Self-Advocacy and Victims with Disabilities

This module discusses the importance of encouraging individuals with disabilities to build their self-advocacy skills to gain independence and control of their lives. If they are victims of sexual violence, self-advocacy can be critical to their recovery and to regaining a sense of power in their lives.[1]

Key Points

- As self-advocates, individuals speak up for themselves, make their voices heard and views known, make their own choices and advocate for their rights. Education and experience empower individuals to gain life skills that promote self-determination (making choices on one's own without the interference of others), independence and, ultimately, self-advocacy.
- Factors that are likely to prevent a person from obtaining skills that promote self-advocacy include:[2] Lack of opportunities for peer education and support; lack of access to information on self-advocacy, self-determination and leadership development; lack of opportunities to make decisions and take risks; low expectations of their capacity to know what is best for them and how to get their needs met; [3] and the existence of societal attitudes that marginalize or devalue people with disabilities. A key factor for people with disabilities to overcome these barriers and become self-advocates is self-awareness—knowing their strengths, their challenges and how their disabilities affect both them and how they interact with others.
- The "dignity of risk" means respecting individuals' choices, as long as their actions are not harmful to themselves or others.[4] Not allowing individuals to take risks means denying a basic educational tool in life—learning from experience and using that knowledge in future opportunities.
- Service providers can teach and/or support persons with disabilities in building their self-advocacy skills. It is crucial for service providers to work *with* the individual to develop knowledge, not *for* the person. [5] Working with the individual supports the goals of independence and self-advocacy. This approach is similar to the victim-centered approach used in the sexual violence field, where the focus is on supporting victims in the decisions they make. Because victimization often involves the sense of a loss of power, supporting victims in their actions, rather than acting on their behalf, helps them regain control.

C6. Self-Advocacy and Victims with Disabilities

Purpose

This module discusses the importance of encouraging individuals with disabilities to build their self-advocacy skills to gain more control of their lives. Self-advocacy education can be a key factor to helping them live as independently as possible. This education—encompassing topics such as life skills, sexuality education, accommodations and accessing resources—can empower persons with disabilities to make informed choices, advocate for their rights and reduce their isolation and their risk of exploitation. If they are victims of sexual violence, self-advocacy can be critical to their recovery and to regaining power in their lives.

To support clients with disabilities in becoming self-advocates, service providers can work from an empowerment model. This model assumes that those seeking help are competent individuals who need understanding, information, support and resources in order to make changes in their lives.[6] People with disabilities are assumed to be responsible for their own decisions.[7] Service providers can offer assistance to help these clients uncover their abilities and make informed choices, to the extent possible and as they are ready.[8] This person-centered model is also the foundation for the sexual assault victim advocacy movement and its approach to working with victims.

Objectives

Those completing this module will be able to:

- Define self-advocacy;
- Recognize the importance of empowerment and self-determination to sexual violence victims with disabilities as they become self-advocates;
- Identify barriers restricting self-advocacy for persons with disabilities; and
- Describe ways that service providers can promote self-advocacy, empowerment and the dignity of risk in their interactions with victims with disabilities.

CORE KNOWLEDGE

What is self-advocacy?

Self-advocacy is about people being in control of their own environments. Education and experience enable individuals to gain life skills that promote independence and self-advocacy. As self-advocates, individuals speak up for themselves, make their voices heard and views known, make their own choices and advocate for their rights. Inherent in the concept of self-advocacy is the belief that all individuals have rights and should be treated with respect (e.g., not like children if they are adults).[9]

Gaining skills related to self-determination—making choices on one's own, without the interference of others—enables people with disabilities to be better self-advocates. Examples of these skills include decision making, problem solving, goal setting and personal control. These skills aid individuals in "knowing when and how to approach others to negotiate desired goals" and "building mutual understanding and trust, fulfillment and productivity."[10] Often, self-advocacy calls for some degree of self-disclosure and risk to reach the goal of mutual understanding.[11] For example, a self-advocate with a cognitive disability may risk having her credibility questioned when disclosing her disability.[12]

FYI—Self-advocacy for sexual violence victims with disabilities may involve persistence in obtaining help from service agencies and providers. For example, it could include challenging people in positions of authority who minimize sexually abusive behavior by a caregiver as an "unintentional touch."

What is the connection between self-advocacy and the disability rights movement?

The following is a very brief and broad explanation. People with disabilities historically had few opportunities to exercise choice[13]—very often, they were labeled, their perceived deficits and

differences were emphasized, and decisions about how they lived were made by professionals and caregivers. Additionally, public policies addressed the needs of persons with disabilities "in ways often shaped by stereotypes of dependency."[14] For example, the lifelong institutionalization of people with developmental disabilities was common, based on the belief that these individuals could not live on their own, but needed to be cared for and protected.

Thankfully, social and legal reform since the 1960s has made it less likely that people are defined by their disabilities and instead viewed as individuals first, capable of making their own decisions. (See *Disabilities 101. Person First Language*.) However, societal discrimination against persons with disabilities and misconceptions about them still exist. Self-advocacy is a tool that people with disabilities can use to counter discrimination and misconceptions.

FYI—An online source for further information and resources is the American Association on Intellectual and Developmental Disabilities, *The Self-Advocacy Movement,* http://www.aamr.org.[15] Also see R. Pennell, Self-Determination and Self-Advocacy: Shifting the Power, *Journal of Disability Policy Studies*, 11(4) (2001), available through http://www.worksupport.com.

What barriers hinder self-advocacy?

Service providers must recognize factors that are likely to prevent a person from obtaining the skills that promote self-determination and independence. These factors include, but are not limited to:[16]

- Lack of opportunities for peer education and support;
- Lack of access to information on self-advocacy, self-determination and the leadership development process;
- Lack of opportunities to exercise choice and take risks;
- Low expectations of the capacity of individuals with disabilities to know what is best for them and how to get their needs met, which fosters the stereotype of helplessness and often results in overprotection;[17] and
- The existence of societal attitudes that marginalize or devalue people with disabilities, which can minimize the positive outcomes of self-advocacy efforts.

FYI—Additional barriers to self-advocacy for persons with disabilities who have been sexually victimized are the lack of knowledge of available resources related to victimization and the lack of support for reporting the crime because perpetrators may be family members, acquaintances or caregivers. (See *Sexual Violence 101. Sexual Victimization of Persons with Disabilities: Prevalence and Risk Factors*.)

How can individuals overcome barriers to self-advocacy?

A key factor to becoming a self-advocate is self-awareness. People with disabilities need to know their strengths and challenges, as well as how their disabilities affect both them and their interactions with others. It is difficult to work through challenges if individuals don't understand the causes or lack the self-awareness to understand their own behaviors. Armed with sufficient self-understanding, people are better able to advocate for their needs in ways that help others

understand and respond. Some examples include:

- Often, when someone seeks services from an agency, the initial contact information is obtained in an office waiting area filled with multiple potential distractions (e.g., noise from a television, radio, ringing phones or others having conversations). If individuals have cognitive disabilities that make it difficult to focus or concentrate and they know that distractions such as these are problems for them, they can request a quiet area to review and answer questions. (See *Tools to Increase Access. Readiness to Serve Victims with Disabilities: A Review of Intake Practices.*)
- Some people with cerebral palsy (CP) react abruptly to touch due to muscle spasms and an over-active startle reflex. If a victim of sexual violence who has CP is having a forensic medical exam and knows that her body responds in this way to touch, she can communicate this fact to the examiner so that adequate time is given for her muscle spasms to stop before trying to continue with the exam. Her disclosure about periodic muscle spasms can also avoid the possibility of this reaction being misinterpreted (e.g., as aggression if she unintentionally kicks the examiner). The victim can also ask the examiner to tell her when and where she is about to touch her during the exam in order to help minimize her involuntary reactions. (See S*exual Violence 101. Sexual Assault Forensic Medical Examination.*)
- Cold examining tables and equipment may also cause muscle spasms for persons with a spinal cord injury; many people with spinal cord injuries have difficulty controlling their body temperatures. If a sexual assault victim with a spinal cord injury shares this information with the medical staff conducting an exam, she will have more success in advocating for the accommodations needed to minimize her discomfort. (See S*exual Violence 101. Sexual Assault Forensic Medical Examination.*)

What is the "dignity of risk"?

The dignity of risk means respecting an individual's choices, as long as her actions are not harmful to herself or others.[18] (See *Sexual Violence 101. Mandatory Reporting*.) The concept of informed consent is an important component of risk taking. It helps individuals understand the consequences of their actions so they are guided in decision making, but can still choose what is desired.[19]

Not allowing individuals to take risks creates barriers to self-advocacy. People with disabilities need to have confidence that they can survive a failure. We all periodically fail at things we try, learn from those failures and then move on. Often, people with disabilities are over-protected and lack the opportunities to learn from failures and understand the consequences of poor choices. For many individuals with disabilities, decisions to take on new experiences are often influenced more by the degree of risk involved rather than the opportunities afforded by the experience itself. Unfortunately, if people are repeatedly told to avoid all new and potentially risky behaviors, they never have the chance to test the true limits of their capabilities.[20] By supporting the dignity of risk, service providers can help to combat learned helplessness and bolster self-respect, empowerment and hope.[21]

A common challenge faced by persons with cognitive disabilities is in their interpersonal relationships. For example, an overly protective parent/caregiver may prefer that the person with the disability not date to ensure protection from sexual victimization. Finding a balance

between vulnerability and healthy sexuality is an example of the dignity of risk. That balance includes providing opportunities for the individual to meet others socially and risking the chance that some of those relationships may not be the ones the parent/caregiver would have chosen for her. It can also include offering sexuality education to help the person make informed decisions and reduce the risk of sexual exploitation.

How can service providers teach and support skills that lead to self-advocacy?

Service providers can teach persons with disabilities self-determination skills that reduce their isolation and provide them with the tools to take greater control over their own lives.[22] It is crucial for service providers to always work *with* the individual to develop knowledge, not *for* the person.[23] Working with the individual supports the goals of independence and self-advocacy. In reality, however, if a person with a disability is using the services of an agency on a very limited basis, service providers may not have the opportunity or time to really teach self-advocacy skills' development. In those instances, a service provider's primary role is to provide support and to respect the client's right to make her own decisions in her own time. This approach is similar to the victim-centered approach used in the sexual violence field, where the focus is on supporting victims in the decisions they make. Because victimization often involves the sense of a loss of power and control, supporting a victim in her actions—rather than acting on her behalf—helps her regain control in her life.

Service providers can also maximize every opportunity within their service delivery system to promote the principles of self determination, regardless of a victim's degree of disability. For example, they can provide a victim with as much information as possible in any given situation to help her gain the knowledge needed to make informed choices about services, along with the knowledge of the potential consequences of her choices. To avoid information overload, however, service providers can ask a victim if she would like the information, the extent of information she wants and how she would like to receive it. A victim, for instance, might prefer to have a service provider give a brief overview of the information available, review a brochure with more details on her own and then call the provider if she has questions at a later point. It is important that agency leadership review their policies and procedures to ensure that client choices are not unintentionally limited by agency procedures. (See *Tools to Increase Access. Readiness to Serve Victims with Disabilities: A Review of Intake Practices* and *Disabilities 101. Tips for Communicating with Persons with Disabilities*.)

(See *Disabilities 101. Guardianship and Conservatorship* for a discussion on promoting self-determination to the extent possible with persons with disabilities who have guardians or conservators.)

Resources

Many resources are available to assist service providers in teaching or supporting victims with disabilities in self-advocacy skills development. A few are listed below.

People First is a national movement that teaches individuals with intellectual disabilities about self-advocacy. There are several People First groups in West Virginia. For information, go to http://www.peoplefirstwv.org/ or call 304-422-3151 or 877-334-6581.

The **Speak Up! Guide**, published by STIR (Steps Towards Independence and Responsibility) and **Shifting the Power,** are both projects of the Clinical Center for the Study of Development and Learning, University of North Carolina at Chapel Hill. Call 919-966-5171 for information.

The full guide, as well as individual chapters, can be accessed through http://www.selfdeterminationak.org/toolkit/speak_up_guide/.

Partners in Policy Making is a competency-based leadership training for adults with developmental disabilities and parents of young children with disabilities. This program provides information, training and resources so that people with disabilities may be empowered to use their voices to influence decision makers. In West Virginia, the Developmental Disabilities Council occasionally offers Partners in Policy Making classes in Charleston. For information, go to http://www.ddc.wv.gov or call 304-558-0416 (voice) or 304-558-2376 (TDD).

One of the core services offered through the **Centers for Independent Living** (CILs) is teaching self help/self-advocacy skills development. To identify service areas, contact the West Virginia Statewide Independent Living Council at 304-766-4624 or visit http://www.wvsilc.org.

West Virginia Advocates is a federally funded organization that works to protect the human and civil rights of persons with disabilities. For information, call 800-950-5250 or visit http://www.WVAdvocates.org.

Legal Aid of West Virginia provides free advocacy services for civil legal problems and offers long-term care ombudsmen and behavioral health advocacy. For information, call 866-255-4370 or visit http://www.lawv.net.

West Virginia Mental Health Consumers' Association provides an array of services and supports for individuals with mental illnesses. These include leadership development, self-advocacy skills training, advocacy and support. For information, call 800-598-8847 or visit http://www.wvmhca.org.

The ***Advocacy Empowerment Wheel***, adapted by the Missouri Coalition Against Domestic and Sexual Violence from the *Power and Control Wheel* developed by the Domestic Abuse Intervention Project (Duluth, MN), summarizes in a visual way the steps that service providers can take to empower clients experiencing interpersonal violence. These steps include respecting client autonomy, acknowledging the injustice of the crime, believing and validating their experiences, respecting confidentiality, promoting access to community services and helping them plan for future safety.[24] This wheel is provided as an attachment to this module and is also available online through http://www.ncdsv.org/publications_wheel.html.

Test Your Knowledge

Refer to the pages in this module as indicated to find the answer to each question.

1. What is self-advocacy for persons with disabilities? *See page C6.2.*
2. On what topics/skill areas should persons with disabilities receive education in order to be successful self-advocates? *See page C6.2.*
3. What barriers can prevent a person from obtaining the skills that promote self-advocacy? How can these barriers be overcome? *See pages C6.3–C6.4.*

4. What is the "dignity of risk" and why is it an important component of self-advocacy? *See page C6.4.*

5. What can service providers do to teach and/or support victim with disabilities in building their self-advocacy skills? *See page C6.5.*

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[1]Partnering agencies refer to the persons they serve as "clients," "consumers" and "victims." For convenience, "victims" and "clients" are primarily used in this module. Also note that the terms "sexual violence" and "sexual assault" are generally used in this module to encompass sexual assault, sexual abuse and other forms of sexual violence.

[2]Drawn in part from J. Johnson, Leadership and self-determination, *Focus on Autism and Other Developmental Disabilities,* 14(1) (1999), 4–16.

[3]This factor is from B. Mitchell, Who chooses?, *National Dissemination Center for Children and Disabilities transition summary*, 5 (1988), as included in STIR (Steps Towards Independence and Responsibility) and Shifting the Power, Speak up! guide (Chapel Hill, NC: Clinical Center for the Study of Development and Learning, University of North Carolina), 18–22, access through http://www.selfdeterminationak.org/toolkit/speak_up_guide/.

[4]Drawn from Day One: The Sexual Assault and Trauma Resource Center, Rhode Island Coalition Against Domestic Violence and PAL: An Advocacy Organization for Families and People with Disabilities, Is your agency prepared to ACT? Conversation modules to explore the intersection of violence and disability (Advocacy Collaboration Training Initiative, 2004), 16.

[5]Day One et al., 9-10, 39.

[6]Day One et al., 39.

[7]Day One et al., 39.

[8]Drawn from Day One et al., 39.

[9]P. Mitchell, The Impact of self-advocacy on families, *Disability & Society*, 12(1) (1997), 43–56.

[10]S. Shore, *Ask and tell: Self-advocacy and disclosure for people on the autism spectrum* (Shawnee Mission, KS: Autism Asperger Publishing Company, 2004).

[11]Shore.

[12]Although males and females are both victimized by sexual violence, most reported and unreported cases are females (see the endnotes in the *Toolkit User's Guide* for a full citation). Therefore, in this module, victims and clients are often referred to as female.

[13]R. Scotch, *Good will to civil rights: Transforming federal disability policy* (Philadelphia, PA: Temple, University Press, 1984). As cited in B. Mitchell.

[14]Scotch.

[15]This and other online documents referenced in this module were available at the links provided at the time the module was written. It is suggested you check the sites for any updates or changes. If you experience difficulty accessing the documents via the links, another option for locating documents is doing a web search using titles.

[16]Bullets drawn in part from Johnson.

[17]Bullet drawn from B. Mitchell.

[18]Drawn from Day One et al., 16. Also see Government of the District of Columbia, Department of Disability Services, *Choice and dignity of risk, slide presentation*, through http://dds.dc.gov/dds (see provider training policies).

[19]Day One et al., 16.

[20]B. Mitchell.

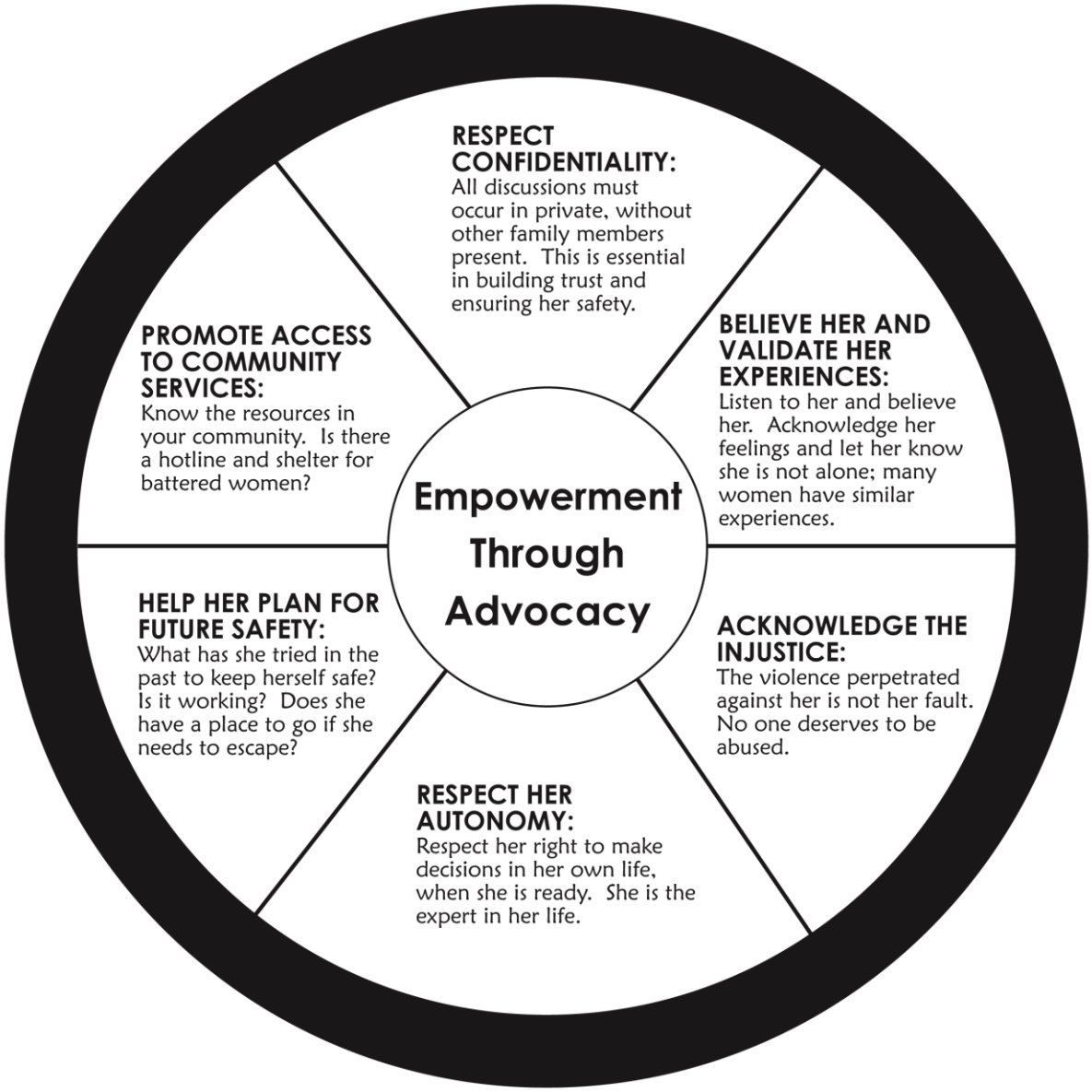
[21]C. Parsons, *The dignity of risk: Challenges of moving* on (paper presented in 2007 at the Mental Health Services Conference in Melbourne, Australia).

[22]P. Schloss, S. Alper & D. Jayne, Self determination for persons with disabilities: Choice, risk and dignity, *Exceptional Children*, 3 (1993), 215–•25.

[23]Day One et al., 9-10, 39.

[24]This wheel is distributed by the National Center on Domestic and Sexual Violence through http://www.ncdsv.org/. This site also provides access to other wheels that have been developed based on the original wheel.

ADVOCACY EMPOWERMENT WHEEL



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The Missouri Coalition Against Domestic Violence
415 E. McCarty
Jefferson City, MO 65101
573.634.4161
www.mocadv.org

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4612 Shoal Creek Blvd. · Austin, Texas 78756
512.407.9020 (phone and fax) · www.ncdsv.org