Disability and Sexuality: Best Practices for Support Professionals

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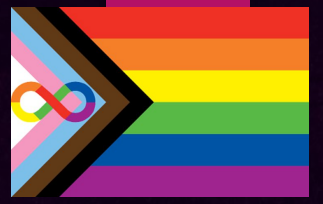
Presenters:



Morrigan Hunter - MA, MSW

I am nonbinary, queer, disabled/ neurodivergent. I work in research and program development with a variety of organizations to address the violence against disabled people and to promote sexual health equity.

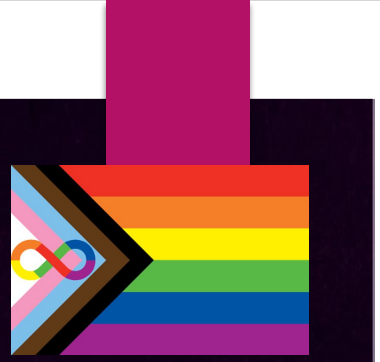
Arryn Akhtenberg - MA

I am a nonbinary, neurodivergent, queer, Jewish former refugee from ethnic violence. I currently work as a clinical therapist with Envision Unlimited's Pathways Dual Care (I/DD-MH) Program, with a focus on neuroaffirming and gender affirming care.

Content warnings:

sexual topics
biases/bigotry
mental health (SI/Sui)
DV/IPV
abuse/neglect
sexual assault

Agenda

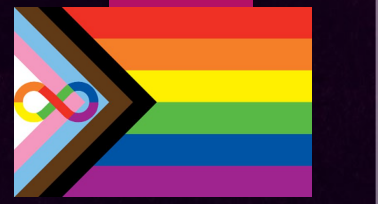


- What is ableism and how does it relate to sexuality?
- What are some ways to counteract ableism?
- What should QIDPs do?

Caveat

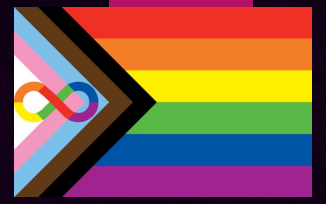
- This is a very large topic and we cannot cover everything that you need to know in this presentation
- We will provide an overview of some of the major issues and provide some suggestions on how to address them
- We are sharing a copy of our slides with you so you can refer to them as a resource
- Please feel free to reach out to us if you want to contract with us for additional training and support

What do we see?



- Who might be usually depicted when we do a Google image search for “ATTRACTIVE PERSON”?
- How likely are you to see a disabled, queer, transgender, or gender nonconforming person?
- What does the likelihood of depiction say about how people are valued based on their identities and characteristics?
- What about historic and current harm towards people carrying minoritized or politically targeted identities?

Intersectional Oppression: Why do we see what we see?



- Eugenics
- Ableism, Infantilism
- Sexism, Misogyny
- Queerphobia, Transphobia, Homophobia
- Racism

Personal Harms

- Are disabled people (who may also be queer or trans) seen and made to feel as:

  - Attractive or beautiful?

  - Sexy/sexual (without being fetishized)?

  - Desirable for relationships?

  - Valued as relationship partners/contributors?

  - Not burdens on others?

Personal Harms

- Disabled people, particularly those who are queer and trans, are more likely than other people to experience the following as a result of existing harmful biases/bigotries:

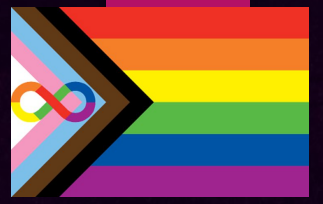
  - Higher rates of physical and sexual assault/abuse

  - Higher rates of anxiety, depression, and suicidality

  - Higher incidences of loneliness

  - Higher rates of relational/attachment trauma

Let’s Start with Language:



- What are the ideas involved?
- What are the identities involved?
- What are the rights involved?
- What language did various people choose for themselves?
- Affirming vs. Unaffirming language use

What Does Research Say About Neurodiversity and Gender/Sexuality?

- Neurodivergent folks are more likely to be gender-nonconforming or trans.
- Neurodivergent folks are more likely to be 2SLGBTQIA+ (non-straight).
- Neurodivergent folks are more likely to pursue alternative sexual/sensual and relationship practices (polyamory, BDSM, kink) because they meet specific neurodiversity-related needs.
- Serving the quality of life of neurodivergent clients requires more comprehensive knowledge and more inclusive support practices on the part of families and professionals.

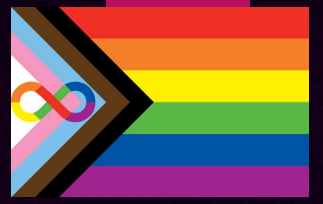
Definitions:

- Gender: a social construct that refers to the behaviors, expressions, roles, and identities of people
  - what does it mean that gender is a construct?
  - who gets to define a person's gender?
- Sex: a person's physical/biological (sometimes reproductive) characteristics
- Intersex: a general term for people who are born with sex characteristics that don't fit the typical definitions of male or female

Definitions:

- Gender Identity: the -personal- sense of one's own gender. Gender identity can correlate with a person's assigned sex or can differ from it.
- Gender Presentation: how a person expresses their gender to the world, usually through means like clothing, hair, accessories, voice, mannerisms, body use and modifications, taking up space.
- Sexuality or sexual orientation: sexual feelings, thoughts, attractions, and behaviors towards other people

Definitions:



- Neurodiversity Paradigm: the idea that all brain/cognitive differences are valid, and that there is no "right" way to think, feel, learn, see the world, or behave.

- Neurotype: how a person's brain develops, communicates, and learns - can sometimes be used in reference to diagnosed conditions.

- Neurodivergent vs. Neurodiverse
  - Neurodivergent refers to the fact that a person is different from others
  - Neurodiverse refers to differences in a group, depending on the group
    Ex: in my friend group there are people with different neurotypes (neurodiverse group), but I'm the only non-autistic (neurodivergent)

Definitions:

- Euphemisms for Disability: Based on discomfort with the term disability (special needs, differently abled). Disability is an informative and not a bad word.
- Mental Age Theory: Harmful because it infantilizes disabled people. All people are their chronological age and have been accumulating lifelong experience.
- Functional Level Language (high vs. low): Denies both the struggle and the support needs of disabled people - talk about access needs instead.
- Person First vs. Identity First Language: Certain disability communities prefer one over the other. Learn a community's disability culture and standards while respecting individual preferences.

Definitions:

- Disability Justice: Created in 2015 by Sins Invalid, outlines 10 principles that promote disability inclusivity (including for neurodivergent, Global Majority, and queer or trans disabled people).
- Access Needs: What a person needs to participate in a space or an activity. All people have access needs, regardless of disability.
- Dignity of Risk: The idea that disabled people can make decisions by themselves (with autonomy), including freedom to make mistakes like nondisabled people.
- Disability Culture: The values, history, ways of doing things, and standards that exist in any disability community like they can exist in any other communities.

Definitions:

- Nonspeaking vs. Nonverbal: The relevant communities generally prefer "nonspeaking" and consider this term less stigmatizing. However, respect individual preferences.
  - Mouthwords (spoken language) are only one kind of speech, and should not be prioritized over other kinds (textual, sign language, etc.)

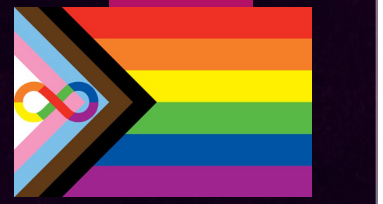
- Augmentative and Assistive/Alternative Communication(AAC): Technology which can facilitate forms of communication other than mouthwords.
  - Can be high-tech such as an iPad device with Proloquo speech software
  - Can be low tech such as letter/symbol boards or picture exchange systems

- All people should have access to communication (including about sex and gender!) in the ways that work for them.

Definitions:

- Queer: umbrella term for people who are not heterosexual or are not cisgender - it is a **reclaimed** term and should not be used adversely.
- Genderqueer: used for a person whose gender identity does not correspond to conventional binary (man/woman) gender distinctions.
- Neuroqueer: for some (not everyone) queerness and neurodiversity overlap. and are inseparable as identities of difference
  - ex: the differences in ways of thinking inform how they look at gender
- Autigender: a neuroqueer identity used by some Autistic folks specifically.

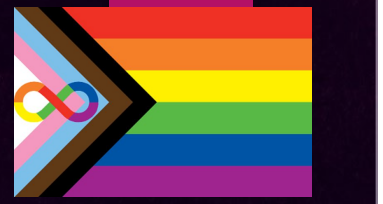
Part II – Ways to counteract biases and promote autonomy



Why is Sexuality Education for Disabled People Important?

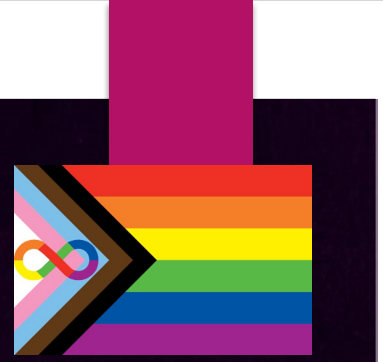
- Sometimes professionals and family members avoid telling disabled people about sex because they think that if disabled people learn about sex, they might be more likely to have sex and incur risks.
- Everyone deserves access to medically accurate and affirming sexuality education.
- Disabled people have the same range of sexual expression (straight, queer, asesexual/aromantic, monogamous, polyamorous, BDSM etc.) as nondisabled people.
- Lack of sexuality education will NOT prevent someone from exploring their sexuality and can put them at risk of adverse outcomes if knowledge is lacking.

What is your role in providing sex ed?



- QIDPs can play an important role in supporting client comfort and knowledge around sexual health through everyday conversations.
- This is particularly important as even with access to formal sexual health education, many of the topics are things that need to be integrated into a person's life to be understood
    - Autonomy around dressing and bathing, being able to say no
- Keeping good boundaries is important to help clients learn to set boundaries themselves
    - Including know what to share and not share about your own life
        - Setting your values aside to support your client in their goals

What happens if a Person Does Not Receive Sex Ed?

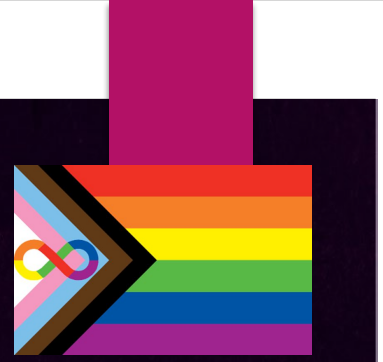


- May lack tools to recognize safety vs unsafety
  - Do they know how to advocate for what they want?
  - Do they know what to do if they feel unsafe?
- This can make them more likely to experience sexual violence and abuse
  - Abuse can have serious adverse effects on overall well-being and may make a person believe that they do not deserve better if they pursue relationships in the future
- May lack AAC devices/ terminology to communicate if bad things happened
  - Many AAC devices do not give adequate vocabulary for discussing sex, including reporting abuse. Devices may need to be programmed or tailored for individual needs and identities.

What happens if a Person Does Not Receive Sex Ed? (cont.)

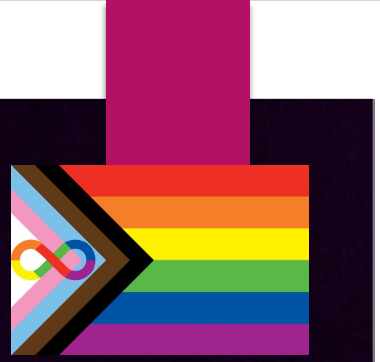
- They may pursue sexuality and intimate relationships in clandestine ways if not allowed to do so openly
  - Not receiving support can put them at increased risk of experiencing and causing harm, including legal trouble
- Sometimes lack of knowledge can result in both sexual exploitation and being exploited
  - Experiences of past abuse may make it difficult to recognize boundaries for self and others
  - Even incidental harm (from lack of knowledge) can be a source of trauma

Not Providing Affirming Sex Ed is Dangerous



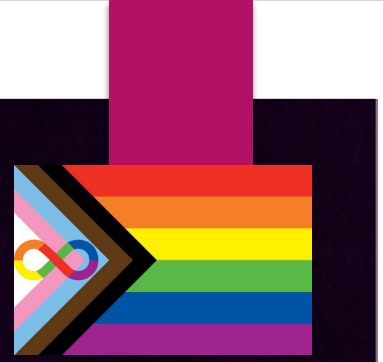
- Disabled people have the same range of sexual expression as nondisabled people
- Not having access to sex ed creates possibility of harm between clients as people explore their sexuality
  - Official records of harm mean legal and personal stigma without context of systemic causes
- Knowing better can also prevent lateral replication/reenactment of sexual trauma (Abuse against other disabled people)
  - Particularly as many disabled people have experienced ableism (and other forms of systemic oppression) around sexuality

Not Providing Affirming Sex Ed is Dangerous



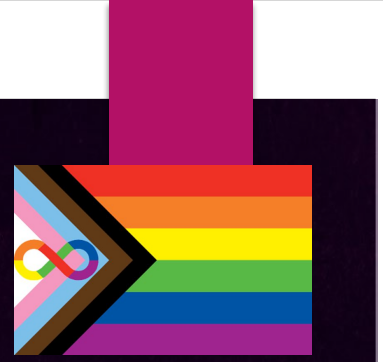
- Self esteem issues and valid/valuable attachment versus loneliness
  - Many disabled people internalize the idea that they are not desirable or attractive
  - They may feel they have to accept mistreatment from partners if they do not want to be lonely
  - They may develop forms of pervasive trauma from suppression of sexuality
  - Affirming sex ed can help them to unlearn internalized ableism

What does affirming sex ed look like?



- Providing opportunities to practice advocating for what they need, recognizing the importance of how to address conflicting access needs
- Validating the needs and experiences of disabled people, including gender identity, sexual orientation, relationship style (such as ethical non-monogamy), and sexual expression (such as kink or BDSM)
- Providing education about internalized ableism and other isms

What does affirming sex ed look like?



- Liberatory sex ed for disabled people centers pleasure and takes a neurodiversity affirming approach rather than a neuronormative approach.
- This means focusing on teaching consent, boundaries, self-advocacy rather than teaching disabled people how to engage in socially normative behaviors
  - Just because something is a norm does not mean that it is consensual
  - For example, norms around hugging, shaking hands, eye-contact may conflict with a person's own bodily autonomy
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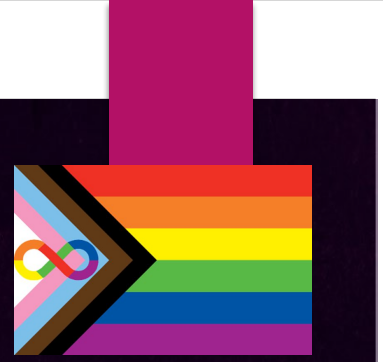
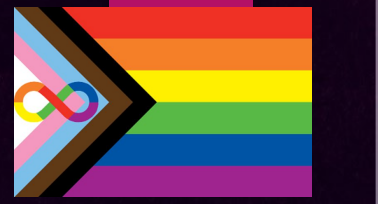
What does affirming sex ed look like?

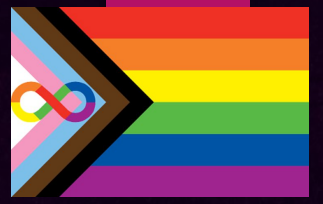


- Is the primary author(s) of the curriculum disabled themselves/ a person with a disability?
- Does the information promote supported decision making, pleasure, and dignity of risk?
- Does the information promote mental age theory, restriction and control, and pathologization of sexual expression?
- Does the information align with the 10 Principles of Disability Justice?

Part III – Recommendations for QIDPs



Where do I begin?

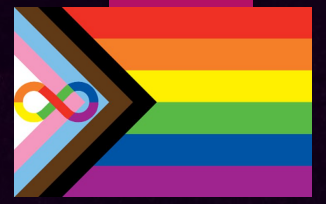


- Critically examine and interrogate your own perspectives on disabled sexuality - watch for influence of relevant biases in your own culture and lived history.
- Be able to draw the line between your values around sex and gender, and what is in the best interests of disabled clients interested in expressing sexuality.
- Become familiar with research on intersections of disability, gender, and sexuality (ex. overlap between neurodiversity and gender/sexuality diversity)
- Develop your own comfort level in being able to have well-boundaried discussions about sex and sexuality with disabled people.

How do I talk to my clients?

- Create space for conversations with disabled clients on topics of gender and sexuality in individual meetings, and if comfortable, in care planning settings.
- Be able to assert a disabled person's rights to gender affirmation and sexual expression, particularly as they overlap with CQL assumptions and principles.
- Ask a person's preferences in discussing any topics of gender and sexuality - emphasize <u>your</u> responsibility to provide emotional safety in these discussions.
- Observe the person's boundaries and comfort - avoid optics of scrutinizing their sexuality, control wanting to know everything in order to help.

Potential challenges



- Recognize the role of individual and systemic marginalization as barriers for disabled people to discuss their sexuality and gender as they see fit.
- Think about and ask questions about sexual health and relationship goals/fulfilment - discuss regular STI screenings and case manage them.
- Watch for internalized ableism and cisheterosexism, know how to affirm disabled people’s rights to safe sexuality of their choosing (including aro/ace).
- Self-educate to give information on topics of queer/trans disabled sexuality, including body autonomy/consent, gender affirmation, sensual/sensory play.

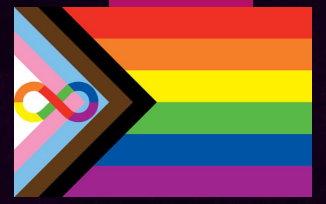
How can I be supportive and affirming?

- Discuss the importance of focus on disabled pleasure as a form of harm prevention and as a way to counteract social and internalized ableism.
- Familiarize yourselves with power disparities that disabled and neurodivergent people experience in their families, with professionals, and in society in general.
- Assess domestic or intimate partner violence (DV/IPV), including for both same neurotype and mixed neurotype (including disabled-nondisabled) relationships.
- Reinforce the person's use of their most accessible and most preferred form of communication about sexuality (e.g., sign language, AAC, mix of several).

How can I model safety and boundaries?

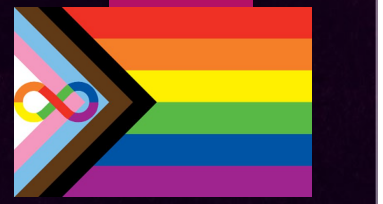
- For people in your own life-modeling consent and bodily autonomy is very helpful
- Respecting a person's no, however they communicate (words, gestures, AAC etc.)
- Not making assumptions about whether or not someone will want to be a parent (people with disabilities can be great parents)
- Recognizing that disabled people can be queer, trans, ace, polyamourous, kinky etc.
- Treating disabled adults as adults, teens as teens
    - Don't infantilize them

Areas for advocacy and action



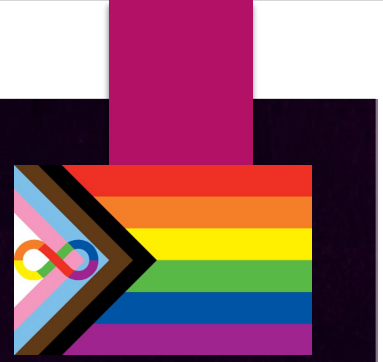
- Advocate for your clients' access to safe and affirming sexual and relationship health education. Seek out additional resources if availability is insufficient.
- Co-advocate with your clients and on their behalf with guardians and family members who may not share values on the topic of disabled sex and sexuality.
- Work within your agency and with knowledgeable colleagues to encourage investment in and establishment of sexual and relationship health programs.
- When asked, help clients plan ahead and get resources (e.g., rooms or sex toys) to have any safe form of sex they see fit (both in relationships and as hookups).

Areas for advocacy and action (cont.)



- In organizations that provide supports to disabled people-are staff trained to provide support and education around sexuality (this includes employment services)?
- In healthcare-Is the physical space and online patient portal accessible to people with a range of access needs? Do providers know how to interact with people with disabilities in a trauma informed way, including around sexuality?

How do I collaborate and refer?

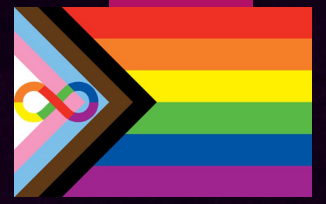


- Refer clients to mental health therapy - have lists of neuroaffirming, sex-positive, BDSM/kink and polyamory aware service professionals for clients.
- Question and push back on behavioral recommendations meant to suppress sexuality and sexual behavior, such as some behavior analytic interventions.
- For nonspeaking/partially speaking clients, refer to Speech and Language professionals who can tailor AAC communication systems to sexuality needs.
- Help keep family members, state or legal guardians, colleagues, and other stakeholders accountable to a disabled person’s human rights on sexuality.

Summary

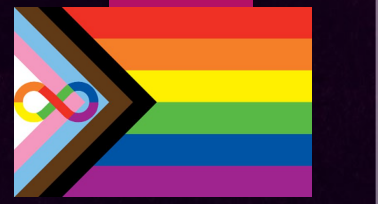
- Disabled people are not confused about their gender and sexual identities. They discover and understand them as well as or better than anyone else.
- Disabled people who lack affirmation and outlets for their sexuality, may develop behavioral concerns that reflect both the extent of their oppression and lack of support, and the resulting interpersonal attachment problems.
- If a nondisabled person can do it, a disabled person should be able to as well.
- Greater (not fewer) resources and knowledge are needed to sufficiently and successfully serve queer/trans disabled people, due to intersecting complexity.

Areas of caution



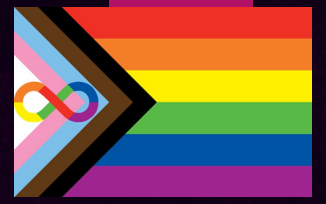
- The pervasiveness of ableism and other biases requires ongoing personal work (learning and unlearning) to counteract those biases showing up in what you do.
- You may face opposition from colleagues and other stakeholders who may not grasp the good impact of affirming practices on the lives of disabled people.
- You will be working in systems which may contain biases and other elements of oppression which have kept supports (including sex ed) from disabled people. (ex. working in religiously-affiliated nonprofits with policies opposed to sex ed)
- You may sometimes feel isolated or disconnected in doing this sort of work because of broad political, social, and workplace circumstances.

Taking care of yourself



- You are not going to be successful in promoting best care practices every time. Be sure to count your successes in proportion to your power to make change.
- Refer to existing knowledge and best practice standards in the field. Keeping up with these developments can be a form of continuing education.
- Cultivate relationships with your supervisors and ask them to intervene with their institutional power when needed to support a person you are serving.
- Organize and increase the institutional power of your advocacy by teaming up with colleagues and others to form interest groups oriented towards promoting trauma informed and affirming care for disabled people.

What can I accomplish?



- Build relationships and show care towards vulnerable people.
- Live and work in accord with client-centered values and politics.
- Make a mark in undoing social and internalized harm.
- Improve mental health and life paths/outcomes for clients.
- Enable opportunities for self-expression and better quality of life.
- Literal suicide prevention.
- Form collaborative relationships with others similarly aligned.

Resources

- Dear Parents Who Want to Keep Their Nonspeaking Children Safe as They Go Out Into the World
- Temple University AAC Sexuality Vocabulary List
- How do you symbolize intimacy? For many AAC programs, not particularly well.
- Autonomy, Self-determination, Dignity of Risk, and Harm Reduction for AAC Users
- Explore the sexual health resources created by Sexual Health Equity for Individuals with Intellectual and Developmental Disabilities (SHEIDD)

Resources

- Proud and Supported Series
- Amaze is a great resource on sex ed for middle school youth, but the content may be helpful for adults
- One of my favorite sex ed curricula (for inclusion and accessibility) is Sexuality for All Abilities
- Training module on providing services to Autistic survivors of sexual assault on college campus

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