



Supporting Survivors with Intellectual/Developmental Disabilities (IDD)

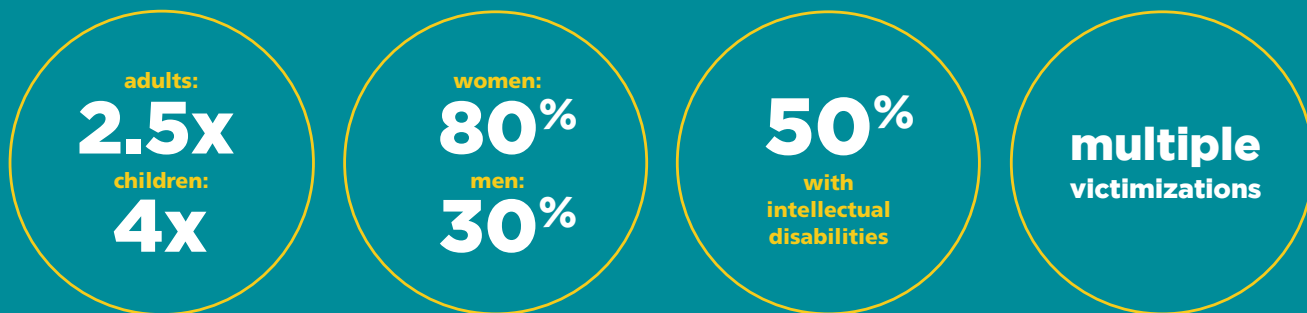
What is IDD?

A Developmental Disability (DD) is defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 as a severe, chronic disability of an individual that is attributable to a mental or physical impairment or combination of mental and physical impairments; is manifested before the individual attains age 22; is likely to continue indefinitely; and results in substantial functional limitations in three or more of the following areas of major life activity (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, economic self-sufficiency); and reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), an Intellectual Disability (ID) is a Developmental Disability and is characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18. (Pennsylvania extends the upper age range to 22 years).

Individuals with IDD may have other co-occurring disabilities including physical disabilities, mental health disabilities, sensory disabilities, medical disabilities, etc.

People with IDD encounter sexual assault and abuse at alarming rates, and commonly experience multiple victimizations.



People with disabilities are targeted for violence at rates **2.5 times** (adults), **4 times** (children) higher than people without disabilities.

Up to **80% of women** and **30% of men** with DD have experienced sexual violence.

At least **50% of people with ID** have been victimized sexually.

It is common for people with IDD to have experienced **multiple victimizations** throughout their lives.

Sexual Violence and People with IDD

People with intellectual and/or developmental disabilities (IDD) experience sexual assault and abuse at alarming rates. In general, people with disabilities are targeted for violence at rates 2.5 times (adults) – 4 times (children) higher than the rate of perpetration against people without disabilities (Davis, 2011; Harrell, 2017). Some reports indicate that up to 80% of women and 30% of men with DD have experienced sexual violence (Coyle, 2016; Disability Justice, 2019) and that at least 50% of people with intellectual disabilities have been victimized sexually (The Arc, 2011; Disability Justice, 2019). Some studies demonstrate prevalence rates as high as 90% (Friedlander, 2018). For transgender people with IDD, incidences of violence are even higher (Disability Rights Education & Defense Fund [DREDF], 2018). Additionally, it is common for people with IDD to have experienced multiple victimizations throughout their lives.

In the vast majority of cases of violence against people with IDD, including sexual abuse and assault, the perpetrator is known to the victim, and often plays a role in providing support or care for the person they are harming (Davis, 2011; Harrell, 2017).

It is important to remember that sexual violence can include a spectrum of unwelcome behaviors, from verbal harassment to physical assault. However, in cases where people are dependent upon others for help with tasks such as dressing, toileting, or bathing, those boundaries may be more likely to be tested or crossed. For example, there may be an increased likelihood that the abuse may “take the form of lack of respect for privacy and unwanted exposure during personal care routines.” This can take on many forms, from inappropriate touching to “forced abortion, sterilization, or pregnancy; and exploitation” (Abramson, 2010, p. 5).

Impact

Experiencing sexual harassment, abuse, or assault can have devastating impacts on a person’s physical, psychological, social, and spiritual well-being, and it is important to remember that no two people will respond in the same way. Physical impacts may include minor to severe injuries, sexually transmitted infections, and increased risk of chronic disease. Survivors may experience headaches, gastrointestinal distress, changes in appetite, disruption of sleep habits, or increased risk of substance misuse or abuse. Psychologically, people may experience higher levels of anxiety and/or depression, suicidality, low self-esteem, or feelings of shame or guilt.

Experiences of sexual violence can also impact a person's social life and relationships. For example, a person who was very social may become more withdrawn or may find it difficult to attend school or work. Survivors may struggle to form or maintain trusting relationships or may experience changes in their libido or sexual behavior (Abramson, 2010; Davis, 2011).

It is important to note that when people have experienced repeated acts of violence, including ableism, racism, sexism, homophobia, transphobia, or other forms of oppression and violence that are related to their identity or identities, the impact and health disparities may be compounded (DREDF, 2018).

Reporting

Most incidences of sexual harassment, abuse, or assault of people with IDD go unreported, and of those that are reported, very few offenders are held accountable (Davis, 2011; Friedlander, 2018). There are many reasons why people may not report to institutional or legal authorities, or even to friends or family. In some cases, a person may be unable to report that they have been abused due to communication limitations/barriers, or they may not even recognize that what they are experiencing is sexual violence, particularly in cases where the abuse has gradually escalated or is being perpetrated by someone who is trusted by the victim. If a person is dependent upon their abuser, they may not want to see that person get in trouble, or may fear what will happen if that person or agency is no longer able to care for or help them.

In a report by the Bureau of Justice Statistics (Harrell, 2017), it was noted that nearly 24% of respondents with disabilities (including IDD) indicated that they did not think the police would respond effectively, because they believed the police would not help. Reporting to law enforcement may be particularly concerning for groups of people with IDD who have a history of being mistreated by police, such as transgender people of color (DREDF, 2018; U.S. Transgender Survey, 2015 a & b).



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Considerations for Prevention & Intervention

1 Prioritize empowerment and choice.

Sexual harassment, abuse, and assault are rooted in oppression and imbalances of power where one person violates the rights of another person. In order to prevent sexual violence or to intervene effectively, efforts must not replicate dynamics of power and control. Unfortunately, people with IDD are often excluded from decision-making ([Disability Rights Pennsylvania \[DRP\], 2018](#)) or are rewarded for reaching behavioral goals associated with following rules and deferring to people with authority. Behavioral goals that support compliance and deference to authority can mimic grooming tactics used by abusers (Abramson, 2010). Creating practices and systems that reinforce a person's ability to make choices and decisions for themselves can help to interrupt imbalances of power that can perpetuate abuse. Additionally, empowerment and choice can be facilitated by ensuring an individual has the tools needed to adequately communicate their needs, feelings and experiences.

2 Emphasize self-determination, autonomy, and personal boundaries.

Everyone has the right to decide what is or is not acceptable for themselves and their bodies (American Association on Intellectual and Development Disabilities, 2018; DRP, 2018). Educating individuals with IDD about their rights to set personal boundaries, to assert themselves, and to have those boundaries respected, can be important steps toward empowerment. It is also essential to train caretakers about their responsibility to regularly ensure that individuals with IDD have access and support to use communication aids/techniques that will allow for communication of needs and experiences as independently as possible, offer choices, and respect the choices and boundaries of the people they are helping.

3 Practicing consent is key.

Consent is an essential component of any healthy relationship or encounter. Consent is the ability to communicate informed agreement to engage in any activity, and involves not only asking for another person's permission to engage, but also accepting their answer. The right to give or deny consent applies to all people, including people with IDD (Pennsylvania Coalition Against Rape [PCAR], 2017a). Although often associated with sexual behavior, consent should be modeled and practiced in all interactions with others (National Sexual Violence Resource Center [NSVRC], 2019).

There may be times when a person does not have the ability to freely or fully consent. This may be due to their disability, but may also be due to other factors, such as their age; a power imbalance between people; use of prescribed medications; use of alcohol or other drugs; or if they are asleep or unconscious. A person has the right to withdraw consent at any time, and just because something was acceptable to them at a different point in time, it should not be assumed that they still feel the same way. This is true for low-stakes situations, such as sharing a snack, and in situations where the stakes are higher, such as sexual activity (PCAR, 2018a). In some cases, a person with IDD may have a legal guardian who has decision-making power. It is important to understand the scope of their guardianship, and to continue to involve people as partners in making decisions that affect them to the greatest extent possible (Mamas & Resnick, 2017).

4 Provide education about healthy relationships and sexuality.

In general, education about healthy relationships and sexuality is lacking, particularly for people with IDD. This can stem from a lack of sexual education in school settings or a misguided belief that people with IDD do not experience sexual feelings or have sexual relationships (Coyle, 2016). Early education about healthy relationships and sexuality, including consent, is an essential part of empowerment, but also can help people establish their own boundaries, and to recognize and advocate for the types of relationships and experiences they want to have (Coyle, 2016).

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5 Prioritize training and funding.

Despite the prevalence of sexual harassment, abuse, and assault of people with IDD, many rape crisis centers are unprepared to meet the needs of survivors (Abramson, 2010). One way rape crisis centers can help to fill this gap is by making a commitment to build their internal capacity. Some examples could involve creating internal workgroups, building community partnerships, completing an internal audit of strengths and challenges related to access, revamping policies to be more inclusive, and prioritizing funding directed at increasing accessibility for survivors with IDD (Smith, et al., 2015). This may include designating funds to provide interpreters for survivors who



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use sign language and/or gestures, or devices to communicate; using plain language when communicating and in publications; ensuring that the building is accessible for people with physical disabilities; providing training for staff; or being flexible with scheduling or other aspects of service provision (i.e. where intake appointments occur, where counseling may be delivered, provide information in other formats besides written instruction/pamphlets/brochures, etc.) to ensure that survivors' individual needs are being met and that they can meaningfully participate in counseling appointments or advocacy activities.

It is also essential to identify community partners within the field of IDD and self-advocates who can help to build the capacity of rape crisis centers to provide meaningful services for survivors with IDD. Community partners and self-advocates can provide training for staff, and help center staff to identify opportunities for growth and change to better serve people with IDD and prevent sexual harassment, abuse, and assault. Funding should be designated to support these collaborations and to compensate partners and self-advocates for their expertise.

Confidentiality

While many professionals may be mandated reporters of abuse against adults with IDD or older adults, PCAR-funded rape crisis counselor-advocates in Pennsylvania are not. Except in cases of child abuse, or when a client threatens harm to themselves or others, a rape crisis counselor-advocate may only disclose a client's information with their informed, documented consent (PCAR, 2013; PCAR, 2017; PCAR, 2018 a, b, c).

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Thank You

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