

Autonomy is Safety: Using Supported Decision-Making to Facilitate the Safety of People with Disabilities

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Victimization of People with Disabilities

The Risk: Violence in the Lives of People with Disabilities

- People with disabilities are more likely to experience violence.
- Limited research exists, but some people with disabilities experience increased risk of domestic and sexual violence than people without disabilities.



People with disabilities are three times more likely to experience rape, sexual assault, aggravated assault, and robbery than those without disabilities.

What We Know

- According to NPR, people with intellectual and/or developmental disabilities are 7 times more likely to experience sexual assault than people without disabilities
- 49% of people with an intellectual disability will experience 10 or more sexually abusive incidents in their lifetimes (Sobsey & Doe, 1991).
- 14% of men with disabilities reported experiencing sexual violence at some point in their life time compared to 4% of men without disabilities.

Risk of Violence is Higher for Certain People with Disabilities

- People with intellectual or cognitive disabilities
- People with psychiatric disabilities
- People with multiple disabilities
- Women with disabilities
- People of color who have disabilities

Factors that Contribute to the Risk

- Devaluation
- Presumed lack of credibility
- Isolation and segregation
- Increased exposure to potential abusers
- Culture of compliance
- Seen as “easy targets”
- Denied education about healthy relationships and healthy sexuality
- Systemic denial of the right to make decisions about relationships
- Negative messaging about relationships and sexuality.

Historic Responses to Victimization

Chat

How has your agency responded to reports of victimization of a person with a disability that you serve?

Historic Responses to Violence Against People with Disabilities

- Emphasis on “safety” and “protection” of people with disabilities
 - Institutionalization
 - Mandatory Reporting
 - Guardianship
- Our historic responses have not been successful in addressing violence against people with disabilities and have not made them safer.

Institutionalization

- The rationale given for institutionalization was a desire to care for and protect people with disabilities (particularly people with intellectual or developmental disabilities and mental health disabilities).
- However, people in institutions were (and are) often dehumanized, abused, and neglected.
- Research has suggested that [82%](#) of violence against adults with developmental disabilities is carried out in institutions or group homes. Furey, Niesen, and Strauch (1994).

Abuse in Institutions

- Why?
 - Extreme power imbalances between staff and people who are living in institutions;
 - Little to no oversight or regulation;
 - Isolation;
 - Attitudes about people with disabilities;
 - Policies and procedures that do not value safety, confidentiality, boundaries, or education;
 - Staff trauma.

Mandatory Reporting

- Originally designed as a response to abuse and assault of people with disabilities who, in the eyes of policy makers, could not advocate for themselves.
- If a person cannot protect him or her self, society must do it for him or her.
- Break isolation, connect people to needed services.
- However, in some cases, mandatory reporting can have unintended consequences which leave a person with a disability more vulnerable.

Mandatory Reporting Unintended Consequences

- Legal definition of “vulnerable adult” or “dependent adult” is sometimes too broad, covering people who have capacity;
- Can undermine the trusting relationship that a person with a disability has with their service providers;
- Can take away autonomy and decision-making power from the person with the disability;
- May make them less likely to report or reach out for services (fear of the unintended consequences);
- Certain types of crimes involve dynamics that make straight forward interventions dangerous.

Guardianship

- First designed to protect adults with disabilities from harmful and difficult situations.
- Replaces decision making authority from the person with the disability to the guardian. Depending on the type of guardianship, the variety of decisions impacted can be vast.
- Plenary or full guardianship: financial decisions, medical decisions, health and welfare decisions
- Limited guardianship: specific to some types of decisions (usually financial and/or medical)

A New Approach: Maximized Autonomy

Benefits of Autonomy

Autonomy and self-determination, or making your own decisions, helps people with disabilities be:

- Healthier;
- More independent;
- More well-adjusted; and
- More able to recognize abuse (more education and support).

One Approach: Supported Decision Making Basics

- Supported decision making is a decision making process where a person with a disability retains his or her decision making abilities by using supporters to help them make choices.
- The person with the disability makes their own decisions.

Supporters Help People...

- Understand options, responsibilities, and consequences of decisions;
- Obtain and understand the information they need that is relevant to those decisions;
- Communicate their decisions.

SDM Supports the Concept of Dignity of Risk

“To deny the right to make choices in an effort to protect the person with disabilities from risk is to diminish their human dignity.”

-Robert Perske, a long-time advocate for people with intellectual disabilities

Dignity of Risk:

- Acknowledges that life comes with inherent, and often times positive, risks
- Encourages individuals who support people with disabilities to balance the urge to “protect” them with autonomy
- Respects and individual's right to take reasonable risks

Principles

1. Adults have the right to make their own decisions.
2. Adults have a right to make decisions you (or others) may disagree with.
3. People should be offered support in order to make their own decisions before decisions are made on their behalf.
4. It is not one size fits all – different solutions and supports work for different people and circumstances.

Team Work!

Supported decision making is nearly always done in a team, which can include:

- Parents
- Friends
- Support staff
- Advocates

This ensures that the person is getting a wide variety of perspectives and protects against abuse or manipulation.

Provides People with Information

- Supporters provide people with disabilities with the information that they need to make decisions, help them weigh the information, and make an informed decision.

Allows for Agreement and Clarity in Relationships

Supported decision-making allows the person to make clear, affirmative decisions about the roles that others will play in the person's life. The person can:

- Articulate roles and responsibilities for various support staff;
- Clarify boundaries;
- Affirmatively consent and outline the consent giving (or withdrawing) process.

Example

Maria is a thirty year old woman with autism. She lives independently in her own apartment with part time aides that provide her with services. Her parents live nearby and she sees them regularly. Recently, at work, she met Steve, who doesn't have a disability. He liked her and asked her on a date. She wasn't sure if she wanted to go on a date with Steve, and wasn't sure how to respond. So she asks her parents and her aides and her parents. What should their responses be?

Responses

Traditional Responses:

- "Maria can't date, she isn't capable of being in a relationship."
- "What if Steve is a bad man who is preying on Maria? We can't let her go out with this strange man."
- "What would Steve want with a woman like Maria?"

Supported Decision-Making Response

Parents and aides who are acting as Supporters would:

- Ask Maria about Steve
- Ask Maria what a date is and help her understand what typically happens on a date
- Help Maria understand what is *not* normal for a date
- Talk to Maria about what a relationship is
- Help Maria develop boundaries and expectations
- Talk to Maria about her choice – she gets to decide whether she wants to go on a date with Steve

Autonomy = Safety

- Autonomy empowers people like Maria to live fuller, safer lives that are self-directed
- Encourages people to evaluate all options and possible consequences
- Gives tools to people with disabilities to promote safe decision making
- Allows for “checks” on the role of supporters

Supported Decision Making Resources

[National Resource Center for Supported Decision Making](#)

[Support My Decision Project, Disability Rights Maine](#)

[The Right to Make Choices: New Resource on Supported Decision-Making](#)

Questions

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Thank you!

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