persons with cognitive disabilities had the highest rate of violent victimization.
- Rate of sexual assault against people with intellectual disabilities is 7x the rate of those without.
 - For women with intellectual disabilities, the rate is 12x higher.

Statistics - Youth

- Youth with disabilities are 2.9x as likely to experience sexual violence as non-disabled peers
- Youth with cognitive disabilities have 4.6x the risk for sexual violence compared to non-disabled peers
- 40-70% of girls with disabilities will experience sexual abuse prior to age 18
- Up to 30% of boys with disabilities will experience sexual abuse prior to age 18

Various Identities

Risk of violence is higher for certain people with disabilities:

- People with intellectual disabilities
- People with psychiatric disabilities
- People with multiple disabilities
- People of color who have disabilities
- Women with disabilities
- LGBTQ+ folks with disabilities



Risk Factors & Barriers to Service

Use the Text Chat feature
to answer the question.

What would cause folks with
I/DD to be at an increased risk
for violence?

- Organizational
- Societal
- Community

LACK OF RESOURCES

Organizations that serve people with disabilities often experience a lack of resources—not only monetary or funding-based, but also a lack of resources related to prevention or intervention.

STAFF TURNOVER

Currently, the disability field is experiencing a staffing crisis; there's more need than supply, and wages are poverty-level and stagnant. This increases turnover, which leads to less oversight and more instability of care.

LACK OF EDUCATION

People with disabilities are often left out of sexual education, which leads to situations where they are uneducated about their body, the way that it works, what's private and what's public, sex, sexuality, sexual health, relationships, and more.

NEGATIVE ATTITUDES

Societal attitudes towards PWD increase risk for abuse, particularly for PWD who are multiply marginalized—people of color, LGBTQ, immigrant populations, or people experiencing homelessness, for example.

EXPERIENCING POVERTY

Many PWD experience poverty, earning less than \$15,000 per year. Although currently the poverty line for a single person under 65 is an annual income of \$11,770, healthcare costs and costs of living with disabilities further limit spending power. Additionally, the American Journal of Public Health estimates that 530,000 American families go bankrupt every year from medical debt.

NO INTERNET ACCESS

Lack of internet access is a large barrier for many PWD, for many reasons including experiencing poverty or homelessness, lack of available providers (particularly in rural communities), or lack of support for being online or accessing the internet. Lack of web access may also mean lack of access to community, assistance, opportunity, employment, and info.

LACK OF EXPERIENCE

Due to the staffing crisis, many people who are providing care to people with disabilities lack caregiving experience, and may not have the support to recognize, prevent, or intervene in victimization of the people who use their services.

LACK OF CONFIDENCE

Staff often lacks confidence to give healthy relationship and healthy sexuality coaching to people who receive services. This may tie in to staff turnover, lack of organizational resources, or lack of staff experience.

OTHERS' LACK OF BELIEF

When PWD disclose sexual violence, many people perceive them as being less credible than a person without a disability, often citing that the person made it up or did not understand what was really happening.

FALSE IDEAS ON SEXUALITY

PWD are often seen as non-sexual beings who do not experience sexual desires, which is not true. People with disabilities experience the same spectrum of desire that people without disabilities do, from the same ages.

LACK OF OPPORTUNITY

The rate of employment for PWD from the Bureau of Labor Statistics was 19.1% in 2019; the rate for people without disabilities was 65.9%. This gap reflects both the low employment rates for PWD as well as the lack of opportunities available. Currently, it is legal to pay PWD subminimum wage for working in certain locations, often referred to as 'sheltered workshops.'

NO PUBLIC TRANSIT

According to the American Public Transportation Association (APTA), 45% of the population of the US lives in an area where there is no access to public transportation. The percent increases for PWD due to weather conditions and inaccessibility of currently available options. Buses with broken lifts, broken elevators in subway stations, or info only given through audio are all examples.

NO PROCEDURAL CLARITY

Sometimes people will not respond properly to something if there's no process to follow. Organizations need to implement abuse reporting procedures and make sure staff understands them.

MISSING BACKGROUND CHECKS

A failure to perform background checks on *all* people in the organization can increase the risk of violence against PWD by providing opportunity for harm. This includes maintenance, volunteers, staff, and so on.

SOCIAL ISOLATION

PWD often experience social isolation due to a variety of factors, including overcontrolled environments, lack of access to transportation, lack of access to the internet, caregiver belief or comfort, lack of staffing, et cetera.

LACK OF ACCOUNT-ABILITY

People who cause harm are often not caught or not held accountable for sexual violence. Though this is a pervasive societal issue, due to the combined social factors it has an outsize impact on PWD.

LACK OF (ACCESSIBLE) TRANSPORTATION

When public transportation isn't an option, private transportation becomes a necessity. Accessible vehicles are often prohibitively expensive, and many people with disabilities are not taught how to drive due to societal attitudes. Ride sharing services like Lyft and Uber are frequently inaccessible and riders who use mobility devices have reported having rides canceled or encountering hostile drivers. Service dog users have experienced similar problems.

Personal vehicle maintenance can also be expensive; the APTA estimates that the average household spends 16 cents out of every \$1 on transportation (16% of their income)—the largest expense after housing. On an annual income of \$15,000, that's \$2,400 per year.

OVER-CONTROLLED ENVIRONMENT

Many people with disabilities experience life within an authoritarian environment where they aren't granted the agency to make their own choices or decisions; this often extends to decisions about their bodies and sexualities.

ASSISTANCE BARRIERS

People with disabilities often experience cultural and societal barriers that impede their abilities to find and access assistance. This may include assistance that is not in ASL for individuals who are deaf or hard of hearing; lack of support from caregivers or staff to acquire assistance; overreliance on verbal communication or evidence; or agencies and organizations that are not equipped to assist people with intellectual or cognitive disabilities.

Conditions That Create Higher Risk for Victimization

- Devaluation
- Presumed lack of credibility
- Isolation and segregation
- Increased exposure to potential abusers
- Seen as “easy targets” or “ideal victims”
- Denied education about healthy relationships, consent, sexuality, and abuse
- Systemic denial of the right to make decisions about relationships
- Negative messaging about relationships and sexuality
- Given little control over life choices
- Economic instability

Culture of Compliance

Consequences:

- desire to please authority
- reliance on social cues
- looking for the answer
- confusion
- anger
- fear
- low self-esteem/confidence
- easily persuaded by others
- tend to over trust authority/service providers
- lack of bodily autonomy



Access to Supports & Services

Why are survivors with I/DD less likely to access/receive services and supports?

- Physical, communication, programmatic, and attitudinal barriers in law enforcement and legal system
- Organizations that serve people with disabilities are unaware of victim services or unsure if victim services would be able to support their clients
- Victim service organizations lack accommodations, staff training, and resources to serve survivors with disabilities and do not reach out to the disabled community, particularly those with I/DD



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Breakout Room

10 minutes

What were some of the conditions and contributing factors to sexual violence that you noticed in these survivor stories?

What are some of the barriers to services that the survivors mentioned or alluded to or that we can interpret from these stories?



Trauma and People with Disabilities

Trauma Responses



Fight, Flight, Freeze, Fawn Responses



Possible Behavior Changes Due to Trauma

- Allegations
- Aggression
- Self-injurious behavior
- Loss of skills
- Obsessive thoughts and/or compulsive behaviors
- Fleeing unexpectedly



Possible Emotional Responses to Trauma

- Excessive crying
- Outbursts
- Avoidance
- Fear based behaviors
- Overeating or refusing to eat
- Becoming withdrawn
- Lashing out at others
- Pretending nothing is wrong



Considerations

- Care providers often place focus on changing the “behaviours” that can arise after an assault, which may be a coping skill but also a form of communication
- People with I/DD are often incorrectly assumed to experience less emotional trauma
- People with I/DD might express distress or trauma responses differently and rather than connect them with help, care providers may assume they are “acting out”

Things to Remember

- People with disabilities are entitled to the dignity, consideration, respect and rights that you expect for yourself.
- Be intersectional: recognize the individual's culture, background, and lived experiences.
- Believe the survivor.
- Treat adults like adults.
- The survivor is the expert in what they need.
- Offer to stop for a break if the survivor is tiring out or getting upset.



Person Centered Services

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Person Centered Thinking

- Underlies and guides respectful listening, which leads to respectful action
- Supports people in having positive control over the a life that is desired and satisfying. Where people are:
 - Recognized and valued for our/their contributions (current and potential) to our/their communities; and
 - Supported by a web of relationships, both natural and paid, within our/their communities



Photo Credit: Disabled and Here

What are Person Centered Thinking Skills?

A set of value based skills that reinforce continuous learning and practices that:

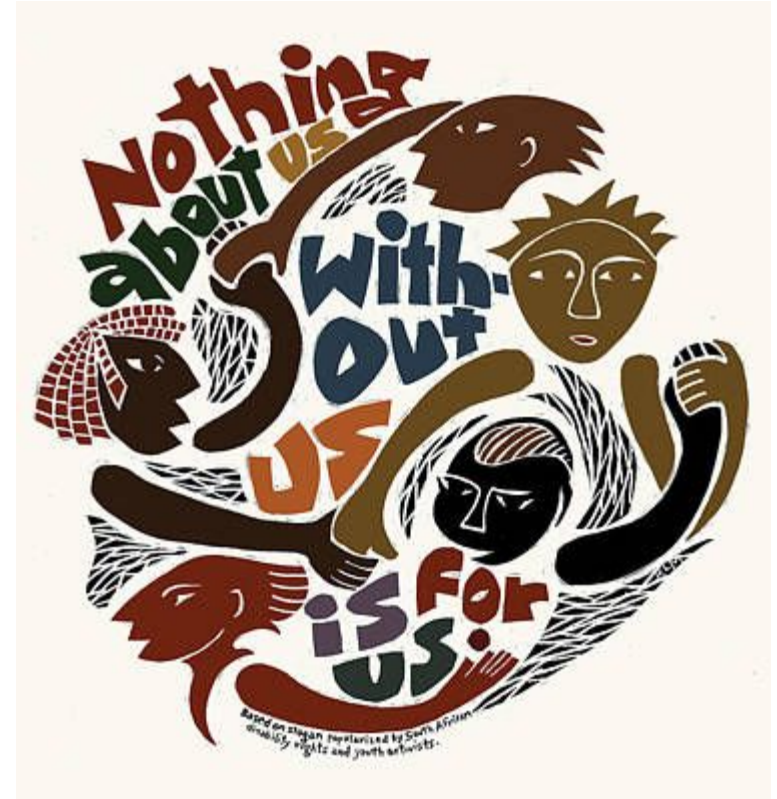
- Help us support rather than fix
- Build the culture of learning, partnership, and accountability
- Work for humans
- Affirm our belief that everyone can learn



Photo Credit: Disabled and Here

Supported Decision Making

- A person with a disability retains their decision making abilities by using supporters to help them make choices
- Supporters are family, friends, advocates, professionals, and support staff that the individual trusts to help them make choices
- **The individual makes the decision, not the supporters**



Dignity of Risk

		Severity				
		Negligible	Minor	Moderate	Major	Catastrophic
Likelihood	Almost certain	5	10	15	20	25
	Likely	4	8	12	16	20
	Possible	3	6	9	12	15
	Unlikely	2	4	6	8	10
	Rare	1	2	3	4	5

- Acknowledging that life comes with varied degrees of risks
- Not all risks are negative
- Respects the rights of individuals to take reasonable risks
- Balancing one's autonomy with another's urge to "protect"
- Making positive choices is a skill that is learned



Accommodations and Accessibility

Behaviors/Communication

- Muttering and/or repeating words or phrases
- Being unable to remember what you talked about
- Being withdrawn
- Not seeming to pay attention
- Getting frustrated and short tempered
- Tensions with other survivors
- Difficulties planning and organizing
- Stamina and fatigue
- Difficulties tolerating stress



- Inconsistent behavior
- Stimming

Communicating with Survivors with I/DD

- Always speak to the survivor and include them
- Try to eliminate distractions
- Ask one question at a time
- Try to avoid Yes or No and Why questions
- Pause after asking questions
- Take breaks
- Be aware of people pleasing and repeating back



Communicating with Survivors with I/DD

- Concentrate
- Be patient
- Ask them to repeat themselves
- Ask if it would be helpful for you to rephrase it
- Consider writing as an alternative means of communicating
- Communication facilitator

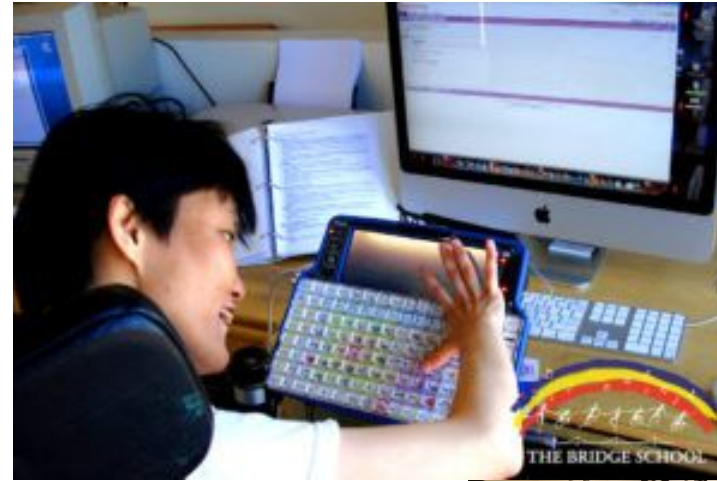
Communicating with Survivors with I/DD

- Consider that people may process information differently, especially depending on the way the information is presented
- Use plain language, but speak to people in an age-appropriate way
- If you are unsure what someone needs or what they are doing, it's okay to ask politely
- If orientation to time is difficult, use common events like daily meals, work or school



Communication Considerations

- Alternative or Augmentative Communication Devices (AAC)
- ASL interpreters
- “Real-time captioning” or Communication Access Realtime Translation (CART) Services
- Offer information in a variety of formats for different learning styles: text, images, auditory
- Ask clarifying questions instead of assuming intent/meaning
- Put written information in plain language



Sensory Considerations

- Are spaces sensory over-stimulating?
- Are there varied lighting options?
- Is there somewhere you can meet that is quiet, has less distractions?
- Do you have noise cancelling headphones or soundmachines?
- Could you provide stim/fidget toys/devices?
- Do you have a safe space if someone gets overwhelmed?
- Is there a comfort item that will help the person feel more at ease?

Physical/Structural Considerations

- Are there accessible public transportation options?
- Are the entrances, parking, meeting areas, restrooms, and seating areas accessible and easy to find?
- Are SART rooms and beds able to accommodate different bodies?
- Is there enough space for wheelchairs, support persons, and interpreters?
- Gait challenges - falls, balance, fatigue, sensory deficit
- Motor skill challenges - writing, typing, fine motor skills

Don't touch or move someone's mobility device unless they ask you to, you receive consent, or it's in harm's way

Intake Forms

- Ask everyone if they need accommodations or assistance
- Offer to fill out/assist with forms for everyone
- Some people might want/need assistance reading or understanding instructions
- Only fill out what is necessary



Hotline

- Do you have a text or online chat function?
- Do you immediately hang up if no one responds?
- Are your hotline workers familiar with video relay services?



Making your Website Accessible

- Make sure your website is setup to work with screen readers and has image descriptions (alt text)
- Do you have a quick escape/fast exit button?
- If your website has images of people, are there images of people with disabilities?
- Is it in plain language?
- Do you have captioning and transcripts of audio and video?



Making your Printed Materials Accessible

- Use plain language
- Use accessible fonts & colors
- Consider adding images
- Have large print versions
- Braille version
- Be willing to discuss it, or walk someone through it



Presentations/Meetings

- Is a translator or ASL interpreter needed?
- Can you orient the person to the space in advance if needed?
- Is there enough space for wheelchairs, support person, ASL interpreters?
- Can the chairs fit people of varied body sizes?
- Have you considered people's sensory needs/challenges?
- If there are materials or a powerpoint, have you offered to provide them in advance or translate them?
- Do you offer breaks? Can the person quietly stim or pace if needed?
- Can the meeting be scheduled so that it doesn't interfere with the person's routines, if they have them?

Disclosing a Disability

Survivors might choose not to disclose a disability because:

- Their disability has been a central part of their abuse
- Their credibility and knowledge has been discounted in the past when they disclosed their disability
- They were discriminated against or excluded, or faced stigma or verbal/emotional abuse due to their disability
- They received unequal treatment due to their disability

Survivors might choose to only disclose their disability when they need specific accommodations.

Service and Support animals

- Do you have a policy about service and support animals?
- Support animals do not have the same privileges as a service animal. How do you determine if a support animal will be allowed?
- What do you do if a staff member is allergic to a service animal?
- What if someone has a fear or phobia of the service animal?
- Do you have a protocol for cleaning up and assisting with care for a service animal when needed?



Additional Tips

- Some people with I/DD find routines helpful
- Sometimes people benefit from prompting when beginning or ending a task
- Plan for more time
- Provide information in different formats to support different ways of learning and comprehending information
- Provide reminders
- Be structured, yet flexible

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