

RESPONDING TO SURVIVORS WITH
AUTISM SPECTRUM DISORDERS:
AN OVERVIEW FOR SEXUAL ASSAULT ADVOCATES

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This project was supported by Grant No. 2011-TA-AX-K023 awarded by the U.S. Department of Justice, Office on Violence Against Women. The opinions, findings, conclusions, and recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the views of the U.S. Department of Justice, Office on Violence Against Women.

NSVRC thanks Emily Koppenhofer from the Pennsylvania Department of Human Services, Bureau of Autism Services and Leigh Ann Davis, The Arc, Criminal Justice Initiatives, Washington, D.C. for their insights and review.

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Hi. My daughter was sexually assaulted at school last fall. I just learned about this... and I should tell you she has autism... high functioning... what do I do?

I am working with a client who has experienced sexual assault. He has autism. Can you help me understand their experience of that?

I have had clients, specifically those with autism, who struggle with social cues and long for acceptance, often times unknowingly put themselves in harm's way. I have a few clients who engage in risky behaviors without regard to consequence because that is how they think to make friends. Explaining consent, acknowledging risks and understanding sex and relationships has been difficult to teach to young adults with intellectual delays.

The situations above reflect real-life dilemmas when sexual violence impacts people with autism spectrum disorders (ASD). Multiple studies have shown that sexual victimization of people with disabilities* generally is among the highest of any group of people. The Bureau of Justice Statistics found the rate of violent victimization for persons with disabilities was nearly three times the rate of those without during a three-year period (U.S. Department of Justice, Bureau of Justice Statistics [BJS], 2014). A more recent BJS report found during the 2010-14 timeframe that persons with cognitive disabilities had the highest rates of total violent crime, serious violent crime, and simple assault among the disability types measured (BJS, 2016).

* We are using person-first language in this document, recognizing that there are some in the disability community who do not support person-first language and others who do.

The bulk of research to date has looked at sexual violence victimization within the broad category of “disability” referring to any person with challenges – physical, intellectual, developmental, or those with multiple disabilities. Less common but more important are studies that examine sexual violence specific to the presence of a particular disability. This research can provide prevalence data but also context and understanding of the experience and population itself – critical to providing proper intervention as well as designing meaningful prevention programs. For example, the 2016 BJS report referenced above found that of the total number of rape/sexual assault victimizations reported, an estimated 69% were committed against persons with multiple disability types (as opposed to those with a single disability type) – the highest percentage among the crime types examined (BJS, 2016).

A newer report from the National Council on Disability finds one of every three female undergraduates with a disability (not specific to ASD) had been sexually assaulted during their time at college. The study also found that students with disabilities are not even “on the radar” of colleges in their sexual assault prevention efforts, policies, or procedures for response and support after an assault, even though many campuses are scrambling to provide appropriate response and prevention programs to students (National Council on Disability, 2018).

A 2017 National Institute of Justice (NIJ)-sponsored study that looked at help-seeking patterns and criminal justice responses to victims of sexual violence with disabilities provided several insights including the notion that survivors with disabilities are reluctant to disclose their victimization for fear they wouldn’t be believed. Provider interviews conducted by the researchers identified a lack of service provision for sexual assault survivors with disabilities and, of note, the lack of comfort level in working with this population. This study was not specific to individuals with ASD, but the larger universe of people with disabilities, although the authors note 25% of participants were recorded as having an intellectual/developmental disability (NIJ, 2017).

Few studies have looked specifically at individuals with ASD, but those that do suggest prevalence rates two to three times higher than individuals without ASD (Brown-Levoie, Vecili, & Weiss, 2014). Mistreatment often starts early. Children with ASD were found to be bullied three to four times more than their peers (Hoover & Kaufman, 2017). The authors

What is Autism?

Autism is a spectrum disorder that affects every individual to a differing degree. Autism is a complex developmental disability. It is a neurological condition with a variety of symptoms that affect individuals in different ways.

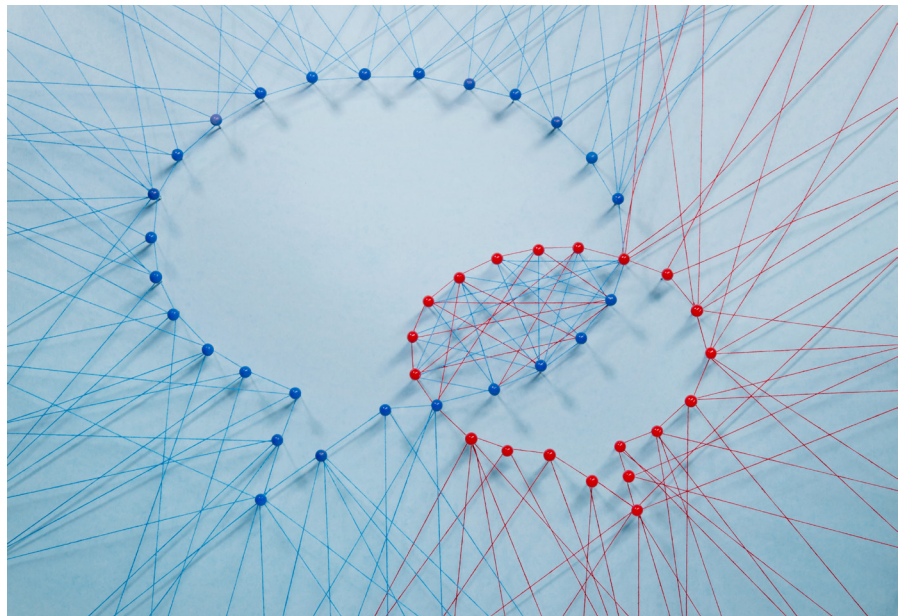
It knows no racial, ethnic, or social boundaries.

People with autism may have difficulties in communication and social understanding. They may also have unusual reactions to sensory input and demonstrate what may be considered inappropriate behaviors. Autism spectrum disorders (ASD) are now known to be more common than previously thought, affecting as many as 1.5 million individuals nationwide. Autism is four times more likely to occur in males than in females.

(Gammicchia & Johnson, n.d., p. 2)

further note that while anti-bullying programs for mainstream students have proliferated, they have found none that focused on children with ASD.

People with ASD live throughout the community. They attend schools, may live with their families, attend religious services, and engage in many activities including jobs. In 2013, the 'sub-types' of autism such as Asberger's Syndrome were combined into a single



diagnosis – ASD. As the term “spectrum” would suggest, there can be a range of individual challenges and strengths – the diagnosis looks different on everyone. People can have limitations in one area and no limitations in others. Some have no language delays and possess average to above-average intelligence but exhibit clinically impaired behavioral and social functioning (Gammicchia & Johnson, n.d.). For most people with ASD, cognitive challenges can significantly affect their ability to interact with others in socially expected ways.

Difficulties in communicating and interacting, such as not understanding social cues, can lead to frustrating and traumatic interactions. Responses that are viewed as odd at best or even disrespectful can lead to situations where the person becomes involved in dangerous and/or potentially victimizing circumstances unwittingly (Edelson et al., 2010). For others, compliance behaviors that are often taught from a young age make individuals less likely to resist an offender's demands or tell someone when they have been victimized (Sevlever, Roth, & Gillis, 2013). Some may not realize what has happened, or is happening, is wrong or could be considered a crime.

The Autism Society has developed a list of responses that may be common for persons with ASD after a traumatic experience. It has been reprinted here to emphasize that behaviors following traumatic events should not be labeled as “behavioral problems” but as responses to trauma. For people with ASD in particular, those responses can become subject to harsh interpretation and consequences.

Ideally all sexual violence advocates have been part of cross-training efforts with the disability community. The sexual assault advocacy community and the disability communities should be working toward cross-training as organizational goals for both. It takes a skillful and patient individual who understands the complexities a person with ASD may be experiencing to incorporate effective communication strategies. Experienced disability providers can offer guidance and suggestions for advocates. Both formal training agreements and MOUs (Memorandums of Understanding) as well as informal relationships

(referrals, consultation, exchanging resources) are extremely important connections that advocates need to serve this group of survivors effectively.

Notable in the NIJ study referenced above were service providers from many fields who didn't identify themselves or other providers they knew as adept in working at the intersection of sexual violence and disabilities (NIJ, 2017, p. 18). There is a larger conversation around agency readiness and commitment to serving disabled survivors that is beyond the scope of this brief publication, but it is urgently recommended. Resources are available for sexual assault agencies to begin addressing this void. One example is *Measuring Capacity to Serve Sexual Assault Survivors with Disabilities*, which presents a structured process for assessing and evolving core services (Vera Institute of Justice, 2015). Accessibility, institutional partnerships, policies, and programmatic capacity are addressed at the organizational level. Other resources, including The Arc's Pathways to Justice training, can assist a sexual assault organization to develop the procedures and training to better serve the needs of this victimized and vulnerable group of survivors. See page 10 for additional resources.

Advocates can begin with the same foundational principles – belief, support, and empowerment that center all advocacy efforts.

Communicate with intention.

Communication skills can be particularly challenging for victims with ASD. Establish the person's preferred communication method. If support professionals are already in place, ask them to interpret if necessary. It may take longer for a person with ASD to process information. Language should be concrete. Examples and instructions that use slang and euphemisms may not

Characteristics of Autism

Persons with ASD may act in any of the following ways in an encounter with crime victim professionals. Care should be taken not to misinterpret some of these actions as deliberate, disrespectful, or hostile; an individual may just be acting according to his or her condition.

Persons on the autism spectrum may:

- not recognize a first responder vehicle, badge, or uniform
- not understand what is expected of them
- not respond to commands or questions
- be unable to communicate verbally
- repeat what is said to them
- communicate only with sign language, pictures, or gestures
- avoid eye contact and look away constantly
- appear argumentative, stubborn, or belligerent
- say "no" or "yes" in response to all questions
- have difficulty judging personal space
- be overly sensitive to sensory input (e.g., lights, noises, crowds)
- have a decreased cognitive ability when experiencing heightened anxiety or frustration

- become anxious or agitated, producing fight or flight responses – such as screaming, hand flapping, attempting to flee, or self-injurious behaviors
- appear to be under the influence of drugs or intoxicants
- have an associated medical condition such as seizure disorder
- be fixated on a particular object or topic, resulting in repeated asking of questions
- give misleading statements
- have problems speaking at the correct volume
- if verbal, be honest to the point of bluntness or rudeness
- not acknowledge pain or trauma
- have the need for a forensic interviewer to assist them in communicating victimization or abuse that may have occurred
- not communicate the extent of trauma due to lack of understanding of sexuality, intimacy, or appropriateness of relationships
- need extra sessions with counselors to feel comfortable to be able to communicate what may have transpired.

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be understood. Speak slowly and wait for a response. People with ASD often don't have an understanding of social cues that might otherwise guide conversation.

Advocates provide the space for a person to share their account and understanding of what happened to them. People with disabilities can and do have consensual sex. Disability advocates refer to this as the right to an everyday life – the same as their peers without disabilities. Conversely, a survivor could be acting out what they have felt unable to express verbally through behaviors or intensification of behaviors. Disruptions in behavior could signal a need for further probing rather than assuming the behavior is part of this disorder (Sevlever et al., 2013). Listen to the survivor and how they describe their experiences.

Connecting with caregivers and significant others. Depending on a survivor's particular needs, they may have caregivers (paid or unpaid) and possibly guardians. The Victim Rights Law Center defines guardianship as a legal relationship giving one person the power to make personal and property decisions for another (Victim Rights Law Center, 2017). Guardians are court-appointed, and the laws governing guardianship will vary from state to state. Your agency should have information available on the types of guardianship defined in your state and the impact of each on issues such as medical care, consent, and other privacy rights.

With consent from the survivor, an advocate should attempt to meet privately without others – caregivers or guardians – in the room. However, if the survivor wants a support person with them or needs them for communication purposes, honor that request. Regardless, the dialog should be between you and the survivor. Sexual assault



advocates know the important roles that personal agency and dignity take on in the life of a person who has been sexually victimized. With that in mind, conversation and attention should be directed to the survivor. Don't ask questions of a caregiver or guardian present when they can be directed to the survivor. Not acknowledging an individual's personal agency reinforces a lack of control in their life and/or over their bodies. It can also reinforce the compliancy and submissive behaviors noted above that many individuals with ASD are taught.

It is important to remember that caregiver abuse is a significant problem in the lives of people with disabilities, so establishing a trusting relationship and building a comfort level directly with the survivor is really important.

While confidentiality rules apply to all victims of sexual violence, legal guardianship may – or may not – require an advocate to provide information regarding your work with the survivor. Again, the agency should take responsibility for knowing guardianship laws of the state and how they interact with your work as an advocate with this survivor.

Accommodate as appropriate. The [Americans with Disabilities Act \(ADA\)](#) requires reasonable modifications to policies, practices, and procedures as necessary to allow individuals with disabilities to participate in all services. For sexual assault survivors without disabilities, the initial meeting with an advocate can feel stressful. For someone with communication and sensory difficulties, that anxiety could be much worse. Provide whatever comfort accommodations are needed to support the person, paying particular attention to

distractions – whether they are noise, confusion, or the presence of other people. If possible, get a list of sensory concerns ahead of time and avoid them. Welcome the individual to bring comfort items if they choose.

Create a space and atmosphere that will feel comfortable and private, allowing the survivor's response to guide those choices whenever possible.

Create a safety plan with the survivor. Assist the survivor in creating a safety plan that is simple and concrete. The Arc suggests the following components:

- ✓ Who to talk to if a person suspects someone wants to hurt or force them to do something.
- ✓ The name of a trusted person that will check in on a regular basis. If possible, carry self-identifying ID and memorize addresses and important phone numbers of trusted caregivers or carry these items in a wallet, on a cell phone, etc.
- ✓ Contact information for the local police and another care provider.
- ✓ Personal rules about ways of staying safe. (The Arc's National Center on Criminal Justice & Disability, 2015)

END ABUSE of People with Disabilities has also created a Safety Planning template that can be customized for working with people with various types of disabilities (see page 9 for further information).

Finally, the development of healthy sexuality education programs designed for children, teens, and adults with ASD could be a huge step towards preventing victimization. Advocates can check out two teaching programs developed within the disability community to assist with prevention and awareness programs. See the resource section for information on Illinois Imagines and Green Mountain Self-Advocates.

Prevention programs should include LGBTQ-based sexual health guidelines as well. Research on connections between autism and gender diversity have become an increasing area of interest as early studies have found a disproportionate number of youth with ASD who identify as LGBTQ (Rudacille, 2016; Strang, 2014).

Going forward, it is hopeful that we move beyond the umbrella label of "disability" used to define a broad swath of people who experience very different challenges. People who are physically or sensory disabled require different response and prevention efforts than those with intellectual or developmental challenges. Efforts to document and present the experiences and challenges of individuals with particular needs can lead to developing intervention and prevention efforts with intention and meaning.

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RESOURCES FOR ADVOCATES

- [A Peer to Peer Guide About Domestic and Sexual Violence](#). 2011. Green Mountain Self-Advocates.
- [Women With Disabilities and Sexual Violence Education Guide](#). 2010. Illinois Imagines Project.
- [Working with People with Cognitive Disabilities](#). 2005. Pennsylvania Coalition Against Rape.
- Advocating for Victims with Intellectual/Developmental Disabilities During a Sexual Assault Forensic Examination [Part 1](#) and [Part 2](#). 2011. Pennsylvania Coalition Against Rape.
- [Supporting Sexual Assault Survivors with Disabilities](#). 2010. California Coalition Against Sexual Assault.
- Serving survivors with guardians: privacy FAQs for advocates, attorneys, and other victim service providers serving domestic violence, sexual assault, trafficking, and stalking survivors. 2017. Victim Rights Law Center. Contact them at <http://www.victimrights.org/contact-us>
- [Safety Planning for People with Cognitive Disabilities](#). 2015. End Abuse of People with Disabilities.
- [#DisabilityToo](#). 2018. Rooted in Rights.

RESOURCES FOR SEXUAL ASSAULT ORGANIZATIONS

- [Measuring Capacity to Serve Sexual Assault Survivors with Disabilities.](#) 2015. Center on Victimization and Safety, Vera Institute of Justice. Washington, DC.
- [Serving Sexual Violence Survivors with Disabilities: A Guide for Rural Dual Multi-Service Advocacy Agencies.](#) 2014. Resource Sharing Project Iowa Coalition to End Sexual Assault. Des Moines, Iowa.
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