WV S.A.F.E. TRAINING & COLLABORATION toolkit

SERVING SEXUAL VIOLENCE VICTIMS WITH DISABILITIES

A project of the

West Virginia Sexual Assault Free Environment (WV S.A.F.E.) Partnership

WV S.A.F.E. Partners:

West Virginia Foundation for Rape Information and Services (WVFRIS)

West Virginia Department of Health and Human Resources (WVDHHR)

Northern West Virginia Center for Independent Living (NWVCIL)

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C. Disabilities 101

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Forward

Service providers are finally recognizing the intersection of two issues: the prevalence of persons with disabilities who are sexually victimized and the prevalence of sexual violence victims who have disabilities. Although one in the same, the response to sexual violence victims who have disabilities may differ depending on their point of entry into the service delivery system. Sexual violence service providers have not been adequately trained in serving victims with disabilities. Disability service providers have not been trained in responding to sexual violence. There has been a lack of recognition that a coordinated community response is needed to ensure that the social service system (collectively comprised of the local, regional and state agencies that serve victims on the local level) effectively and equally meets the needs of these individuals. In West Virginia, through this project, we are bringing together service providers who aid sexual violence victims with those who serve persons with disabilities. Our goal is to increase the access victims with disabilities have to services. It is important to acknowledge that "getting to this place" did not happen overnight; rather, it required consciousness-raising and community organizing by dedicated activists. In essence, "getting to this place" is the story of two social movements—the anti-sexual violence movement and the disability rights movement—maturing into a "second wave" of activism and joining together to address needs of previously underserved populations.

The beginnings for both movements grew from the 1950s to the 1970s when minority groups—most notably African Americans, gays and lesbians, women and people with disabilities—began ardently fighting to secure their civil rights. Early in the women's rights movement, women began to speak out about their personal experiences of sexual violence. In the decades to follow, tremendous progress was made toward supporting sexual violence victims. Rape crisis programs were established in counties throughout the United States to offer crisis intervention, support and advocacy for victims, as well as community awareness and prevention. A significant body of literature and research emerged that increased public concern about sexual violence. Legislative changes—including the enactment of state laws to ensure victim rights and federal laws such as the Rape Control Act in 1975 and the Violence Against Women Act of 1994—were enacted that have increased the efficacy of the criminal justice and medical community responses to sexual violence.[1]

Encouraged particularly by the civil rights and women's rights movements, large-scale cross-disability rights activism began in the late 1960s with the goal of ending social oppression. That oppression kept children with disabilities out of the public schools and sanctioned discrimination against adults with disabilities in employment, housing and public accommodations. As part of this movement, the independent living movement emerged to support the choice of living in the community for people with even the most severe disabilities. The first independent living center opened in 1972; by the beginning of 2000, there were hundreds of such centers across the country and the world. In the meantime, a series of landmark court decisions and legislative changes—including the enactment of the Rehabilitation Act of 1973, the Individuals with Disabilities Education Act of 1975 and the Americans with Disabilities Act of 1990—secured for individuals with disabilities unprecedented access to their civil rights.[2]

These victories for the two movements, as critical as they were, have not ended sexual violence or discrimination against persons with disabilities.[3] There is still a great need for continued activism. By coming together in localities across the country, as we are beginning to do in West Virginia, these movements are able to take the important next steps of educating one another and combining their resources to create positive systems change for sexual assault victims with disabilities. We hope you find the *West Virginia S.A.F.E. Training and Collaboration Toolkit: Serving Sexual Violence Victims with Disabilities* to be a useful resource to facilitate this cross-training and improve the response and partnerships across agencies and movements in your community.

Acknowledgements

The work of creating a toolkit involves the expertise and assistance of numerous individuals. The WV S.A.F.E. partnership is grateful to the individuals listed below for their contributions in the creation of this toolkit.

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Each of the three project partners coordinated the writing of the modules (in conjunction with the Project Consultant) within the sections pertinent to their disciplines. Each partner reviewed all of the modules during the development and pilot phases of the project. After each module was piloted and then reviewed and approved by the Office on Violence Against Women, the modules were then edited by the Toolkit Project Coordinator and Project Consultant.

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- Sexual Assault Help Center
- Task Force on Domestic Violence, "HOPE", Inc.
- Rape and Domestic Violence Information Center
- Northern West Virginia Center for Independent Living
- West Virginia Department of Health and Human Resources (Marion, Ohio and Preston counties)

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WV S.A.F.E. Training and Collaboration Toolkit—Serving Sexual Violence Victims with Disabilities[4]

This toolkit offers guidance for service providers on working collaboratively to integrate accessible services for sexual violence victims with disabilities into the existing social service delivery system. *The purpose is to provide the information and resources needed to begin the process of collaborating and cross-training among relevant agencies. Using the tools in the toolkit, agencies can build their capacity to offer responsive, accessible services to sexual violence victims with disabilities.* The toolkit's focus is on adult and adolescent victims with disabilities.

The concept for and contents of this toolkit evolved over a four-year period from the work of a project coordinated by several West Virginia statewide/regional agencies and piloted by local agencies from three counties. Although the toolkit is written for a West Virginia audience, other states and communities are welcome to adapt the materials to meet their needs.

This *User's Guide* explains the toolkit's features and organization as well as the pilot project.

Toolkit Features

The toolkit's main feature is a collection of educational modules intended to:

- **Facilitate dialogue and collaboration among partnering agencies** to improve the accessibility and appropriateness of services across systems for sexual violence victims with disabilities (see the *Collaboration 101* modules);
- **Build individual providers' knowledge** related to fundamental issues in providing accessible and responsive services to sexual violence victims with disabilities (see *Disabilities 101* and *Sexual Violence 101* modules); and
- **Provide tools to facilitate assessment and planning by individual agencies** to improve the accessibility and appropriateness of their services for sexual violence victims with disabilities (see the *Tools to Increase Access* modules).

The toolkit was developed with the recognition that both individual and partnering agencies will adapt the toolkit materials to assist them in providing accessible and appropriate services to sexual violence victims with disabilities. NOTE:

- Individuals and agencies can use all of the modules and materials or select only the modules and materials that address their specific needs.
- Individuals and agencies can decide the sequencing of the modules that meets their needs, depending on factors such as the types of services each agency provides, who will be trained (designated or all staff, volunteers, students, board members), etc.
- Collaborative groups can decide the selection and sequencing of the modules to utilize based on the partnering service providers, strengths and gaps in the current response, level of existing collaboration among service agencies, issues that need to be addressed, etc.
- Individual agencies and partnerships may wish to add information and discussions on other pertinent issues not addressed through the modules.

Because the toolkit is available online, those using it can benefit from new material that may periodically be added. The toolkit can be accessed at http://www.fris.org/ to check for updates.

Background: Toolkit Development

In 2006, the West Virginia Foundation for Rape Information and Services (FRIS) received a grant from the U.S. Department of Justice, Office on Violence Against Women (OVW) to examine and implement changes to local and state systems that respond to women with disabilities and deaf women who are victims of sexual assault. Entitled *West Virginia Sexual Assault Free Environment* (WV S.A.F.E.), the resulting collaboration consists of three core team partner agencies: FRIS, the West Virginia Department of Health and Human Resources (DHHR) and the Northern West Virginia Center for Independent Living (NWVCIL).[5]

This collaborative's broad mission is to identify and address state and local gaps and barriers in services and policies that impede the provision of effective, accessible and seamless services to survivors of sexual assault among women with disabilities and deaf women. The shared vision is:

> *".. [C]reating permanent systems change at all levels of the sexual assault and disability systems and state policy in which effective services for women with disabilities and deaf women are fully integrated into the existing structure of victim services and advocacy."*

The statewide partnership, and subsequent participation of their counterparts in three counties (Marion, Ohio and Preston counties), conducted needs assessments and developed a strategic plan. The plan included the following short-term goals and objectives:

1. Foster collaboration among local service providers who interact with survivors with disabilities (to overcome fragmentation of services). Objectives: Coordinate and implement on-going partnership meetings and formalize collaborative processes among pilot site partners.

2. Build a sustainable common knowledge base among local service providers and among statewide partnering agencies. Objectives: Develop and implement a capacity building plan to strengthen the knowledge base and sustainable practices.

3. Ensure services and supports are accessible and responsive to the needs of women with disabilities and deaf women. Objectives: Assess accessibility with pilot site and state partners and implement prioritized components of accessibility transition plans.

The toolkit is the result of the sustainable cross-training component of this four-year project. Note that the materials are applicable to serving all adult/adolescent victims of sexual violence (recognizing the vast majority are women) and that the term "persons with disabilities" became inclusive of deaf persons, unless otherwise indicated.

Note also that while a limited number of agencies officially partnered in this pilot project, the benefit to victims can increase when the partnership is welcoming of any agency that might provide services to victims with disabilities. To that end, longer-term goals include: expanding local pilot site partnerships to include all points of entry into the service delivery system for victims with disabilities; improving the accessibility of those points of entry; providing ongoing capacity building opportunities; and replicating this systems-change model in additional counties in West Virginia.

Toolkit Organization

Toolkit Components. The toolkit offers a set of four separate components: *A. Collaboration 101, B. Sexual Violence 101, C. Disabilities 101* and *D. Tools to Increase Access.* Each component is comprised of a series of informational modules.

Structure of the modules within each component. The individual modules within these components are primarily organized into two main sections: *Core Knowledge* and *Discussion*. Some modules include both sections while others include only the *Core Knowledge* or the *Discussion* section. Several of the *Tools to Increase Access* use a checklist, rather than a narrative format. All of the remaining modules include a cover page featuring a brief overview and the key points. Each also includes an introduction describing the purpose, objectives and any preparation needed.

- ***Core Knowledge:*** Depending on the content, the *Core Knowledge* section provides basic information on the topic. It may also include *Test Your Knowledge* questions to evaluate what was learned. These can be useful both for the reader and for supervisors who may choose to use the questions to gauge the knowledge of staff and volunteers.

  The *Core Knowledge* section is intended for individual use—e.g., for self-paced learning, one-on-one training of employees such as agency orientation or continuing education, volunteer trainings, review prior to an agency or multi-agency discussion, etc.

- ***Discussion:*** The *Discussion* section is designed for use in a group setting, either within an agency or with outside partnerships. Each *Discussion* section indicates the estimated time frame for the dialogue and the preparation needed, if any; describes suggested activities and questions (targeted to create a common knowledge base, improve agency response and build collaboration); and ends with a closing assessment of what was learned during the discussion and changes providers/agencies plan to make as a result of the discussion.

- ***Resources:*** Some modules also include related forms and/or other sample materials.

The modules were developed to maximize agencies' finite resources for in-house and multi-agency training. To that end, an effort was made to offer *Core Knowledge* sections that simplified complex topics as much as possible. It is a delicate balance to find a format in which the information provided can be easily understood but that provides enough detail to assist the reader in offering responsive assistance to victims with disabilities. As appropriate in each *Core Knowledge* and *Discussion* section, guided probes and case scenarios are included to assist service providers in applying the information to impact service delivery changes both within their own agencies and their communities.

Cross-referencing of modules. The modules were generally developed so they can be used independently of one another; however, a few make reference to other modules as prerequisites. Reference to other modules is also made throughout the modules so the reader can easily gain further knowledge on a particular topic.

Terminology used. Across all modules, the following should be noted:

- Agencies that interact with sexual violence victims and persons with disabilities typically refer to the individuals they serve as "clients," "consumers" and/or "victims." For convenience, "victims" and "clients" are primarily used.

- The terms "sexual violence" and "sexual assault" generally will be used to encompass sexual assault, sexual abuse and other forms of sexual violence.

- In recognition that the vast majority of victims of sexual violence are female and the vast majority of offenders are male,[6] individual victims are often referred to using female pronouns and individual offenders are often referred to using male pronouns. This use of pronouns in no way implies that males are not victims of sexual violence or that females are not offenders; it is written in this format solely for the ease of reading the material.

Reproduction of materials. The non-commercial use and adaptation of these modules to increase knowledge about serving sexual violence victims with disabilities is permitted. Please credit any material used from this toolkit to the West Virginia Sexual Assault Free Environment (WV S.A.F.E.) project, a partnership of the West Virginia Foundation for Rape Information and Services, the Northern West Virginia Center for Independent Living and the West Virginia Department of Health and Human Resources (2010).

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[1]This paragraph was drawn primarily from California Coalition Against Sexual Assault, *A vision to end sexual assault—The CALCASA strategic forum report* (2001), as well as J. Meyers, *History of sexual assault prevention efforts* (Colorado Coalition Against Sexual Assault, 2000) and P. Poskins, *History of the anti-rape movement in Illinois*. All can be accessed through http://new.vawnet.org/category/index_pages.php ?category_id=576.

[2]This paragraph was drawn from University of California Berkley, *Introduction: The disability rights and independent living movement* (last updated 2010), through http://bancroft.berkeley.edu/collections/drilm/index.html.

[3]Adapted from University of California Berkley.

[4]Note that the format used in this *User's Guide* was in part modeled after the Office for Victims of Crime's *Sexual assault advocate/counselor training, trainer's manual* (Office of Justice Programs, U.S. Department of Justice), https://www.ovcttac.gov/saact/index.cfm.

[5]An additional partner, the West Virginia University Center for Excellence in Disabilities, participated in the first two years of the project.

[6]Although males and females are both victimized by sexual violence, most reported and unreported cases are females (C. Rennison, Rape and sexual assault: Reporting to police and medical attention, 1992–2000 (Washington, DC: Bureau of Justice Statistics, Office of Justice Programs, U.S. Department of Justice, 2002), 1, http://bjs.ojp.usdoj.gov/index.cfm?ty=tp&tid=92; and P. Tjaden & N. Thoennes, *Prevalence, incidence and consequences of violence against women: Findings from the National Violence Against Women Survey* (Washington, DC: National Institute of Justice, Office of Justice Programs, U.S. Department of Justice, 1998), 2–4, http://www.ojp.usdoj.gov/nij/publications/welcome.htm. Regarding sex offenders, males make up the vast majority, but females also commit sexual crimes. In 1994, less than 1 percent of all incarcerated rape and sexual assault offenders were female (L. Greenfeld, *Sex offenses and offenders: An analysis of data on rape and sexual assault, U.S. Department of Justice, Bureau of Justice Statistics* (Washington, DC: 1997). As cited in R. Freeman-Longo, *Myths and facts about sex offenders* (Center for Sex Offender Management, 2000), http://www.csom.org/pubs.

Disability Laws

This module provides a broad overview of seven major laws designed to ensure that people with disabilities have equal access to the goods, services and opportunities offered to the general public. Having a basic understanding of civil rights laws relevant to people with disabilities can help service providers improve their ability to refer to appropriate resources should clients reveal that they have been victims of discrimination due to a disability.[1] An increased awareness of these laws can lead agencies to voluntarily comply with disability laws and, subsequently, improve access to their own services for persons with disabilities.

Key Points

- The **Americans with Disabilities Act (ADA)** prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunication.[2] *Title I* addresses employment discrimination. *Title II* requires that state and local governments give people with disabilities an equal opportunity to benefit from their programs, services and activities. *Title III* mandates public entities to comply with basic nondiscrimination requirements prohibiting exclusion, segregation and unequal treatment of people with disabilities, as well as with requirements related to architectural standards for new and modified buildings. *Title IV* requires telephone companies to establish telecommunications relay services and requires closed captioning of federally funded public service announcements. *Title V* addresses miscellaneous items.
- The **Fair Housing Act (FHA)** prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status and national origin. West Virginia also has a Fair Housing Act that has nine protected classes, adding blindness and ancestry to the seven protected classes in the federal legislation. The West Virginia Human Rights Commission lists 10 protected classes, adding age.
- The **Air Carrier Access Act (ACAA)** seeks to minimize problems that travelers with disabilities face as they try to access public domestic or foreign air carriers.
- The **Civil Rights of Institutionalized Persons Act (CRIPA)** authorizes the U.S. Attorney General to investigate conditions of confinement at state and local government institutions. Its purpose is to uncover and correct problems that can negatively impact the health and safety of people living in these institutions.
- The **Rehabilitation Act** prohibits discrimination on the basis of disability in programs conducted by federal agencies and those receiving federal financial assistance, as well as in federal employment and in employment practices of federal contractors.
- The **Architectural Barriers Act (ABA)** states that buildings and facilities that are designed, constructed or altered with federal funds, or leased by a federal agency, must comply with the federal standards for physical accessibility.
- The **Individuals with Disabilities Education Act (IDEA)** requires public schools to make available to all eligible children with disabilities a free and appropriate public education in the least restrictive environment and specific to their individual needs.[3]

C1. Disability Laws

Purpose

This module provides a broad overview of major laws designed to ensure that people with disabilities have equal access to the goods, services and opportunities offered to the general public. The information in this module is intended to provide guidance, not advice, on basic rights and obligations under federal disability laws and provide you with resources where you can learn more. It does not cover every law that may have protections for individuals with disabilities.

Consider the following scenarios and questions:

1. *A nursing home patient seeks your assistance, saying she and several other residents were repeatedly sexually abused by staff, but no facility administrators will respond. What civil rights disability law can help remedy this problem and what federal entity can be contacted?*
2. *You have a client who is blind and has a service animal. She is seeking safe housing in a new apartment complex that does not allow pets. What law addresses her related legal rights? What resources are available to help her with this problem?*
3. *A client who uses a wheelchair is seeking services from your agency, but your offices are located on an inaccessible second floor. What law details your agency's legal obligation to this client?*
4. *If a woman who uses a wheelchair applies for a job with your agency and your offices are located on an inaccessible second floor, what is your agency's legal obligation?*
5. *A client with HIV/AIDS tells you that she has a job interview scheduled. Although she appears healthy, she is concerned that if the employing agency learns of her medical condition, it will not hire her. Can the agency ask prospective staff if they have a disability?*
6. *A client who is receiving support services through your agency shares her worry about securing developmentally appropriate K-12 education for her child who has Down syndrome. She fears the mainstream public school program will not meet her child's special needs, but she does not have the money for a private school. What law might ensure her child specialized services through public schools?*

These scenarios and questions illustrate why it is important for service providers to have a basic understanding of civil rights laws relevant to people with disabilities. Not only can this awareness help service providers make appropriate referrals to outside resources should clients reveal that they have been victims of discrimination due to a disability, it can lead agencies to voluntarily comply with those laws and, subsequently, improve access to services for persons with disabilities. (As you read this module, find the answers to the above questions. Compare your answers with those provided on pages *C1.9–C1.10* of this module.)

Objective

Those who complete this module will be able to:

- Discuss major laws that promote equal access to goods, services and opportunities for people with disabilities.

CORE KNOWLEDGE What civil rights disability laws does this module discuss?

The seven key laws discussed in this module include: The Americans with Disabilities Act, the Fair Housing Act, the Air Carrier Access Act, the Civil Rights of Institutionalized Persons Act, the Rehabilitation Act, the Architectural Barriers Act, and the Individuals with Disabilities Education Act.

FYI This module presents a considerable amount of information. It is intended to be a point of reference for service providers to quickly locate information on disability laws. Given the complexity of these laws, an effort has been made to provide simple summaries of their main features and related resources.

FYI Much of the information in this module is drawn from A Guide to Disability Rights Law (U.S. Department of Justice, Civil Rights Division, Disability Rights Section, 2005), http://www.ada.gov/cguide.htm. Also see J. Brennan, *The Disability Law Handbook* (DBTAC Southwest ADA Center, 2009), through http://dlrp.org/html/publications/ and *Federal Laws Prohibiting Job Discrimination: Questions and Answers* (U.S. Equal Employment Opportunity Commission, 1998), http://www.eeoc.gov/facts/qanda.html. These resources may be useful if questions arise about disability laws that are beyond the scope of this module.

What is the Americans with Disabilities Act?

The Americans with Disabilities Act (ADA) of 1990 is a comprehensive civil rights law that prohibits discrimination on the basis of disability in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunication.[4] An individual with a disability is defined by the ADA as "a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment,[5] or a person who is perceived by others as having such an impairment. The ADA does not specifically name all of the impairments that are covered."[6] A major life activity is one the average person can perform with little or no difficulty such as breathing, walking, talking, hearing, seeing, working and self care.[7] The ADA is divided into five sections or "titles" with each covering a different area. Titles I through IV are particularly applicable to local service providers/agencies. (Some ADA requirements are discussed in *Tools to Increase Access. Physical Accessibility Checklist for Existing Facilities*.)

Title I: Employment

- Requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others. To be qualified, a person with a disability must have the skills, experience and education the job requires of all applicants.
- Prohibits discrimination in recruitment, hiring, promotions, training, pay, social activities and other privileges of employment; restricts interview questions related to a person's disability before a job offer is made; and requires employers to provide accommodations for employees who have disabilities unless doing so would cause an undue hardship for the employer.[8] (See *Disabilities 101. Accommodating People with Disabilities*.)

Related resources:[9]

- Charges of employment discrimination on the basis of disability may be filed at any U.S. Equal Employment Opportunity Commission (EEOC) field office. To find the EEOC field office in your geographic area, contact: 800-669-4000 (voice), 800-669-6820 (TTY) or go to the EEOC website at http://www.eeoc.gov/. In West Virginia, the Human Rights Commission is the entity that hears employment discrimination cases. They can be contacted at 304-558-2626 (voice) or 888-676-5546 (voice). Also see http://www.wvf.state.wv.us/wvhrc/.

- For more information on Title I, contact the appropriate EEOC field office in your geographic area. Publications and information on EEOC-enforced laws may be obtained by calling 800-669-3362 (voice) or 800-800-3302 (TTY).
- For more information on how to accommodate a specific individual with a disability, contact the Job Accommodation Network at 800-526-7234 (voice/TTY). Also see http://askjan.org.

Title II: State and Local Government-Funded Programs and Services
(including public transportation and non-profit service providers)

- Requires that state and local governments give people with disabilities an equal opportunity to benefit from their programs, services and activities (e.g., public education, employment, transportation, recreation, health care, social services, courts, voting and town meetings).[10]
  - Those covered under Title II are required to follow specific architectural standards in new construction and when doing alterations to their existing buildings. Government entities must make sure that people with disabilities are not excluded from government services, programs or activities just because buildings built before the ADA are not accessible. If the building is not accessible, the services they offer must be (e.g., by offering the same programs and services at an alternate location that is accessible).[11]
  - Accessibility is not limited to access for those who use a wheelchair or otherwise have difficulty with mobility. It includes access to effective communication for those who are deaf or hard of hearing, are blind or have low vision, and/or have speech difficulties.
  - Public agencies are not required to take actions that would result in undue financial and administrative burdens.[11] They are required to make reasonable modifications to policies, practices and procedures where necessary to avoid discrimination, unless they can demonstrate that doing so would fundamentally alter the nature of the services, programs or activities being provided.[12]
- Requires public transportation services, such as city buses, rail transit and subways, to be accessible to people with disabilities. They must comply with accessibility standards in newly purchased vehicles and provide paratransit services where they operate fixed route bus or rail systems (unless it would result in an undue burden).[13] Paratransit services supplement public transit fixed route systems by providing door-to-door transportation for persons with disabilities who can't use a fixed route service.[14]

Related resources:[15]

- Complaints related to Title II violations may be filed with the U.S. Department of Justice within 180 days of the date of discrimination. Contact the U.S. Department of Justice, Civil Rights Division, Disability Rights Section—NYAV, 800-514-0301 (voice) or 800-514-0383 (TTY). Also see http://www.justice.gov/crt/.
- Questions and complaints about public transportation should be directed to the Office of Civil Rights, Federal Transit Administration U.S. Department of Transportation, 888-446-4511 (voice/TTY). Also see www.fta.dot.gov/ada.

Title III: Public Accommodations

- Covers businesses and nonprofit service providers that are public accommodations. Public accommodations are defined as private entities that own, lease, lease to or operate facilities such as restaurants, retail stores,

hotels, movie theaters, private schools, convention centers, doctors' offices, homeless shelters, transportation depots, zoos, funeral homes, day care centers and recreation facilities including sports stadiums and fitness clubs. Transportation services provided by private entities are also considered public accommodations.

- Mandates that public accommodations comply with basic nondiscrimination requirements that prohibit exclusion, segregation and unequal treatment of people with disabilities, and has requirements related to architectural standards for new and modified buildings. For information on these requirements, go to www.ada.gov.[16]

Related resource:[17]

- For more information on Title III, contact the U.S. Department of Justice, Civil Rights Division, Disability Rights Section-NYAV, 800-514-0301 (voice) or 800-514-0383 (TTY). Also see http://www.justice.gov/crt/.

Title IV: Telecommunications

- Requires telephone companies to establish telecommunications relay services, 24 hours a day, seven days a week to allow callers with hearing and speech disabilities to communicate with each other through a third party communications assistant.[18] (See *Disabilities 101. Accommodating Persons with Disabilities.*)
- Requires closed captioning of federally funded public service announcements.

Related resource:[19]

- For more information on Title IV, contact the Federal Communications Commission, 888-225-5322 (voice) or 888-835-5322 (TTY). Also see www.fcc.gov/cgb/dro.

Title V: Miscellaneous Items

- Clarifies that states and the U.S. Congress are covered by all provisions of the ADA.
- Provides for recovery of legal fees for successful proceedings pursuant to the ADA.
- Establishes a mechanism for technical assistance, along with instructions to many federal agencies required to implement/enforce the ADA.[20]

What is the Fair Housing Act?[21]

The Fair Housing Act (FHA), as amended in 1988 (first passed in 1968), prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status and national origin. It is unlawful to discriminate in selling or renting housing or to deny a dwelling to a buyer or renter because of a disability. The FHA also addresses issues such as financing, zoning, new construction design and advertising. West Virginia passed a Fair Housing Act in 1992 and amended it in 2006.[22]

The chart below describes in brief the Federal FHA and West Virginia's Fair Housing Act and related resources.

Federal FHA:

- Applies to housing owned/financed by the federal government or housing projects having loans insured by the federal government that include four or more multifamily units with an elevator (if no elevator exists, all ground floor units of four or more).

- Requires owners of housing facilities to make reasonable exceptions in their policies to afford people with disabilities equal housing opportunities. For example, if the housing project has a no pet policy, the landlord would have to modify this policy if the tenant is a person who is blind and uses a service animal.
- Requires landlords of existing facilities to allow tenants with disabilities to make reasonable access-related modifications to their private living space, as well as common use spaces in older buildings. It does not require landlords to pay for changes requested by a person with a disability.
- Requires standards for new multifamily housing in buildings that are ready for first occupancy after March 13, 1991 and have an elevator and four or more units: public and common areas must be accessible to persons with disabilities; doors and hallways must be wide enough for wheelchairs. All units must have an accessible route into and through the unit; accessible light switches, electrical outlets, thermostats and other environmental controls; reinforced bathroom walls to allow later installation of grab bars; and kitchens and bathrooms that can be used by people in wheelchairs. If a building with four or more units has no elevator and will be ready for first occupancy after March 13, 1991, these standards apply to ground floor units. See www.hud.gov/offices/fheo/FHLaws/yourrights.cfm for more information.

West Virginia's Fair Housing Act:

- States have the right to make their laws stricter than federal regulations, but they must, at least, offer the same protections as the Federal FHA.
- West Virginia has nine protected classes, adding blindness and ancestry to the seven protected classes within the federal legislation. The West Virginia Human Rights Commission lists 10 protected classes, adding age.
- The authority and responsibility for administering the WV Fair Housing Act is with the WV Human Rights Commission, which is required by law to investigate fair housing complaints and enforce the fair housing laws of the state.

Related resources:

- There are several ways to file a fair housing complaint. Use the form available through the U.S. Department of Housing and Urban Development's (HUD) website at www.hud.gov/complaints/housediscrim.cfm; call HUD at 800-669-9777; or print a form, complete and mail it to the Office of Fair Housing and Equal Opportunity, HUD, Room 5204, 451 Seventh St. SW, Washington, DC 20410. In West Virginia, call the WV Human Rights Commission in Charleston at 304-558-2616 or 888-676-5546. The Fair Housing Initiatives Program (FHIP) at the Northern West Virginia Center for Independent Living can also be contacted at 304-296-6091. For more information on requirements, technical guidance questions and answers, go to www.FairHousingFIRST.org or call 888-341-7781 (voice/TTY).

What is the Air Carrier Access Act?

Congress passed the Air Carrier Access Act (ACAA) in 1986. In 1990, the U.S. Department of Transportation implemented provisions of the ACAA by publishing regulations to minimize problems that travelers with disabilities face as they try to access public domestic or foreign air carriers.[23] Requirements address an array of issues, including boarding assistance and certain accessibility features in newly built aircraft and new or altered airport facilities.[24] ACAA prohibits discrimination due to disability, except if the individual would endanger the health or safety of other passengers. Other exceptions exist for planes with fewer than 30 seats where available boarding chairs cannot be used in the limited space of a smaller plane. This act also covers individuals with a temporary disability (e.g., a broken leg).[25]

ACAA related resources:

- If you want to file a complaint related to access to air travel, you have two resources. Each airline is required to have a Complaints Resolution Official available to resolve disagreements between passengers and the airline. If that avenue is not effective, complaints can be filed with the Aviation Consumer Protection Division, U.S. Department of Transportation, 800-778-4838 (voice) or 800-455-9880 (TTY) or through http://airconsumer.ost.dot.gov.[26]

What is the Civil Rights of Institutionalized Persons Act?

The Civil Rights of Institutionalized Persons Act (CRIPA) authorizes the U.S. Attorney General to investigate conditions of confinement at state and local government institutions such as prisons, jails, detention centers, juvenile correctional facilities, publically-operated nursing homes and institutions for individuals who have psychiatric or developmental disabilities. It does not apply to private facilities. Its purpose is to uncover and correct serious problems that put the health and safety of people in these institutions in danger. The Attorney General does not have authority under this act to investigate isolated incidents or to represent individual institutionalized persons. However, the Attorney General may initiate civil law suits where there is reasonable cause to believe that conditions are so "egregious or flagrant," that they are subjecting residents to "grievous harm" and that they are part of a "pattern or practice" of resistance to residents' full enjoyment of constitutional or federal rights, including Title II of the ADA and section 504 of the Rehabilitation Act (see below).[27]

CRIPA related resource:[28]

- For more information, or to bring a related issue to the attention of the Attorney General, contact the U.S. Department of Justice, Civil Rights Division, 877-218-5228 (voice/TTY) or through www.usdoj.gov/crt/split.

What is The Rehabilitation Act of 1973?

The Rehabilitation Act of 1973, often called the Rehab Act,[29] prohibits discrimination on the basis of disability in programs conducted by federal agencies, programs receiving federal financial assistance, in federal employment and in the employment practices of federal contractors. Standards for determining employment discrimination under this act are the same as those in the ADA, Title I.[30]

Section 501 of the Rehab Act focuses on affirmative action and nondiscrimination in employment by federal agencies. *Section 503* requires affirmative action by federal government contractors and subcontractors. *Section 504* requires that no qualified individual with a disability "shall be excluded from, denied the benefits of, or be subjected to discrimination under" any programs or activity that either receives federal financial assistance or is conducted by any executive agency or the United States Postal Service.[31]

The Rehab Act covers nearly all government entities, colleges, universities and trade schools, along with many private schools, day care centers and most health care facilities. Each federal agency has its own regulations that apply to its programs, including providing reasonable accommodations for employees with disabilities, program accessibility, effective communication and accessibility requirements for new construction and alterations.[32]

Section 508 of the Rehab Act has accessibility requirements for electronic and information technology used by the federal government. This section requires federal government websites to be usable by people who are blind or have low vision and/or who are deaf or hard of hearing. These sites can be operated in a variety of ways and do not rely on a single sense or ability of the user.[33]

(Some Rehabilitation Act requirements are discussed in *Tools to Increase Access. Physical Accessibility Checklist for Existing Facilities.*)

Rehabilitation Act related resources:[34]

- Section 501: See resources under the ADA, Title I.
- Section 503: Contact the Office of Federal Contract Compliance Programs, U.S. Department of Labor, 202-693-0106 (voice/TTY) or through www.dol.gov/ofccp/.
- Section 504: Contact the U.S. Department of Justice, Civil Rights Division, Disability Rights Section—NYAV, 800-514-0301 (voice) or 800-514-0383 (TTY) or through www.ada.gov.
- Section 508: Contact the U.S. General Services Administration, Office of Government Wide Policy, IT Accessibility and Workforce Division (ITAW), 202-501-4906 (voice/TTY) or www.gsa.gov/section508.

What is the Architectural Barriers Act?

The Architectural Barriers Act (ABA) of 1968 states that buildings and facilities that are designed, constructed or altered with federal funds, or leased by a federal agency, must comply with the federal standards for physical accessibility. ABA requirements are limited to architectural standards in new and altered buildings and in newly leased facilities. It does not cover the activities conducted in these buildings.[35]

ABA related resource:[36]

- For more information or to file a complaint, contact the U.S. Architectural and Transportation Barriers Compliance Board, 800-872-2253 (voice) or 800-993-2822 (TTY) or www.access-board.gov.

What is the Individuals with Disabilities Education Act?

The Individuals with Disabilities Education Act (IDEA), first enacted in 1990,[37] requires public schools to make available to all eligible children with disabilities[38] a free and appropriate public education in the least restrictive environment and specific to their individual needs.[39]

IDEA requires schools to develop an individualized education program (IEP) that reflects the individual needs of these eligible children. This plan must be developed by a team of knowledgeable persons and must be reviewed annually. Not all children with disabilities are eligible for IEP services. The child must, by reason of the disability, need special education and related services in order to receive services under IDEA. Related services include any specialized transportation, assistive technology, speech therapy, counseling and occupational/physical therapy services needed in order to receive and benefit from a public education. If parents disagree with the proposed IEP, they can request a due process hearing and review by an independent hearing officer.[40]

IDEA related resources:[41]

- For more information, contact the Office of Special Education and Rehabilitative Services, U.S. Department of Education, 202-245-7468 (voice/TTY) or www.ed.gov/about/offices/list/osers/osep.
- Your local school district likely has a special education program which offers information about IEPs and related services available in its schools.

Questions to consider:

1. What does your agency have to do to make your services accessible to clients as per the requirements of civil rights disability laws (particularly the ADA, Title II and Section 504 of the Rehabilitation Act)?
2. What has your experience been in interacting with clients with disabilities who indicated they have been discriminated against in some way due to a disability (or you suspect were discriminated against even if they don't disclose discrimination)?
3. Were you able to help these clients understand that they may have been discriminated against and identify and connect them with resources to help them address the discrimination? If yes, what are examples? If not, why? What were the challenges?

Return to page C1.2 of this module to the six scenarios. The following are the answers to the questions posed in those scenarios.

1. If the nursing home is a public facility or provides services on behalf of the state or local government, its residents are protected through the *Civil Rights of Institutionalized Persons Act (CRIPA)*. The Attorney General does not investigate individual cases, but will **follow up with "flagrant conditions" that cause "grievous harm" to residents**. Contact the U.S. Department of Justice, Civil Rights Division.

2. The federal *Fair Housing Act (FHA)* requires owners of housing facilities owned/financed/insured by the federal government to **make reasonable exceptions in their policies to afford people with disabilities equal housing opportunities.** *The West Virginia FHA* has similar stipulations. The Department of Housing and Urban Development (HUD) is a federal resource. The WV Human Rights Commission and the Fair Housing Initiatives Program (FHIP), a program of the Northern West Virginia Center for Independent Living, are two West Virginia resources.

3. For agencies that are state/local government funded, *Title II of the Americans with Disabilities Act (ADA)* requires that **if the building is not accessible, the services your agency offers must be.** So, for example, your agency could offer the person services at an alternate accessible location (services that are equivalent to those offered at the main location in terms of quality and provided in a comparable safe, welcoming and supportive environment). If your agency receives federal financial assistance, *Section 504 of the Rehabilitation Act* would also apply, requiring that no qualified individual with a disability be excluded from or denied the benefits offered by your agency.

4. According to *Title I of the ADA,* **your agency's legal obligation to this person would depend on if she is the most qualified applicant for the job and whether your agency could make reasonable accommodations without undue hardship.** For example, could this person fulfill the job duties at another office location that is accessible? Would the cost of renting/using this accessible location cause undue hardship for the agency? **Whether your agency employs more than 15 staff members would also influence its obligation.** If your program receives federal funds, the *Rehabilitation Act, Section 504*, could also be applied in this situation.

5. According to *Title I of the ADA*, "an employer **may not make a pre-employment inquiry on an application form or in an interview as to whether, or to what extent, an individual has a disability. The employer may ask a job applicant whether he or she can perform particular job functions.** If the applicant has a disability *known* to the employer, the employer may ask how he or she can perform job functions that the employer considers difficult or impossible to perform because of the disability, and whether an accommodation would be needed. A job offer may be conditioned

on the results of a medical examination, provided that the examination is required for all entering employees in the same job category regardless of disability, and that the information obtained is handled according to confidentiality requirements specified in the Act. After an employee enters on duty, all medical examinations and inquiries must be job related and necessary for conducting the employer's business."[42]

6. Through the *Individuals with Disabilities Education Act (IDEA)*, the child would likely be **eligible for free public education specific to her needs** and provided in the least restrictive environment. To ensure the appropriateness of the education provided, schools are required to develop an individualized education program (IEP) for each student.

These questions can be considered by individual readers and/or discussed among agency employees and with representatives from partnering agencies.

Test Your Knowledge

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

You are not expected to have memorized the information about disability laws, but rather to be able to locate reference information (e.g., when a client thinks she has been discriminated against by her employer due to a disability) and then be able to review the law with others (e.g., clients and other staff).

1. The Americans with Disabilities Act (ADA) prohibits discrimination on what basis? *See page C1.3.*
2. The ADA, Title I: Employment, applies to employers with how many employees? What does it require of these employers? What persons with disabilities qualify under Title I? *See page C1.3.*
3. What does the ADA, Title II, require of state and local government funded agencies regarding the programs, services and activities they offer? What does it require related to architectural standards? What does it require related to public transportation services? *See page C1.4.*
4. How does the ADA, Title III, define public accommodations? What does Title III prohibit in public accommodations? *See pages C1.4–C1.5.*
5. What does the ADA, Title IV, require of telephone companies? What does it require related to federally funded public service announcements? *See page C1.5.*
6. The federal Fair Housing Act (FHA) prohibits housing discrimination on the basis of what seven protected classes? What does it require of owners/landlords? What protected classes does the West Virginia Fair Housing Act include, in addition to those covered by the federal FHA? *See pages C1.5–C1.6.*
7. What problems does the Air Carrier Access Act (ACAA) seek to address for persons with disabilities? *See page C1.6.*
8. What does the Civil Rights of Institutionalized Persons Act (CRIPA) authorize the U.S. Attorney General to do and what is its purpose? *See page C1.7.*
9. What types of discrimination does the Rehabilitation Act prohibit? What do Sections 501, 503, 504 and 508 of this act respectively address? *See page C1.8.*
10. What does the Architectural Barriers Act (ABA) require related to federally funded or leased buildings and

facilities? *See page C1.8.*

11. What does the Individuals with Disabilities Education Act (IDEA) require of public schools, up through grade 12? *See page C1.8.*

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[1]Partnering agencies refer to the persons they serve as "clients," "consumers" and "victims." For convenience, the term "clients" is primarily used in this module.

[2]U.S. Department of Justice, Civil Rights Division, Disability Rights Section, *A guide to disability rights law* (2005, updated 2006), http://www.ada.gov/cguide.htm. 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.

[3]U.S. Department of Justice.

[4]U.S. Department of Justice.

[5]Having a "record of" refers to having a history of being a person with a disability or being misdiagnosed or misclassified as having a disability when the person does not. As cited in J. Brennan, *The disability law handbook* (DBTAC Southwest ADA Center, 2009), through http://dlrp.org/html/publications/.

[6]U.S. Department of Justice.

[7]Brennan.

[8]U.S. Department of Justice. Undue hardship means "an action that requires significant difficulty or expense when considered in relation to factors such as a business's size, financial resources, and the nature and structure of its operations."

[9]U.S. Department of Justice, except for the West Virginia specific information.

[10]U.S. Department of Justice.

[11]U.S. Department of Justice (bullet).

[12]U.S. Department of Justice (bullet).

[13]U.S. Department of Justice (first two sentences in bullet).

[14]Drawn from Brennan.

[15]U.S. Department of Justice (bullets).

[16]U.S. Department of Justice (bullets).

[17]U.S. Department of Justice (bullet).

[18]U.S. Department of Justice (bullet).

[19]U.S. Department of Justice (bullet).

[20]Bullets drawn from Work World—Empowerment through Decision Support Technology, *Americans with Disabilities Act*, http://www.workworld.org/wwwebhelp/americans_with_disabilities_act_ada_.htm.

[21]Section drawn from U.S. Department of Justice, except for West Virginia specific information.

[22]See *WV State Code, Chapter 5, article 11-A (WVC§5-11A)* through http://www.legis.state.wv.us/WVCODE/code.cfm.

[23]Brennan (first two sentences of paragraph).

[24]U.S. Department of Justice.

[25]J. Brennan (last three sentences of paragraph).

[26]U.S. Department of Justice.

[27]U.S. Department of Justice (paragraph).

[28]U.S. Department of Justice.

[29]J. Brennan.

[30]U.S. Department of Justice.

[31]U.S. Department of Justice.

[32]Drawn from J. Brennan.

[33]Drawn from J. Brennan.

[34]J. Brennan and U.S. Department of Justice (bullets).

[35]J. Brennan (paragraph).

[36]J. Brennan (bullet).

[37]National Resource Center on AD/HD, IDEA, http://www.help4adhd.org/education/rights/idea.

[38]Infants and toddlers with disabilities (birth-2) and their families receive early intervention services under IDEA Part C. Children and youth (ages 3-21) receive special education and related services under IDEA Part B. As cited in U.S. Department of Education, *Building the legacy of IDEA 2004,* http://idea.ed.gov/.

[39]National Resource Center on AD/HD.

[40]U.S. Department of Justice (paragraph).

[41]U.S. Department of Justice (bullet).

[42]Equal Employment Opportunity Commission, *ADA: Questions and Answers,* http://www.eeoc.gov/facts/adaqa1.html.

Person First Language

This module seeks to assist service providers in using inclusive and respectful language that values people with disabilities.

Key Points

- Person first language places the focus on the person, not the disability. For example, "an individual with epilepsy" is a person-focused phrase, while "an epileptic person" is disability-focused. This shift in language eliminates labeling and instead helps us view individuals with disabilities with respect.
- Avoid using negative terms that stereotype, devalue or discriminate against persons with disabilities, such as "handicapped," "disabled," "special needs," etc. Use positive language that is not outdated or offensive.
- Person first language that is acceptable to individuals with disabilities can change over time. Also, some persons with disabilities may prefer terminology that is not person first language, while others find that person first language makes speaking and writing complicated. For these reasons, simply asking the person what terms they prefer is often the best course of action when speaking or referring to individuals with disabilities.
- You may have co-workers who don't use person first language. Some ways to encourage person first language would be to model appropriate terminology and to share this module with them. You can also encourage victims to speak up if they are uncomfortable with the language being used and feel it needs to be addressed.[1]

C2. Person First Language

Purpose

This module seeks to assist service providers in using inclusive and respectful language that values people with disabilities. The term "person first language" means communication that recognizes the person first, then the disability. Person first language is "an objective way of acknowledging, communicating and reporting about disabilities. It eliminates generalizations, assumptions and stereotypes."[2]

Objectives

After completing this module, participants will be able to:

- Describe how the words used to refer to persons with disabilities often focus on the disability rather than the individual;
- Discuss how outdated and offensive language perpetuates negative stereotypes of persons with disabilities and reinforces the attitudinal barriers they face; and
- Replace stereotypical and devaluing language related to individuals with disabilities with respectful and positive language.

Part 1: CORE KNOWLEDGE

Why person first language?

There are many social barriers to full community inclusion for people with disabilities. One of the greatest barriers is language. It is common in Western society to either refer to a person with a disability as a "disabled person" or to use all inclusive categories such as "the disabled" or "the handicapped." A person might also be described by their medical diagnosis (e.g., an epileptic). Not only can this language reflect a negative view of persons with disabilities, it can have a direct impact on how persons with disabilities perceive themselves and their worth in society. The term "handicapped" implies that someone is at a disadvantage. Service providers who view persons with disabilities as less able or less skilled may not encourage self-sufficiency with their clients who have disabilities or may unnecessarily modify their goals. Limited expectations can rob clients of their individuality and imply that they are their disability rather than what they really are—persons with disabilities.

Person first language places the focus on the person, not the disability. For example, "an individual with epilepsy" is a person-focused phrase, while "an epileptic person" is disability-focused. This shift in language helps us reject labeling and view individuals with disabilities as deserving of respect.[3] It recognizes that people are not defined by their disability anymore than they should be characterized solely by their hair color, race, gender, nationality, etc.[4,5]

FYI When interacting with persons with disabilities, ask yourself if the disability is even relevant to your conversation or needs to be mentioned when referring to them.[6]

What terms are inappropriate?

It is important to avoid using negative terms that stereotype, devalue or discriminate against persons with disabilities.[7] Here are a few examples:[8]

- "Handicapped" is an outdated term that can create negative images.[9] The word originates from an Old English game in which the losers were left with their "hands in their caps" and considered to be at a disadvantage.[10] It also is thought to refer to war veterans who held their caps in their hands as they begged for money.[11] In reality, a handicap is often a disadvantage that occurs as the result of a disability and environmental and/or attitudinal factors. For example, a person with a disability who uses a wheelchair is handicapped when he faces a set of stairs and there is no ramp for equal access. The stairs create the disadvantage, not the disability.
- "Disabled" is often used to describe something that is broken or injured. For example, a broken-down car may be described as a "disabled vehicle." People with disabilities, however, are not broken nor do they need to be fixed.[12]
- Words soliciting empathy such as "suffers with" or "afflicted with" have been used when describing people with disabilities.[13] People with disabilities are sometimes depicted as "heroes" for doing everyday activities. It also may be said that people with disabilities have to "fight to overcome their challenges," but more often the real fight is to be treated as equal to everyone else.
- The term "special needs" can generate pity. However, it is not the disability that makes a person special, but characteristics (e.g., talents, skills and individuality).[14]
- The words "normal," "healthy" or "whole" might be used when speaking about people without disabilities as compared to those with disabilities. These terms imply that people with disabilities are not normal, healthy or whole.[15] Another way to convey a similar message of inferiority compared to a person without a disability is saying someone is "mentally challenged," "physically challenged," or "cognitively challenged."

FYI Some legal terms used in state sex offense laws to describe persons with disabilities—for example, "incapacitated," "mentally defective" and "a person suffering from mental disease or defect"—clearly do not represent person first terminology. But, while these terms would not be our choice of language, they currently are in many laws. Although we must use these terms in this and other modules to explain state laws and their application, first responders are urged to avoid use of offensive legal terms in their interactions with victims. (See *Sexual Violence 101. West Virginia Laws on Sexual Assault and Abuse.*)

What are examples of person first language?

The following chart provides examples of currently accepted person first language for specific disabilities and medical conditions, as well as very brief explanations of why the old descriptors are inappropriate.[16] *It is by no means a comprehensive chart of terms; you are encouraged to consider additional examples or determine whether the currently accepted terms listed are still the most appropriate to use.*

Outdated or Offensive Terms	Reasons	Currently Accepted Terms
• Deaf and dumb • Dumb	• Implies mental incapacitation • Simply because someone is deaf does not mean that they cannot speak	• Deaf person • Non-verbal • Hard of hearing • Person who does not speak • Unable to speak • Uses synthetic speech
• Hearing impaired • Hearing disability • Suffers a hearing loss	• Negative connotation of "impaired" and "suffers"	• Deaf • Hard of hearing
• Slurred speech • Unintelligible speech	• Stigmatizing	• Person with a communication disability • Person with slow speech
• Confined to a wheelchair • Wheelchair-bound	• Wheelchairs don't confine; they make people mobile	• Uses a wheelchair • Wheelchair user • Person who uses a wheelchair
• Cripple • Crippled	• Old English, meaning "to creep" • Also used to mean "inferior" • Dehumanizing	• Has a disability • Physical disability
• Deformed • Freak	• Implies repulsiveness, oddness • Dehumanizing	• Multiple disabilities • Severe disabilities
• Crazy • Insane • Psycho • Maniac • Nut Case	• Stigmatizing • Considered offensive • Reinforces negative stereotypes	• Behavioral disorder • Emotional disability • Person with a mental illness • Person with a psychiatric disability

• Retarded • Mentally defective • Slow or simple • Moron or Idiot	• Stigmatizing • Implies a person cannot learn	• Cognitive disability • Developmental disability (use "mental retardation" sparingly)
• Mongoloid	• Considered offensive	• Person with Down syndrome
• Stricken/Afflicted by MS	• Negative connotation of "afflicted" and "stricken"	• Person who has multiple sclerosis
• CP victim	• Cerebral palsy does not make a person a "victim"	• Person with cerebral palsy
• Epileptic	• Stigmatizing	• Person with epilepsy • Person with seizure disorder
• Fit	• Reinforces negative stereotypes	• Seizure
• Birth defect	• Implies there was something wrong with the birth	• Congenital disability
• Deinstitutionalized	• Stigmatizing • Groups people into one category • Not focused on individual	• Person who used to live in an institution
• Midget	• Outdated term • Considered offensive	• Person of short stature • Person with dwarfism

Are there exceptions to person first language "rules?"

Yes. Some groups of persons with disabilities have been vocal about choosing terms to describe themselves that are not person first terminology. For example, the community of Deaf people prefers to use deaf with a capital D to denote the Deaf culture and the Deaf community, not the hearing loss.[17] In some communities of the blind, "he's blind" or "person without sight" is preferred over he has "blindness."[18] Also, some persons with autism prefer "autistic person" rather than "person with autism."[19] People with disabilities who reject person first terminology may see it "as devaluing an important part of their identity and falsely suggesting that there is, somewhere in them, a person distinct from their condition."[20] Rather than viewing their condition (e.g., deafness, autism and blindness) as a disability, they may view it as a trait.[21]

In addition, some who write or speak about disabilities may reject person first terminology because they think it can make sentences long, repetitive and unwieldy.[22] They also may question if the use of this terminology changes attitudes and if, in fact, it draws more negative attention to the disability.[23]

While acknowledging these exceptions and criticisms, it is important to remember that the promotion of person first language in recent decades has facilitated a healthy debate. It has stimulated conversations about what terminology best represents persons with disabilities as valuable members of our communities with equal status to persons without disabilities. For service providers, familiarity with person first language can help them strive

to use language when speaking or referring to clients with disabilities that will lead to positive client outcomes (e.g., greater satisfaction with services provided, more rapid healing from trauma, increased self-esteem, more job productivity, etc.).

FYI According to Tim Harrington, in *The Ten Commandments of Communicating with People with Disabilities,*[24] terms for disabilities have changed over the years and probably will continue to do so. "That's why the best and usually most appreciated course of action is to ask the person what terms they prefer." In addition, Harrington said to keep it simple—the most common way we all prefer to be acknowledged is by our name.

Another recommendation is to listen to the language used by a person with a disability and take your cues from what is said.[25]

Questions to consider:

1. Think about examples of outdated or offensive terminology you have heard used in your work setting to describe people with disabilities. Did or could use of these terms impact service providers' interactions with, or their perceptions of, persons with disabilities? In what ways?

Here are two examples:

a. *A rape crisis center volunteer advocate tells her supervisor that she received a crisis hotline call from a "mental patient" at an inpatient psychiatric program. While the victim may, in fact, be dealing with a mental illness, the label of "mental patient" may limit the advocate's recognition of the many facets of the victim beyond her mental state: the trauma she has faced, the connection of her mental health with her experience of sexual assault, and her capacity to heal from the sexual assault.*[26] *Rather than criticizing the advocate for her terminology, the supervisor can point out why the term "mental patient" might be offensive, acknowledge that the advocate in no way meant to be offensive, and then discuss more acceptable terminology. (See Disabilities 101. Working with Victims with Mental Illnesses.)*

b. *A service provider receives a call from a nurse at the hospital saying he is needed to assist a "downs victim" of sexual assault. In the past, individuals with Down syndrome were referred to as "downs people" or "downs kids." By labeling a person a "downs victim," the service provider and the nurse might make several assumptions about the victim. For instance, they might assume that someone with Down syndrome will have significant cognitive limitations and lack the capacity to make his/her own decisions. However, because Down syndrome affects everyone differently, cognitive limitations could be significant to minimal. They might also assume that the difficulty the victim has in communicating is due to the Down syndrome, when in fact, it could be the victim's response to the trauma. Both of these assumptions could lead to a misunderstanding about the circumstances and needs of the victim, inappropriate service provision, and subsequently minimize the victim's autonomy in making decisions about his healing. (See Disabilities 101. Self-Advocacy and Persons with Disabilities.)*

2. When interacting with a sexual assault victim with a disability, what could you do to minimize the likelihood that your language will alienate the victim? Some suggestions are offered below. (*See Sexual Violence 101. Crisis Intervention.*)

- Refer to victims with disabilities by their names.
- Ask victims with disabilities open-ended questions about the assault and their circumstances/needs so that they can guide you in providing appropriate services and/or in making referrals. Ask them to tell you the best way to facilitate communication with them (e.g., they may use equipment such as word boards or speech synthesizers, need an interpreter or prefer to communicate through an intermediary who is familiar with their pattern of speech). If you are having difficulty understanding the person, don't pretend you

understand or assume you understand when you do not. Instead, listen patiently, paraphrase back what you think you heard and allow the person to confirm your understanding or to restate what she said.

- Listen carefully to what victims with disabilities say to learn what terminology is acceptable to them and evaluate if the disability is relevant to your conversation or needs to be mentioned when referring to them. For example, a victim who uses a wheelchair recounts to the service provider how the offender repeatedly took advantage of her limited mobility. She experienced the feelings of powerlessness and vulnerability because she was not able to defend herself. In this case, the victim's disability is relevant to the conversation. Also, the fact that she uses a wheelchair may impact which services she utilizes (e.g., she may prefer telephone rather than face-to-face support).
- Avoid terminology that is not person first. For example, don't refer to a person with a severe stutter as a "stutterer" or "stuttering person." Don't say her speech is unintelligible.
- Limit referencing a person's medical diagnosis as it can divert attention from her need for victim services. For example, don't refer to a victim who uses a wheelchair as a "quadriplegic" or a "quad."

3. Based on what you have learned in this module, what changes will you make in your terminology related to persons with disabilities?

Test Your Knowledge

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

1. What is the purpose of using person first language when talking with or referring to people with disabilities? What are some examples of how person first language is different from disability-focused language? *See page C2.2.*
2. What terms should service providers avoid if they are using person first language to speak with or refer to persons with disabilities? Why? What are acceptable alternatives? *See pages C2.2–C2.4.*
3. What are some examples of exceptions to person first language "rules?" *See page C2.4.*
4. What is the best course of action when speaking with individual clients with disabilities to ensure that they are comfortable with the language used to refer to them? *See page C2.5.*

Part 2: DISCUSSION

Projected Time for Discussion

1.25 hours

Purpose and Outcomes

This discussion is designed to help participants apply the information presented in *Part 1: Core Knowledge* of this module to their collaborative work with sexual violence victims with disabilities. The discussion could be incorporated into forums such as agency staff meetings, orientations and continuing education programs, as well as multi-agency meetings or trainings. Anticipated discussion outcomes include an increased understanding of barriers and challenges experienced by victims with disabilities; enhanced ways to create a welcoming environment through appropriately worded agency policies, procedures and materials; increased awareness of how the spoken and written language can promote respect for and understanding of persons with disabilities; and greater comfort and competency in interacting with and assisting victims who have disabilities.

Refer to the learning objectives at the beginning of this module for specific outcomes.

Preparation

- Ensure that the meeting is held at an accessible location. Ask participants prior to the meeting if they need any accommodations—if so, work with them to secure accommodations.
- Select the facilitator. The facilitator should be familiar with issues facing persons with disabilities in general and knowledgeable about person first language and its application.
- Participants and the facilitator should review *Part 1: Core Knowledge* of this module before the discussion.
- Request that participants bring in copies of written materials from their respective agencies that refer to clients with disabilities (e.g., policies and procedures, training and informational materials and public awareness materials).
- Bring the following supplies and materials to the meeting: flipcharts and colored markers, sufficient copies of participant materials, office supplies (tape, pens, paper, etc.) and a clock/watch to monitor time. Optional items include name badges and table tents.

Suggested Activities and Questions

The words we use to describe persons with disabilities are often indicative of our attitudes towards them and can significantly influence our interactions with them. This discussion focuses on using person first language with individuals with disabilities who use our services to facilitate positive outcomes for them (e.g., rapid healing from trauma, increased self-esteem, more job productivity, etc.).

1. **Invite participants to identify/review the discussion ground rules to promote open communication.** Utilize the following principles: *(10 minutes)*

- An environment of mutual respect and trust is optimal. Everyone should feel comfortable expressing their opinions and feelings about the various topics.
- Avoid personalized comments that are negative as they can lead to defensiveness and confrontation among the participants and ultimately may shut down dialogue.
- Be clear about what information discussed during this meeting is confidential and what the expectations are for confidentiality in the context of this partnership.

2. **In a large group setting, ask each participant to briefly discuss the extent to which person first language is used in their agency's materials.** *(5 minutes)*

3. **Ask participants to pair off and talk about examples** of when, in their interactions with clients with disabilities, a person's disability might be relevant to the conversation or needs to be mentioned when referring to them. Are there situations where their disability is not relevant? *(5 minutes)*

Follow with a large group discussion on this topic. *(5 minutes)*

4. **Ask participants to individually review the following scenario and then break into three small groups to discuss the subsequent questions.** *(10 minutes)*

In the course of the preliminary investigation of a sexual assault case occurring at a place of employment (both the victim and offender participate in a vocational training program at the local thrift store), the police investigator spoke with the 25-year old victim, her mother, the victim advocate, the nurse examiner who conducted the forensic medical examination, a representative from Adult Protective Services (APS), and a case manager with the vocational program. During those

conversations, the investigator referred repeatedly to both the victim and offender as "retarded," "mentally defective" and "simpleminded."

Questions:

a. What reaction do you think each person would have to the investigator's choice of words? What stereotypes do these words perpetuate? Why do you think the investigator used these particular terms? What impact do you think the use of these terms might have on the progression of the case and on the victim's recovery? What other terms could the investigator have used that would have been more acceptable?

b. What could the participating providers do to (1) minimize the damage done by the investigator's use of terminology; and (2) prevent this scenario from reoccurring? What could they do if a colleague uses inappropriate language?

c. The police investigator was the "bad guy" in this scenario. But recognize that any one of your community partners may find themselves in the position of the investigator and make inappropriate language choices. Also, your agency's policies may use outdated/offensive terminology. In what ways might community partners collaborate to encourage the use of positive and respectful language with persons with disabilities? How could local persons with disabilities be involved in this collaboration? (For example, they might help review agency publications to ensure person first terminology is used, or help develop training materials.)

5. **Facilitate a large group discussion, with each group reporting back its comments on the above questions.** For timing purposes, consider having the first group report back on (a), the second group on (b), and the third group on (c). *(30 minutes)*

6. **Closing.** Ask each participant to write down how the information gained from this module discussion will:

- Change the way they interact with individual clients;
- Change the way they partner with other agencies to assist clients; and
- Promote change in their agency's policies, practices or training programs.

Then facilitate a large group discussion on this topic. *(10 minutes)*

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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]United Cerebral Palsy, *People first language,* through http://www.ucp.org. 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.

[3]A. Logsdon, *Person first language –Focus on the person first is good etiquette,* through http://www.about.com/.

[4]K.S. Lawrence, *Guidelines for reporting and writing about people with disabilities* (Schiefelbush Institute, 1996). As cited E. Bass, *Speaking and writing about people with disabilities: Disability, handicap or challenge? What to call it and how to say it,* http://www.cloudnet.com/~edrbsass/edpeoplefirst.htm.

[5]There may be instances where a person with disability does view her/his disability as a defining trait. The key, however, is that only that person has the right to make this decision for her/himself.

[6]United Cerebral Palsy.

[7]United Cerebral Palsy.

[8]These bullets, with the exception of the last one, were drawn in part from K. Snow, *To ensure inclusion, freedom, respect for all, It's time to embrace people first language* (revised 2008), 2, through http://www.acdd.org/pfl.pdf.

[9]Drawn from Snow.

[10]*Miriam Webster Online Dictionary*, through http://www.merriam-webster.com/; and Snow.

[11]Drawn from Snow.

[12]Bullet from Snow.

[13]Drawn from Snow.

[14]Bullet from Snow.

[15]This bullet was drawn from National Center on Workforce and Disability, Institute for Community Inclusion, *Watch your language* (Boston, MA: University of Massachusetts), through http://www.onestops.info/subcategory.php?subcat_id=402. This article was originally adapted from material developed by Mid-Hudson Library System, Outreach Services Department, 103 Market Street, Poughkeepsie, NY 12601.

[16]The chart was excerpted/minimally adapted from the National Center on Workforce and Disability, Institute for Community Inclusion.

[17]J. Folkins, *Resource on person-first language, the language used to describe individuals with disabilities* (American Speech Language, Hearing Association, 1992), through http://www.asha.org/default.htm.

[18]Logsdon.

[19]See *Person-first language and autism, Neurodiversity and the prejudice of politically correct terminology*, through http://autismaspergerssyndrome.suite101.com/.

[20]Excerpted/adapted from Wikipedia, *People first language*, http://en.wikipedia.org/wiki/People-first_language.

[21]Excerpted/adapted from Wikipedia.

[22]C. Edwin Vaughan, *People-first language: An unholy crusade* (National Federation of the Blind, 1997), http://www.blind.net/. Also referenced in Wikipedia.

[23]Vaughn, in *People-first language: An unholy crusade*, noted that the awkwardness of the person first language called attention to a person as having some type of "marred identity" He drew the concept of "marred identity" from E. Goffman, Stigma: Notes on the management of spoiled identity (Englewood Cliffs, New Jersey: Prentice Hall, 1963).

[24]I. Ward & Associates, *The ten commandments of communicating with people with disabilities* (1994).

[25]Logsdon.

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

Tips for Communicating with Persons with Disabilities

This module offers service providers practical information for communicating with persons who have disabilities.[1] It seeks to build providers' confidence and skills in communicating with clients who have disabilities helping to create a welcoming and respectful environment for them to receive support and services.

Many of the modules in *Sexual Violence 101 and Disabilities 101* also explore communication considerations specific to sexual violence victims with disabilities.

Key Point

- This module offers general tips for communicating with persons with disabilities, as well as tips that are specific to persons with certain types of disabilities. The best way to apply these tips is not to memorize them and try to use them all in every interaction with persons with disabilities, but rather to pick and choose the ones which seem most appropriate for a specific situation.[2]

C3. Tips for Communicating with Persons with Disabilities

Purpose

This module offers practical information for communicating with persons who have disabilities. When service providers do not have frequent interactions with people with disabilities, they may feel uncomfortable communicating with them. They may also fear that they will impede communication by saying or doing something inappropriate or offensive. It is helpful to have some basic tips to follow when speaking to a person with any type of disability, while understanding that some disabilities require more specific communication accommodations. This module seeks to build service providers' confidence and skills in communicating with persons with disabilities, helping to create a welcoming and respectful environment for them to receive support and services.

This module provides general tips for communicating with persons with disabilities. It also includes specific considerations when interacting with sexual violence victims with disabilities. Many of the modules in *Sexual Violence 101 and Disabilities 101* explore these considerations in greater depth.

Objectives

Those who complete this module will be able to:

- Discuss tips for communicating with persons with various types of disabilities; and
- Identify challenges that service providers face related to communicating with persons with disabilities and strategies that can help them overcome these challenges.

DISABILITIES 101

Preparation

• Review *Disabilities 101. Person First Language.*

Part 1: CORE KNOWLEDGE

The best way to apply the communication tips offered in this module is not to memorize them and try to use them all in every interaction with persons with disabilities, but rather to pick and choose the ones which seem most appropriate for a specific situation.[3]

What are key general considerations when communicating with persons with disabilities?[4]

Communication involves speech, language and processing. Different types of disabilities impact communication differently. Cognitive disabilities, for example, impact the processing of information and not necessarily the speech. The same communication assistive device will not be appropriate for every type of disability.
A person who has a disability is a person who is entitled to the dignity, consideration, respect and rights you expect for yourself.
Do not be afraid to make a mistake when communicating with someone with a disability. Anticipate how you would react if you were in a similar situation.
Treat adults as adults. Address people with disabilities by their first names only when extending the same familiarity to all others present. Never patronize people with disabilities by patting them on the head or shoulder.
Take time to listen. If your agency has a policy regarding standard session times (e.g., one hour in length), adaptations may need to be made. Shorter sessions over longer periods may reduce frustration for some clients. Adapt to the individual; not everyone will need extra time.
Relax. If you don't know what to do, allow the person who has a disability to help guide you. Ask the person what support they need from you.
If you offer assistance and the person declines, do not insist. If it is accepted, ask how you can best help, and then follow their direction. Do not take over.
If someone with a disability is accompanied by another individual, address the person with the disability directly rather than speaking "through" the other person.
In general, if individuals are upset, they are more difficult to understand. For victims of sexual violence, it might be helpful to initially talk about something other than the trauma that they experienced to become familiar with their communication patterns. Sometimes working as a team can be helpful in trying to understand a client, as long as it is not embarrassing for the client—either by asking if there is someone the client trusts to assist or by involving someone else on your staff.
Speak naturally. It's fine to use common expressions like "I see" or "see you later" with a person who is blind, or "let's walk over here" with a person who uses a wheelchair.
When communicating with individuals who use a wheelchair, sit at their level. Do not touch the wheelchair and, if you inadvertently bump into their wheelchair, excuse yourself as you would if you bumped into another person. Wheelchairs and other mobility devices are often considered an extension of the person and should be treated as such.

Use terminology that places the person before the disability (instead of "an epileptic," use "a person with epilepsy"). Refer to the person first and then the situation, illness or disability—if that information is relevant to the conversation.[5] (See *Disabilities 101. Person First Language*.)

By being fully present to persons with disabilities, you can build rapport with them. If you show them you are caring and want to understand their situation, they will be more likely to open up to you. Do not make assumptions about a person's abilities and needs based on her appearance.[6]

Have a plan for the next steps in communicating. For example, consider in advance ways to respond in a variety of situations with clients, such as when someone calls for help in a crisis but cannot clearly communicate her needs.

Remember these keys to communication: (1) Be honest—It's acceptable to tell a person you do not understand the message she is trying to communicate to you; and (2) ask if there is anything you can do to make the interaction better.[7,8]

FYI These and other general tips are discussed in the 26-minute film and accompanying written material, *The Ten Commandments of Communicating with People with Disabilities* (I. Ward and Associates, 1994). It is available for loan through the Resource Center of the Corporation for National and Community Service at http://www.nationalserviceresources.org/. It is also used in *Part 2: Discussion* of this module.

FYI With sexual violence victims with disabilities, it is helpful to try to determine the relationship between the suspected offender and the victim. If the offender is the victim's caregiver, you will need to know what the relationship means to the victim in terms of practical and emotional issues.

What are some tips for communicating with individuals with cognitive disabilities that affect speech?[9]

A cognitive disability can impact a person's ability to (1) understand what they see and hear, and (2) interpret social cues and body language. A person with a cognitive disability "may have trouble learning new things, making generalizations from one situation to another and expressing themselves through spoken or written language."[10] A cognitive disability can be the result of brain trauma during birth or an accident or illness that affects the brain. For many clients with cognitive disabilities, communications with service providers and the actual service provision will be no different than for clients without disabilities. However, some clients' communication methods may be nonverbal—they may, for example, use gestures, diagrams or demonstrations. Some tips on communicating with persons with cognitive disabilities that affect speech are listed below.

Be respectful and patient. It may take more time to communicate with clients with cognitive disabilities than it does with other clients with whom you work.

Speak directly to the person, make eye contact before speaking and say the person's name often.

Individuals with cognitive disabilities might be very concrete in their thinking. Phrase questions and statements in a way that avoids ambiguity or confusion. Try to avoid idioms, clichés, expressions and technical terms. Use simple language (e.g., "a lot of feelings" instead of "overwhelmed").

Don't speak too fast.

Keep sentences short. Break complicated instructions or information into smaller parts (e.g., "tell me what happened" instead of "tell me what happened and who did it").

Avoid using leading or "yes and no" questions when communicating. If you are smiling and nodding when you ask a question, you may receive a nod and a smile, but no real information. People of all levels of ability can be led by the actions of another person.
If a person you are talking with has trouble focusing or staying on track, help her by rephrasing or repeating questions.
If the person is having trouble remembering dates or times, try using memory cues. For example, ask a sexual assault victim what was on TV when the assault occurred, if the assault happened near her bedtime or if it occurred on the day she went to church.
If you are unsure if a person understands what you are saying, ask her to repeat it in her own words.
Listen to all of the information the person provides and believe what you are told. Make every effort to get accurate information from the person with a cognitive disability before relying on information from others.
If what the person is telling you seems to be factually incorrect, consider if it is possible that she has misinterpreted your question.
For persons with a cognitive disability who are unable to communicate through oral language, work with them to identify their preferred method of communication (e.g., through body movements, sounds, communication boards, drawing, anatomically correct dolls or pictures, etc.). Determine the best way to accommodate their preferences. (See *Disabilities 101.Accommodating Persons with Disabilities*.)

FYI As in the general population, false disclosures of sexual assault are infrequent among victims with disabilities. It is more likely that a victim with a disability may retract a disclosure of victimization due to fear, confusion or pressure.

What are some tips for communicating with individuals with sensory disabilities?[11]

Speech
Be patient. Refrain from finishing words or completing sentences for others. Take your time. Ask for their preferred method of communication. Don't assume it will be through another person.
Talk to people with communication disabilities as you would talk to anyone else, not slower or emphasizing enunciation.
Ask the person for help, if needed, in communicating with her. If she uses a device such as a manual or electronic communication board, ask her how best to utilize it. If she does not have the preferred device with her, discuss how to accommodate her needs (e.g., obtain the device from another source). (See *Disabilities 101.Accommodating Persons with Disabilities*.)
If you do not understand what an individual is saying, do not pretend that you do. Tell her that you do not understand. Ask the person to repeat what she has said or perhaps spell out a word or two. Ask if writing it down is an option.
Rephrase back what you thought the person said, giving her an opportunity to correct or confirm your understanding.

Vision
Repeat your name to the person and introduce others by name and title each time you initiate contact until the person is familiar with each voice.
If new people enter the room, introduce them. Inform the person with the disability when someone is leaving the room.
If the person uses a service animal, do not pet or otherwise distract the animal without the person's permission.
Describe the layout of the room and all procedures in detail before they occur. You can use clock cues (e.g., "the chair is at 5:00") and point out obstacles in the path of travel such as planters, water fountains, etc.
It is appropriate to touch the person's arm lightly when you speak so she knows you are speaking to her.
Assist the person with completing any intake or treatment forms only after you have read the forms aloud in their entirety to her. Have forms and resources available in accessible formats such as large print or Braille, useable by a screen reader, or on audiotape.
Offer assistance if it seems needed. If accepted, ask the person how best to assist her. Do not attempt to physically lead the person without asking first; allow the individual to hold your arm and control her own movements. If you are assisting an individual in seating, place the person's hand on the back or arm of the chair and allow her to seat herself.
Hearing
Find out how the person best communicates (e.g., speech/lip reading, writing, sign language or an interpreter).
If needed, provide a safe, trusted and qualified interpreter. The West Virginia Commission for the Deaf and Hard of Hearing maintains a statewide directory of interpreting service providers and references. They can be accessed at www.wvdhhr.org/wvcdhh under the Commission's resource section. If the person is a sexual violence victim, an interpreter who is also trained in the area of sexual violence would be ideal.
If there is an interpreter present, speak directly to the person who is deaf or hard of hearing and not to the interpreter. This approach may seem awkward as that person may need to focus on the interpreter and may not make eye contact with you. Communicate through writing if necessary and appropriate until the interpreter arrives.
If you do not know sign language, use paper and pencil. Don't be embarrassed to use this method—getting the message across is more important than the medium used. But remember that American Sign Language (ASL) is not spoken English, with unique sentence structure and other differences, so communicating through writing can be challenging for a person who uses ASL. Therefore it is critical that you reiterate back to the clients your understanding of their responses.
If the person reads lips, then the following communication tips may be helpful. • Approach the person from the front or signal your entry into the room. Identify who you are and make sure that you look directly at the person as you speak.

- Gain the attention of the person (e.g., by placing your hand lightly on the person's shoulder) before beginning to talk.
- Do not shout. Speak at your normal volume unless the person asks you to talk louder—hearing aids make sound louder, not clearer.
- Look directly at the person while speaking. Speak in a clear, expressive manner, but do not over-enunciate or exaggerate words.
- To make it easier for the individual to lip read, face the light source, speak clearly in a normal tone, keep your hands away from your face, and use short, simple sentences.
- Do not turn your back or walk around while talking. Note that if you look away, the person may assume the conversation is over.

If you decide to communicate through writing, don't talk while you are writing a message. The person cannot read your note and your lips at the same time.

What are some tips for communicating with persons with mental illnesses?[12]

(For detailed information on this topic, see *Disabilities 101. Working with Victims with Mental Illnesses.*)

Mental illness refers to a group of behavioral or psychological conditions that may "disrupt a person's thinking, feeling, moods and ability to relate to others."[13] These conditions may be categorized by anxiety, mood swings, depression and a loss of contact with reality and result in "a diminished capacity for coping with the ordinary demands of life." However, it is important to note that many mental illnesses are effectively managed with medications and other forms of therapies that result in recovery. Unfortunately, in spite of the progress made in treating mental illnesses, negative prejudice and stereotyping can be some of the most painful aspects of these disabilities.[14]

For clients with mental illnesses who are also victims of sexual violence, the trauma of the violence often adds additional stresses and challenges that need to be addressed by medical and mental health professionals. For example, someone on medication who has experienced trauma may need to be monitored closely for changes in her medical needs. Many service providers report working with significant numbers of sexual violence victims with mental illnesses; they can work collaboratively to offer holistic, victim-centered services. (See *Sexual Violence 101. Understanding and Addressing Emotional Trauma.*)

Some tips on communicating with persons with mental illnesses are listed below.

Don't assume a person with a mental illness will be violent. People with mental illnesses do NOT have a greater propensity towards violence than anyone else.[15]

Approach the person in a calm, nonthreatening and reassuring manner. The person may be overwhelmed by delusions, paranoia or hallucinations and be afraid of or feel threatened by you.[16]

Help the person feel they are in control of/regaining control of the situation.

Hold conversations with the person in a setting free of distractions, with as few people present as possible.

Keep conversations simple and brief, being friendly and patient, but keep in mind that rational discussions may not be possible on some or all topics.

Be aware that individuals experiencing delusions, paranoia or hallucinations may be able to accurately provide information outside of their false system of thoughts, including details related to their sexual victimization.
If the person is agitated, but poses no immediate threat to anyone's safety, **allow her time to calm down before engaging her in conversation** or transition her to a safer/calmer conversation. Take breaks and offer to continue the conversation at another time as needed.
Break the speech pattern of those individuals who talk compulsively by interrupting them with simple questions (e.g., What is your birth date?).
Understand that hallucinations are real to individuals experiencing them, so don't try to convince them that their hallucinations do not exist. Reassuring them that they are safe is the most important aspect of providing support.
Acknowledge paranoia and delusions by empathizing with her feelings, but neither agree nor disagree with her statements.
Avoid excessive whispering, joking and laughing as these behaviors could be viewed as dangerous to someone with paranoia.
Avoid casually touching the person or standing too close.
Give simple instructions for what you ask the person to do.
Be honest. Being dishonest can increase a person's fears and suspicions. She will be able to figure out when you are not being honest.

Below are some common symptoms of different types of mental illnesses and what accommodations can be made to facilitate communication.[17]

Behavior/Characteristic	Adaptation
Confusion about what is real	Be straightforward and simple
Difficulty in concentrating	Be brief and repeat as necessary
Over stimulated	Limit input, don't require concentration
Poor judgment	Don't expect rational discussion
Preoccupation with internal world	Get the person's attention
Agitation	Recognize the agitation and if possible, transition to a safer/calmer conversation
Fluctuating emotions	Do not take words or actions personally
Fluctuating plans	Stick to one plan
Little empathy for others	Recognize this as a possible symptom of a mental illness
Withdrawal	Initiate conversation
Belief in delusions or hallucinations	Don't argue; respond to needs and feelings
Fear	Stay calm
Insecurity	Be caring and accepting

What are some tips for communicating with persons with autism?[18]

Be aware that "autism is a neurological disorder that affects the functioning of the brain." Although the effects vary greatly, autism may impact communication, social skills and processing information.
Know that the person may be socially awkward and have difficulty making eye contact and interpreting nonverbal cues, such as facial expressions, gestures and tone of voice.
If the person has difficulty in interpreting nonverbal cues, be clear, direct and specific in your communications.
Keep in mind that the person may be sensitive to touch, sounds, light or color.
Be patient, since the person may tend to focus on particular objects.
Be aware the person may quietly talk to herself frequently.

It is critical that sexual violence victims who have disabilities, just like those without disabilities, are empowered to make their own decisions about what they need to survive and heal from the sexual assault. Service providers, family and friends must avoid taking over and trying to "fix" them or their situations.[19] (See *Disabilities 101. Self-Advocacy and Victims with Disabilities.*)

Questions to Consider

- Think of a time when you felt uncomfortable interacting with a client because of a disability-related communication barrier. What was it about the situation that made you uncomfortable? What did you do or what could you have done to adjust and overcome the barrier?
- In your work, do you tend to interact more frequently with persons with specific types of disabilities? What do you find are the greatest challenges in communicating and creating a welcoming and respectful environment for persons with disabilities to receive support and services? What successes have you had in dealing with these challenges?
- Based on what you have learned in this module, what changes will you make in how you communicate with clients with the following disabilities:
  - Cognitive disabilities?
  - Sensory disabilities related to speech, vision and hearing?
  - Mental illnesses?
  - Autism?

Test Your Knowledge

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

1. What are examples of general considerations when communicating with persons with disabilities? *See pages C3.2–C3.3.*
2. What are some tips for improving communication with individuals with cognitive disabilities who have difficulty in communicating? *See pages C3.3–C3.4.*

3. What are some suggestions for communicating with individuals with sensory disabilities (speech, vision and hearing)? *See pages C3.4–C3.6.*

4. Give some examples of tips for communicating with persons with mental illnesses. *See pages C3.6–C3.7.*

5. What are some tips for communicating with persons with autism? *See page C3.8.*

Part 2: DISCUSSION

Projected Time for Discussion
2.5 hours

Purpose and Outcomes

This discussion is designed to help participants apply the information presented in *Part 1: Core Knowledge* of this module to their collaborative work with sexual violence victims with disabilities. The discussion could be incorporated into forums such as agency staff meetings, orientations and continuing education programs, as well as multi-agency meetings or trainings. Anticipated discussion outcomes include increased understanding of barriers and challenges experienced in communicating with victims with disabilities; identification of ways to enhance communication; and greater comfort and competency in interacting with victims with disabilities.

Refer to the learning objectives at the beginning of this module for specific outcomes for this module.

Planning for the Discussion

- Ensure that the meeting is held at an accessible location. Ask participants prior to the meeting if they need any accommodations—if so, work with them to secure accommodations.
- The facilitator should have knowledge about communicating with persons with disabilities and be familiar with the activity selected under the *Suggested Activities and Questions* section. If Activity #1 is selected, the film, *Ten Commandments of Communicating with People with Disabilities,* should be acquired for viewing. (In West Virginia, this film should be available on loan from the local rape crisis center.)
- Participants and the facilitator should review *Part 1: Core Knowledge* of this module before the discussion, as well as *Disabilities 101. Person First Language.*
- Bring the following supplies and materials to the meeting: flipcharts and colored markers, sufficient copies of participant materials, office supplies (tape, pens, paper, etc.) and a clock/watch to monitor time. The proper audiovisual equipment will be needed if the video/DVD will be shown. Optional items include name badges and table tents.

Suggested Activities and Questions

1. **Invite participants to identify/review the discussion ground rules to promote open communication.** Utilize the following principles: *(10 minutes)*

- An environment of mutual respect and trust is optimal. Everyone should feel comfortable expressing their opinions and feelings about the various topics.
- Avoid personalized comments that are negative as they can lead to defensiveness and confrontation among participants and ultimately may shut down dialogue.
- Be clear about what information discussed during this meeting is confidential and what the expectations are for confidentiality in the context of this partnership.

2. **Introduce the topic.** This discussion is geared toward helping participants identify what they find difficult in communicating with persons with various types of disabilities and to consider how to best apply the communication tips offered in *Part I: Core Knowledge* of this module to their work settings.

3. **Video/DVD presentation and discussion.** *(60 minutes)*

a. Arrange for the viewing of *The Ten Commandments of Communicating with People with Disabilities*. It includes a series of vignettes that, in a humorous way, demonstrate what not to do when communicating with people with disabilities while suggesting more appropriate alternatives.

b. Utilizing the resource guide available with the video/DVD, discuss how each of the suggested tips impacts working with victims with disabilities.

c. Identify which tips highlight areas of training needs of your colleagues/agencies and discuss ways in which those communication tips can be shared.

4. **Interactive exercise.** (This activity can be done independently of Activity #1.) *(60 minutes)*

a. The facilitator should read the following instructions to the group:

Although based on the game of charades, the purpose of this activity is not to successfully guess what is being communicated, but to experience and observe the potential frustration in the communication process. When communication is challenging, often either the sender or receiver of the message just gives up out of frustration. In the game of charades, the topics are inconsequential, such as movie titles or television shows. In communicating sexual victimization, the messages are personal and traumatic. In this version of charades, two volunteers are needed for each demonstration. One person (portraying a sexual violence victim with a disability) will convey messages to another member of the group (portraying a service provider) using limited verbal communication. The remaining members of the group will observe. The messages can be written by the remaining group members and given to the volunteer who is portraying the victim. The messages should include the type of disability that the victim has, identify the form of sexual victimization and detail the help that is needed. Just as there are a range of disabilities, also keep in mind the range of sex crimes (e.g., harassment, fondling, different forms of rape). In these scenarios, try to keep it realistic in terms of role playing as if the person were actually seeking your services.

After giving the group the instructions, facilitate the interactive exercise.

b. After 3 to 4 minutes of the exercise (or after the message is successfully communicated), end the scenario and as a group discuss the following questions:

   1. What aspects of the message made the communication difficult (type of disability, type of victimization, etc.)?

   2. What emotions did you observe—both verbally and non-verbally—on the part of the victim? What emotions were conveyed by the service provider?

   3. What assistive devices could have helped facilitate the communication? (Alphabet/communication board, interpreter, anatomically correct dolls, paper and pencil, etc.)

c. If there is time, a new "service provider" and "victim" can be selected for the exercise and communicate a new message that is provided by the group by repeating the above steps. Below are points to bring up during the discussion:

- Each person with a disability is different. Enter every interaction with an open mind and without assumptions.
- Just because someone has a communication disability does not mean they have an intellectual disability.
- Your tone and manner can impact communication. Your tone and facial expressions should match those of the person with whom you are communicating. For example, when speaking with an adult, do not use the same tone you would use when speaking with a child.

5. Ask the participants if they tend to interact more frequently in their work with persons with specific types of disabilities. Facilitate a discussion about what they see as the **greatest challenges in communicating and creating a welcoming and respectful environment for persons with disabilities to receive support and services**. Ask them to describe any *general* successes they have had in dealing with these challenges. *(15 minutes)*

6. **Closing.** Ask each participant to write down how the information gained from this module discussion will:

- Change the way they interact with individual clients;
- Change the way they partner with other agencies to assist clients; and
- Promote change in their agency's policies, practices or training programs.

Then facilitate a large group discussion on this topic. *(10 minutes)*

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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]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), Handout #1, 1.

[3]From Day One et al., Handout #1, 1.

[4]The material in this section was primarily excerpted/slightly adapted from Adaptive Environments Center, Inc., Fact sheet 3, Communicating with people with disabilities (1992), through http://www.adata.org/. Adaptive Environment Center, Inc. was authorized by the National Institute on Disability and Rehabilitation Research to develop information and materials on the Americans with Disabilities Act. Most of these tips are also mentioned in the film/accompanying written material, I. Ward & Associates, *The ten commandments of communicating with people with disabilities* (1994).

[5]Day One et al., 8.

[6]Day One et al., Handout #1, 1.

[7]Day One et al., 8.

[8]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.

[9]Information in this section is primarily excerpted/slightly adapted from Wisconsin Coalition for Advocacy, Wisconsin Coalition Against Domestic Violence, Wisconsin Coalition Against Sexual Assault, and Independence First, *Cross training workbook: Violence against women with disabilities,* Appendix G: Screening and assessment information (Violence Against Women with Disabilities Project of Wisconsin, 2004), through http://www.disabilityrightswi.org/. Additional tips were drawn from Day One et al., Handout #1, 1. Note that all 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.

[10]S. Bruyere & T. Golden, *Working effectively with persons who have cognitive disabilities, Implementing the Americans with Disabilities Act series* (ILR Program on Employment and Disability, Cornell University, 1994).

[11]This section is excerpted/slightly adapted from several sources: Day One et al., Fact sheet 3, Communicating with people with disabilities; and Wisconsin Coalition for Advocacy et al.

[12]Drawn from NAMI NJ Law Enforcement Education Program, *The police response to mental illness crisis* (2008), http://www.naminj.org/programs/lee/lee.html. This publication was adapted in part from Police Executive Research Forum (PERF), The police response to people with mental illnesses (Washington, D.C., 1997).

[13]Mental illness "does not include simple intoxication, transitory reaction to drug ingestion, organic brain syndrome or developmental disability." PERF, 6.

[14]Drawn from NAMI NJ Law Enforcement Education Program, 2.

[15]PERF, 3.

[16]The remaining bullets in this section are from PERF, 8.

[17]Day One et al., Handout #1, 3. Originally adapted from R. Woollis, *When someone you love has a mental illness* (Texas Commission on Law Enforcement, 1997).

[18]Portland Community College, *Career and employment guide for job seekers and employees with disabilities and guide for employers: How to recruit, interview, hire and accommodate people with disabilities, Communications tips* (Portland, OR: 2003).

[19]Drawn from Day One et al. 10–11.

Accommodating Persons with Disabilities

This module provides suggestions and resources for service providers to assist persons with disabilities who need accommodations. Accommodations are often essential to enable sexual assault victims with disabilities to access and benefit from the programs and services available to them.[1]

Key Points

- "An accommodation" is a broad term that is used to describe a modification to goods, services and structures that allows for inclusion and participation by persons with disabilities. Accommodations discussed in this module are mainly modifications to goods and services rather than to structures. Some common accommodation tools to modify goods and services include: auxiliary aids and services that promote effective communication, assistive technology used to perform tasks that would otherwise be difficult or impossible due to a disability, and personal services that assist individuals with daily living tasks that they cannot accomplish on their own.
- In order to find out if accommodations are needed and what accommodations are appropriate, service providers must ask all clients what works best for them.

C4. Accommodating Persons with Disabilities

Purpose

This module provides suggestions and resources for service providers to assist individuals with disabilities who need accommodations. All the *Disabilities 101* modules in this toolkit to some extent incorporate issues pertinent to accommodations, because accommodations are often essential to enable sexual assault victims with disabilities to access and benefit from the programs and services available to them.

NOTE: This module is NOT intended to be a guide for meeting the requirements of the Americans with Disabilities Act (ADA) of 1990. The requirements under this law vary based on criteria such as, but not limited to, whether the entity is public or private, the nature of the business and how that business or service provider is funded. (See *Disabilities 101. Disability Laws.*) If a service provider is working towards full compliance with the ADA, it is recommended that they seek the assistance of a qualified individual who is trained in the regulations specific to their entity. The Disability and Business Technical Assistance Center (DBTAC), Mid-Atlantic ADA Center in Rockville, MD is a resource for addressing compliance issues related to the ADA. Call 800-949-4232 or go to www.adainfo.org for assistance.

Objectives

Those who complete this module will be able to:

- Discuss resources that enhance access to services for persons with disabilities;
- Recognize common tools, equipment and aids available to increase independence, facilitate communication and increase the ability of a person with disabilities to participate and/or benefit from programs and services; and
- Challenge the assumption that it is expensive and difficult to accommodate individuals with disabilities.

CORE KNOWLEDGE What are accommodations?

An "accommodation" is a broad term that is used to describe a modification to goods, services and structures that allows for inclusion and participation by persons with disabilities. Accommodations discussed in this module are mainly modifications to goods and services rather than to structures, such as an interior or exterior of an office. Some common accommodation tools to modify goods and services include:

- **Auxiliary aids and services** is a term used by the U.S. Department of Justice to describe a wide range of services and devices that promote effective communication.[2]
- **Assistive technology** (AT) refers to any device used to perform a task that would otherwise be difficult or impossible due to a disability. We all use AT devices every day. An electric can opener is easier to use for some than a hand-held can opener. Glasses make it possible for those with less than perfect vision to read. Computers and technology assist us in communicating and in gaining knowledge without physically leaving our current locations. There is some overlap between auxiliary aids and AT devices.
- **Personal services** refer to a wide range of services and providers available to assist individuals with daily living tasks that they cannot accomplish on their own (e.g., an attendant from a home health agency may assist a person with physical disabilities with bathing and dressing).

These accommodations can help equalize the opportunity for persons with disabilities to access your services.

How do you find out what accommodations a person needs?

A valuable resource available to service providers to learn how to accommodate a client's disability is the individual client.

> "The key to finding low-cost solutions is to foster open communication with the person needing the accommodation and to think broadly about the possibilities and resources available to them and to your organization. Each individual will have a unique approach to his or her own disability. Recognize that finding reasonable adaptations is a process of creative problem solving."[3]

It is important to note that not all people with similar disabilities will benefit from the same accommodation. The *Title II Technical Assistance Manual,* developed by the U.S. Department of Justice, provides an example as to why "one size doesn't fit all:"[4] Some individuals who were deaf at birth, or who lost their hearing before acquiring language, use sign language as their primary form of communication. They may be uncomfortable or not proficient with written English, thus making use of a notepad an ineffective tool for communication. Individuals who lose their hearing later in life, on the other hand, may not be familiar with sign language and can communicate effectively through writing. This example demonstrates why it is critical to **ask each individual what works best for them. What is effective for one could be ineffective for another**.[5] (See *Disabilities 101. Tips for Communicating with Persons with Disabilities.*)

FYI Those providing accommodations to sexual assault victims with disabilities must be trained to maintain the confidentiality of the information shared, with the exception of cases where mandatory reporting is required by the state. (See *Sexual Violence 101. Confidentiality* and *Sexual Violence 101. Mandatory Reporting.*)

It is also important that service providers have a basic understanding of sexual assault victimization and work to avoid inadvertently re-traumatizing victims. For example, those providing personal services should understand that victims may be very cautious, distrustful and even afraid of them at first and may prefer a provider of a specific gender. Providers may need to learn what triggers emotional distress for each victim (e.g., if they were

sexually assaulted by another caregiver, a victim may be anxious when someone new provides assistance with bathing, toileting and dressing). Providers also need to be efficient and caring, giving victims as much control as possible over how services are delivered. Interpreters must have the ability to dialogue about sexual victimization using accurate terms that avoid victim-blaming and to fully describe what is being discussed. They need to understand that it may be very difficult for victims to talk about the sexual violence. (See the *Sexual Violence 101 modules,* in particular *Sexual Violence 101. Understanding and Addressing Emotional Trauma.*)

What are examples of auxiliary aids/services and AT devices?

The following chart offers some examples of (1) auxiliary aids and services designed to promote effective communication and (2) AT devices used to perform tasks that would otherwise be difficult or impossible due to a disability. Note that technology is constantly changing; over time, examples on this list may become obsolete as more technologically advanced equipment is developed.

Examples of Auxiliary Aids/Services	Examples of Assistive Technology (AT)
Assistive listening device that amplifies sound.	A **wheelchair**, whether manual or power, that enhances a person's mobility.
A **Brailler** that converts documents into Braille.	**Computer software** (e.g., screen reader programs) that allows for a person who is blind to use it through vocalization of the written word on the computer screen and/or use of Braille.
Large print materials, in at least 18 to 20 font, is best practice. It is important to determine what size font works best for a person with a visual disability.	**Speech synthesizer** that allows a person who has speech difficulties to type her message into computerized equipment that then vocalizes what she has typed.[6]
Captioning for televisions and visual presentations that can enhance visibility.	**Communication board or device**, accessed by a touch screen that can have words programmed into it.
A **TTY machine**, a telecommunication device often used when communicating with someone who is deaf, allows the user to type and receive messages instead of speaking into or listening on a phone.	A **talking watch** or **calculator** and **books on tape**.
Text messaging through cell phones is another economical way for a person who is deaf or hard of hearing to communicate.	A **flasher for a door bell** so an individual who is deaf will know that someone is at the door.
Video relay service uses a web camera and computer or video phone to transmit images to a video interpreter.	**Raised letters or Braille** on directional signage aids a person with a visual disability.

Qualified sign language interpreters aid in communication. Being able to sign does not guarantee that a person is a qualified interpreter. It does not certify that a person can process spoken communication into the proper signs, or that he or she possesses the proper skills to observe someone signing and change their signed or finger-spelled communication into spoken words. A qualified interpreter does not necessarily require certification; qualifications are linked more closely to the ability to interpret receptively and expressively.[7]	**Writing guides** are overlays that individuals with low vision can use for tasks. For example, a writing guide for check writing designates areas for dates, amounts of money and signatures.
Closed circuit television (CCTV) is a device that will enlarge text much like an overhead projector. Printed materials are placed on the magnifier, which enlarges and projects them onto a screen similar to a television.	A **magnifier**, for a television screen is placed on the floor in front of the television and magnifies the image.
A **tape recorder** can transform written documents, such as intake forms and agency policies, into an audio format that can be used by someone who is blind and does not read Braille.	A **decoder** helps individuals with older televisions have access to closed captioning. Most new televisions have decoder functions built into them.
	A **modified eating** utensil that allows individuals with limited use of their hands to feed themselves.

FYI "Professionals may assume that accommodating people with disabilities in their programs will be prohibitively expensive. **In fact, accommodations are often cost-free or quite inexpensive.** There is not always a need for accommodations, as many people with disabilities own the equipment they need for everyday life and will need only minimal assistance from others."[8]

What are examples of personal services?

As mentioned earlier, a variety of personal services are typically available in a community to assist individuals with the tasks of daily living. Tasks might include bathing, toileting, grooming, feeding and dressing oneself, getting in and out of bed, transferring in and out of a wheelchair, preparing meals, performing housework, taking medications, managing finances, communicating with others, going on errands and accessing activities outside of the home. Personal services are often coordinated by a range of community-based providers, depending upon the needs of the person with disabilities. Services are often provided by a spectrum of attendants, such as qualified certified nursing assistants (CNAs) for in-home care, housecleaning service employees for routine or seasonal cleaning, drivers for transportation services, senior nutrition program employees that prepare and deliver meals, advisors for financial management services, etc.

If your agency provides residential services, such as shelter or transitional housing, it is important to determine what resources are available within the community to meet your clients' needs for personal services. To ensure that persons with a disability can equally participate in all of the services you provide, meeting these basic needs is critical. Because of the personal nature of the services being provided, it is recommended that home health care agencies are utilized that allow individuals with disabilities to select their own attendants. Although agencies

provide training for the staff that perform these duties, the best training is that which is provided by the individual who needs the service.

What key resources for accommodations are available to persons with disabilities in West Virginia?

Auxiliary aids/services and AT devices:

- The **West Virginia Commission for the Deaf and Hard of Hearing** can assist in locating qualified interpreters (www.wvdhhr.org/wvcdhh or 866-461-3578).
- The Federal Communications Commission (FCC) uses the 711 dialing code for access to the national **Telecommunications Relay Services** (TRS). TRS enables persons who are deaf, hard of hearing or have a communication disability to use the telephone system via a text telephone (TTY) or other device to call persons with or without such disabilities who do not have a TTY.

  Example: Martha, who is deaf, wants to call her doctor using TRS because her doctor does not have a TTY. Martha can use her TTY to dial 711. She will automatically be connected to a TRS operator. Martha will give the operator her doctor's phone number and a message. The operator will place a call to Martha's doctor. The operator serves as a link for the call, relaying the text from Martha's TTY messages in voice to the doctor, and converting to text for Martha what the doctor says in response.

  For more on TRS or 711, go to http://www.fcc.gov/cgb/consumerfacts/trs.html and http://www.fcc.gov/cgb/consumerfacts/711.html.[9]
- The **West Virginia University Center for Excellence in Disabilities** (CED) operates a program called Powerful Tools for Living as part of the WV Assistive Technology Services project. Through this project, there are AT resource centers throughout the state that serve as AT loan libraries and demonstration centers. These centers provide individuals with the opportunity to learn about and try AT prior to purchase to ensure that the AT is effective in addressing their needs. They are also resources for the community at large when seeking AT resources. To learn more, go to www.cedwv.org or call 877-724-8244.
- Many individuals with disabilities live on very limited incomes and have difficulty affording the assistive technology they may need. The **West Virginia Division of Rehabilitation Services** operates an assistive technology revolving loan fund, funded by the state legislature, which provides low interest loans to qualified individuals with disabilities to purchase AT. For more information, go to www.wvdrs.org or call 800-642-8207.

  In addition, the **Centers for Independent Living** within the state operate a Community Living Services program that also provides funding to individuals with disabilities to purchase AT or pay for home modifications to improve accessibility. To locate service areas for the centers, go to www.mtstcil.org.
- Additional sources for purchasing simple solutions for AT needs are online stores such as **Maxi Aids** and **Independent Living Aids**. These companies provide aids to enhance independent living skills; www.maxiaids.com provides aids for all disabilities (800-522-6294) and www.IndependentLiving.com specializes in providing low vision and hearing loss aids (800-537-2118).

Personal services:

- The **WV Department of Health and Human Services** (DHHR) and the **Bureau of Senior Services** (BOSS) provide resources for personal assistance services. Qualified individuals may be able to gain in-home personal assistance services through two Medicaid waiver programs, one for persons with intellectual

disabilities and one for seniors and persons with other disabilities. Go to www.wvseniorservices.org or call 877-987-3646.

- Those who do not qualify for the federally funded Medicaid programs may be eligible to receive support from a state funded personal assistance service called the Ron Yost Personal Assistance Services Program. Go to www.wvsilc.org for information on the **WV Statewide Independent Living Council** at or call 304-766-4624.

How can access to services be improved when structural barriers exist?

Although this module is not intended to address structural barriers, the following modifications are relatively inexpensive and easy to implement and can help to improve overall access to your services:

- A portable ramp can help if a few steps limit access to your agency.
- Rearranging tables, display racks, desks or other furnishings can increase space for individuals who use a wheelchair.
- A shower chair can increase independence for someone who may have difficulty standing to shower.
- Lowering shelves or racks holding printed materials or supplies can improve access.
- Providing services at an alternate, accessible location enables persons with physical disabilities to utilize your services.
- Putting blocks under a table to raise it up can allow someone using a power chair or wheelchair to fit comfortably at the table.

For additional information on taking the next steps in addressing physical barriers to services, the DBTAC, Mid-Atlantic ADA Center is a resource (see contact information on page *C4.1* of this module). (Also see *Tools to Increase Access. Physical Accessibility Checklist for Existing Facilities*.)

Questions to consider:

1. What types of accommodations does your agency make?
2. What accommodations could be easily implemented to make your agency more accessible to sexual violence victims with disabilities?
3. What steps need to be taken to implement the process and acquire these accommodations?
4. What can your agency do to facilitate creative problem solving with every victim with a disability to identify any needed and appropriate accommodations?

(Also see *Tools to Increase Access. Programmatic and Policy Accessibility Checklist, Tools to Increase Access. Readiness to Serve Victims with Disabilities: A Review of Intake Practices,* and *Tools to Increase Access. Developing a Transition Plan.*)

These questions can be considered by individual readers and/or discussed with other agency employees.

Test Your Knowledge

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

1. What is an accommodation? *See page C4.2.*
2. In order to determine if accommodations are needed for a client and, if so, what accommodations are appropriate, what is a critical step for service providers to take? *See page C4.2.*
3. What accommodation tools are described in this module? *See page C4.2.*
4. What are examples of each of those tools? *See pages C4.3–C4.4.*
5. What resources for accommodations are available to persons with disabilities? *See pages C4.5–C4.6.*

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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]The Americans with Disabilities Act, *Title II technical assistance manual* II–7.1000, Equally effective communication, through http://www.ada.gov/taman2.html. 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.

[3]Mobility International USA, *Helpful tips for accommodating people with disabilities,* http://www.miusa.org/idd/IDDresourcecenter/hrtoolbox/helptipstxt/view.

[4]Title II technical assistance manual II–7.1100, Primary considerations.

[5]Title II technical assistance manual II–7.1100, Primary considerations.

[6]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 are often referred to as female.

[7]Title II technical assistance manual, II–7.1200, Qualified interpreters.

[8]Mobility International USA.

[9]The information about TRS and 711 was drawn from these websites.

Working with Victims with Mental Illnesses

This module provides service providers with general information to assist them in serving sexual violence victims who have a mental illness.[1]

Key Points

- A mental illness is a medical condition that causes a mild to severe disruption in a person's thinking, emotions, mood, ability to relate to others and daily functioning. There are many types of mental illnesses; they can be temporary or chronic in nature and usually are treated with medications and other forms of therapy.[2] Persons with mental illnesses are at higher risk of sexual victimization than the general population.
- Service providers should simply clarify with victims their needs and desired assistance and offer accommodations as necessary, rather than making assumptions about the root causes of behaviors (e.g., that they are reactions to sexual violence or indicative of a mental health issue). Service providers' responses must stay within the scope of their professional role and level of expertise.
- Victims who have a mental illness may face barriers in accessing services. Service providers should consider that —
  - Responders' misconceptions about mental illnesses can prevent victims from being taken seriously. Service providers must address their own fears and discomforts about working with persons with this type of disability before engaging with them.
  - Caregivers may be offenders. Service providers can help victims who are abused by their caregiver plan for safety and differentiate between healthy and unhealthy relationships with caregivers, as well as support victims in addressing their needs.
  - The perceived lack of credibility of these victims' accounts of what occurred is a key reason why sex offenders target this population and why these victims are reluctant to come forward. When they do come forward, service providers must treat them with the same respect and empathy as they do with any other victim.
  - Being able to trust service providers may be difficult for some victims (e.g., those with feelings of paranoia or anxiety). Maintaining the confidentiality of victim information—unless there is a need for a mandatory report—is one way that service providers can build trust and help victims move toward recovery.
  - Sexual violence may exacerbate some types of mental illnesses.
- Victims with mental illnesses should be aware of the potential consequences of disclosing sexual violence (e.g., changes in mental health treatment, loss of a caregiver or even institutionalization). Service providers can aid victims in considering their options.

C5. Working with Victims with Mental Illnesses

Purpose

A 24-year-old female Army officer discloses to you that she was sexually assaulted several months ago while she was at a military rehabilitation center—she was injured in combat, losing a foot. She was also dealing with post-traumatic stress and depression. She hasn't reported the assault—the perpetrator was another patient who told her that nobody would believe her since she was a "nut case." She doesn't want him to "drag her reputation through the mud" or jeopardize her career. She is calling mainly because she is scared that since the assault, her overall feeling of despair is intensifying.[3]

Service providers outside of the mental health field assist sexual violence victims who also have a mental illness. This module offers basic information and guidance on the initial response to these victims, while urging service providers to stay within the scope of their professional role and skill level when they respond.

As illustrated in the scenario above, sex offenders often target individuals who have a mental illness. These individuals may be less willing or able to report sexual violence. If they do disclose victimization, their account of what happened may be questioned. Unfortunately, the stigma associated with mental illnesses may lead these victims to do without the vital help they need. This module can be a tool for service providers to explore how to counter this stigma in their work. Ultimately, a service provider's goal when responding to sexual assault victims is not to determine whether or not victims have a mental illness, but how to best offer them support and accommodate their needs so they can deal with their reactions to the violence and begin to heal.

Objectives

Those completing this module will be able to:

- Discuss what mental illness is and its prevalence in the United States;
- Describe the risk of sexual victimization for persons who have a mental illness;
- Identify behaviors that may be indicative of a mental illness and possible accommodations to enable victims coping with such behaviors to discuss and address their needs; and
- Discuss barriers to accessing services that victims who have a mental illness may face and related considerations for service providers.

Preparation

- Review *Disabilities 101. Tips for Communicating with Persons with Disabilities*.

Part 1: CORE KNOWEDGE

What is a mental illness?

A mental illness is a medical condition (which can be temporary or chronic) that causes a mild to severe disruption in a person's thinking, emotions, mood, ability to relate to others and daily functioning. It often results in a diminished capacity for coping with the ordinary demands of life and can cause reactions to distress that society considers extreme. It can be treated, in many instances very successfully, with medications and other forms of therapy. It is *not* the result of personal weakness, lack of character, poor upbringing or a lack of intelligence.[4]

There are many different conditions recognized by health professionals as mental illnesses. A few examples include clinical anxiety, depression, mania, post-traumatic stress and schizophrenia.[5] Mental health professionals typically

refer to the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* (DSM) to diagnose these conditions.[6,7]

FYI Service providers outside of the mental health field do not need to be experts on mental illnesses. It is not their role to attempt to make clinical diagnoses or rule out the possibility that a victim may have a psychological condition. However, when providers increase their knowledge and comfort level in working with victims who have a mental illness and overcome associated misconceptions, they are better positioned to help these victims achieve their goals.

FYI Keep in mind that a victim who has a mental illness is not defined by that disability. When working with a victim with a mental illness, always ask yourself and the victim if the disability is even relevant to your conversation. (See *Disabilities 101. Person First Language*.)

What is the prevalence of mental illnesses in the United States?

An estimated 26 percent of Americans ages 18 and older—about one in four adults—are diagnosed with a mental disability in a given year.[8] A much smaller proportion of the U.S. population—about 6 percent or 1 in 17—experience serious mental illnesses that cause a severe disruption in functioning.[9]

FYI Individuals can experience multiple co-occurring medical conditions. For example, a person may have anxiety and depression. A person with cerebral palsy may experience post-traumatic stress. Someone with schizophrenia may be deaf.

How prevalent is the sexual victimization of persons with mental illnesses?

In the U.S., one in six women and one in 33 men has been the victim of an attempted or completed rape in their lifetime.[10] (See *Sexual Violence 101. Sexual Victimization of Persons with Disabilities: Prevalence and Risk Factors.*) Studies reveal much higher rates of victimization for persons with mental illnesses:

- One study showed that 87 percent of a sample of individuals with severe mental illnesses had been sexually or physically assaulted within their lifetime. The women in this study were 16 times more likely to report having been the victim of a violent crime in the past year than women from a general population sample.[11]
- Sexual abuse in childhood is associated with higher rates of mental illnesses, poorer outcomes for mental health treatment and re-victimization as adults.[12] Higher rates of childhood sexual abuse are reported by adolescents and adults with diagnosed mental illnesses and range from 6 to 50 percent, whereas general population studies of reported rates of childhood sexual abuse range from 13 to 17 percent for women and 2.5 to 5 percent for men.[13]

What behaviors are indicative of a mental illness? How do service providers accommodate victims displaying these behaviors?

There are some common indicators that an individual may have a mental illness. Each indicator in the chart below is defined by a group of behaviors. Service providers may observe these behaviors as they interact with victims or victims may disclose them. However, some of these behaviors may actually be reactions a victim has to sexual violence. (See *Sexual Violence 101. Crisis Intervention, Sexual Violence 101. Indicators of Sexual Violence* and *Sexual Violence 101. Understanding and Addressing Emotional Trauma.*) With this in mind, **service providers must avoid making assumptions about root causes of behaviors and simply clarify with victims their circumstances, needs and desired assistance.** They can also offer accommodations to aid these victims in discussing and addressing their needs (see the following chart for examples).

DISABILITIES

Remember that the response in each case depends on the situation. (See *Sexual Violence 101. Crisis Intervention* and *Sexual Violence 101. Safety Planning.*)

FYI The suggestions for accommodations listed below build upon tips cited in *Disabilities 101. Tips for Communicating with Persons with Disabilities.* They are intended to guide service providers as they do initial intake or crisis intervention with clients who have been sexually victimized. A referral for mental health treatment may be warranted in some instances. *Reviewing these suggestions is not a substitute for the specialized training a mental health professional receives to be able to diagnose and treat persons with specific mental illnesses.* Also see the end of *Part 1: Core Knowledge* and *Part 2: Discussion* for case scenarios and dialogue about accommodations and considerations.[14]

Anxiety: characterized by being constantly on edge, restless and agitated, and/or having seemingly excessive intrusive thoughts, obsessive fears and/or ruminations about a traumatic event.

Possible accommodations during the initial response: Talk with the person in an environment as free from distractions as possible. Help her calm down; be accepting of her feeling of anxiety and believe she can overcome it. Ask her simple questions to help break any patterns of compulsive talking (e.g., about obsessive fears). Note that, initially, it may be difficult for her to separate her fears from reality. Work with her to build a trusting relationship before challenging her reality. Discuss what she wants to do to get through her fears and help her identify her needs for assistance. Be aware that if she is very agitated, the conversation may need to continue at another time.

Depression: characterized by pervasive feelings of hopelessness and despair, unshakable feelings of worthlessness and inadequacy, withdrawal from others and/or the inability to engage in productive activity. May manifest as physical symptoms (fatigue, stomach pain or sleep disturbances) and emotional symptoms (inability to concentrate, irritability or low mood).

Possible accommodations during the initial response: Convey acceptance, caring and hope to the person. Initiate conversation if needed. Help her identify ways to regain control of the situation, identify her needs and develop a plan to address these needs.

Disorientation: characterized by a dazed expression, memory loss and/or inability to give the date or time, identify current location, recall recent events and/or understand what is happening.

Related to disorientation is **dissociation**, a mental process that causes a lack of connection in a person's thoughts, memory and sense of identity. With severe dissociation, a person may appear distant or catatonic and have little memory of the dissociation.[15]

Possible accommodations during the initial response: Talk with the person in an environment as free from distractions as possible. Get her attention. Initiate conversation if needed. Be brief, simple and repeat as necessary. Attempt to identify her needs for assistance. Be patient but aware that discussion may not be possible at this time.

Hallucinations or delusions: characterized by hearing voices, seeing visions, delusional thinking and/or excessive preoccupation with an idea or thought. Often associated with severe mental illnesses. Also common with persons under the influence of drugs or alcohol.

Possible accommodations during the initial response: Be accepting, calm, straightforward, caring, nonthreatening and reassuring. Keep the conversation simple and brief. Be aware that rational discussion may not be possible on some or all topics. Don't argue or try to differentiate her hallucination or delusion from reality; instead, respond to her feelings and needs and help her identify what assistance she would like to address her needs. If she is agitated but poses no immediate threat to anyone's safety, allow her time to calm down before engaging her in conversation, or transition her to a safer/calmer conversation. Take breaks as needed.

Mania: characterized by expansive or irritable mood, inflated self-esteem, decreased need for sleep; increased energy; racing thoughts; feelings of invulnerability; poor judgment; heightened sex drive and impulsive sexual acts; and/or denial that anything is wrong. Associated with the use of some substances. A person with bi-polar illness may cycle between feelings of depression and mania.

Possible accommodations during the initial response (also see above under "Depression"): Be straightforward. Get the person's attention if needed. Ask simple questions to break the pattern of racing thoughts. If she is over-stimulated, don't pressure her to concentrate. Don't expect a rational discussion. If she is agitated but poses no immediate threat to anyone's safety, allow her time to calm down before engaging her in conversation, or transition her to a safer/calmer conversation. Take breaks as needed. Help her in identifying her feelings and needs and in developing a realistic plan to address those needs.

Substance abuse: When presented with a life stressor such as sexual victimization, many individuals self-medicate with drugs or alcohol to help them temporarily lessen the pain and other negative feelings.[16] Persons with specific mental illnesses have an increased risk for substance abuse.[17] Substance abuse may aggravate a pre-existing mental illness and reactions to sexual violence.

Possible accommodations during the initial response: Approach the person in a calm, nonthreatening and reassuring manner. Keep the conversation simple, brief and focused. Help her identify her needs and create a plan to address those needs. If she is under the influence of alcohol or drugs, recognize that she may not be able to have a rational conversation and may need to continue talking at another time. If she is agitated but poses no immediate threat to anyone's safety, allow her time to calm down before engaging her in conversation. Do not attempt to force her into treatment.

Suicidal thoughts: characterized by talking about suicide, including remarks such as "I wish I were dead or hadn't been born;" obtaining items that could be used to commit suicide, such as a gun or pills; withdrawing from social contact and wanting to be left alone; dramatic mood swings, such as being emotionally high one day and deeply discouraged the next; being preoccupied with death, dying or violence; feeling trapped or hopeless about a situation; abusing alcohol or drugs; changing normal routines, including eating or sleeping patterns; risky or self-destructive behaviors, such as driving recklessly; giving away belongings or getting affairs in order; saying goodbye to people as if they won't be seen again; and/or acting out of character, such as becoming very outgoing after having been shy. Although most persons with suicidal thoughts do not attempt or commit suicide, the extent of suicidal thoughts should be evaluated and re-evaluated as circumstances require (e.g., if a client who has talked to you about suicide in the past now tells you she has a written suicide plan and has acquired the means to commit suicide).[18] Studies indicate that more than 90 percent of persons who commit suicide have a diagnosable mental disability,[19] most commonly depression or substance abuse.[20] It is not the disability itself that increases the risk of suicide, but the combination of a mental illness and life stressors.[21]

Possible accommodations during the initial response: Ask the person about her suicidal thoughts. Asking won't push her into doing something self-destructive; rather, it offers her a chance to talk about her thoughts and may reduce the risk of acting on these thoughts.[22] If she is at imminent risk of suicide or just made an attempt, seek immediate emergency assistance according to your agency's policies and stay with her until help arrives.[23] If risk is not imminent, offer to assist her in developing a plan for her safety. (See *Sexual Violence 101. Crisis Intervention* and *Sexual Violence 101. Safety Planning.*)

What barriers to accessing services may victims who have a mental illness face? What are related considerations for service providers?

See the chart below. Keep in mind that the focus of a service provider's initial response to a disclosure of sexual violence should be to offer support, validation, information, crisis intervention and hope as needed for the victim to heal. Mental illnesses may influence the type of accommodations needed, as discussed above, but they should not be the focus of the response unless it is the victim's choice.

People with mental illnesses face significant stigma and discrimination. While progress has been made in the treatment and public awareness of mental illnesses, the stigma related to this form of disability still results in prejudice and stereotyping. For example, the media often portrays individuals with mental illnesses as "scary" or "dangerous," yet fails to recognize they are much more likely to be the victims of a crime. Another example is that a prosecutor may not pursue charges because he views the victim's account as unreliable solely because she has schizophrenia.

How to help: Service providers must address their own fears and discomforts about working with these victims before engaging with them. Their ongoing support for victims with mental illnesses is critical to facilitate healing, regardless of community reactions and criminal justice outcomes. (See *Disabilities 101. Person First Language* and *Disabilities 101. Tips for Communicating with Persons with Disabilities*.)

Persons with mental illnesses may be sexually assaulted by a caregiver. They may be reliant on others to carry out the tasks of daily living that they cannot accomplish on their own. Sex offenders who are caregivers may take advantage of this imbalance of power and victimize their charges. They may be able to "get away" with their crime by convincing their victims that sexually abusive behavior is a legitimate component of their caregiving responsibilities (e.g., by saying they were just bathing the person's genital areas). They may persuade their victims that what they think happened was in fact a nightmare or hallucination or that the victims were too intoxicated or medicated to remember events correctly. (See *Sexual Violence 101. Sexual Victimization of Persons with Disabilities: Prevalence and Risk Factors.*)

How to help: Service providers can help victims of sexual violence perpetrated by caregivers consider their safety risks and options. They can help victims understand the differences between healthy and unhealthy relationships with caregivers, as well as support victims in addressing their needs to the extent possible. (See *Sexual Violence 101. Safety Planning.*) Depending upon the circumstances, service providers may be required to report the victimization to local authorities. (See *Sexual Violence 101. Mandatory Reporting*.)

The credibility of the victim's account of sexual violence is often questioned. Offenders may be able to keep victims with mental illnesses from seeking help or reporting by telling them that no one will believe them. If victims do disclose sexual violence to others, offenders very likely will attack the credibility of their account of what occurred. Sex offenders often target people with mental illnesses because they recognize that their claims of sexual violence may be ignored or discounted by investigating authorities and the courts.

How to help: Service providers must remember that it is not their responsibility to determine the credibility of victims' accounts of sexual victimization. If the case is one requiring a mandated report, it is sufficient that there is a suspicion that sexual violence occurred. (See *Sexual Violence 101. Mandatory Reporting*.) When a victim with a mental illness does come forward, she deserves to be treated with the same respect and empathy as any other victim. When service providers ignore, immediately discount or question a disclosure of sexual assault, they are re-victimizing the victim. Even individuals who are experiencing delusions or hallucinations may be able to provide accurate information related to their sexual victimization.

FYI Although it is not common, it is possible that a person could hallucinate that they were sexually assaulted and be unable to separate the hallucination from reality. Regardless of the evidence in such a case, service providers should recognize that the person believes the assault occurred and may be traumatized. They can offer support to the person to deal with the impact of the trauma she is experiencing and assist her with her related needs (crisis intervention, safety planning, linking her with mental health treatment if permitted and warranted, etc.). (See *Sexual Violence 101. Understanding and Responding to Emotional Trauma.*)

Being able to trust service providers may be difficult for some victims. Helping a victim in need infers a sharing of problems, concerns and anxieties. This sharing cannot be done without trust between the victim and the service provider. That trust is built upon mutual respect and the understanding that discussions are confidential. However, gaining trust is sometimes difficult when working with a person who has feelings of paranoia, anxiety and/or a history of being abused or discounted by others.

How to help: Service providers must demonstrate they are trustworthy by maintaining the confidentiality of information that victims share with them, unless the case requires a mandatory report or the victim consents to releasing the information to specific individuals or agencies. (See *Sexual Violence 101. Mandatory Reporting* and *Sexual Violence 101. Confidentiality.*) Service providers should:

- Not assume that a victim lacks competency to make her own decisions or needs a guardian. In West Virginia, only the courts have the power to make these determinations for residents. (See *Disabilities 101. Guardianship and Conservatorship.*)
- Not assume that the victim's information should automatically be shared with her guardian—in reality, service providers and victims must assess this need on an individual case basis.
- Not assume that it is necessary to involve a mental health treatment provider.

Being able to trust service providers may be the first step for a victim towards gaining the confidence and resources needed to make a report or to recover.

A mental illness may exacerbate a victim's reactions to sexual violence (e.g., triggering depression, anxiety, hallucinations, dissociation or suicide attempts).

How to help: Service providers can help victims realize that a mental illness may intensify their reactions to the sexual assault and discuss the options available that may help relieve their symptoms, including utilizing local mental health resources. Note that victims may or may not already be working with a local mental health provider and may or may not welcome their interventions. (See *Sexual Violence 101. Understanding and Addressing Emotional Trauma.*)

If victims appear to be a danger to themselves or others, they may require immediate emergency assistance. Service providers should follow their agency's policies regarding specific actions to take in these situations. (See *Sexual Violence 101. Mandatory Reporting* and *Sexual Violence 101. Crisis Intervention.* Also see the previous section in this module on suicidal thoughts and possible accommodations.)

The fact that a victim has a mental illness may influence the consequences that she faces when she discloses sexual violence, such as having her abusive caregiver taken away and her independence reduced, changing mental health treatment and/or even being institutionalized (e.g., because she is perceived as being a threat to herself/others and/or unable to live on her own).

How to help: Service providers can encourage victims with mental illnesses to discuss their concerns and options regarding the potential consequences of disclosing/reporting. For example, a victim may disclose a sexual assault along with increased anxiety and substance abuse, but be reluctant to talk with a mental health provider because she doesn't want to increase her medication or participate in inpatient treatment. The service provider can help the victim consider her needs and options related to self-care.

DISABILITIES 101

To close *Part 1: Core Knowledge*, let's return to the scenario that opened this module and discuss how service providers might respond. Here's the scenario:

> *A 24-year-old female Army officer discloses to you that she was sexually assaulted several months ago while she was at a military rehabilitation center—she was injured in combat, losing a foot. She was also dealing with post-traumatic stress and depression. She hasn't reported the assault—the perpetrator was another patient who told her that nobody would believe her since she was a "nut case." She doesn't want him to "drag her reputation through the mud" or jeopardize her career. She is calling mainly because she is scared that since the assault, her overall feeling of despair is intensifying.*

A service provider's initial response to this victim might include:

- Validating her for seeking help, regardless of whether she reports the assault to law enforcement;
- Asking her what assistance she would like, explaining the agency's services and any limitations;
- Asking her if she feels safe (from the offender or if there is a danger of self-harm);
- If she reports that she doesn't feel safe from self-harm, follow agency policy for activating immediate emergency assistance;
- Asking her to talk more about her reactions to the victimization and her related feelings, fears and concerns;
- Asking her what she would like to do to deal with these feelings, fears and concerns and what would help her to regain control of the situation;
- Discussing available options to address her needs (including her contacting a counselor or mental health provider to further explore how to deal with the despair);
- Discussing if she requires accommodations to address her needs and to access resources; and
- If she permits, helping her plan for her future safety and the next steps in addressing her concerns.

(For more specific discussion on initial responses, see *Sexual Violence 101. Understanding and Addressing Emotional Trauma, Sexual Violence 101. Crisis Intervention* and *Sexual Violence 101. Safety Planning*.)

Even if you do not complete *Part 2: Discussion* of this module as part of a group dialogue, it may be helpful to review the activities in that section, especially those with the case scenarios. They provide the opportunity to practice responding in different situations to persons who may have a mental illness and to think about how to accommodate their needs.

FYI It may be helpful for those agencies that do not have in-house mental health expertise to partner with a local mental health provider, particularly one with experience in working with sexual violence victims. When agencies partner in this way, they help staff recognize their agency's scope of service and limitations in assisting victims with mental illnesses, as well as to know if and when to reach out to an outside mental health provider for specialized assistance (e.g., for consultation to guide their own response to a victim or to connect an interested victim to appropriate treatment services).

Test Your Knowledge

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

1. What types of disruptions can a mental illness cause? What are examples of different types of mental illnesses? *See page C5.2.*
2. One in how many people suffers from a serious mental illness? *See page C5.3.*
3. Is the prevalence of sexual victimization among persons with mental illnesses less than, equal to or greater than it is among the general population? *See page C5.3.*
4. What are examples of common indicators of various mental illnesses and possible accommodations victims might need? *See pages C5.4–C5.5.*
5. What should service providers do if a victim is suicidal? *See page C5.5.*
6. What are examples of societal misconceptions about mental illnesses that might impact sexual assault victims? *See page C5.6.*
7. What can a service provider do to assist persons with mental illnesses who were victimized by their caregivers? *See page C5.6.*
8. What are examples of how the issue of credibility can influence a community's response to a person with a mental illness who discloses sexual assault? How can a service provider help a victim deal with credibility issues? *See page C5.6.*
9. How might a mental illness influence a victim's reactions to sexual violence? How can a service provider help? *See page C5.7.*
10. What are examples of potential negative consequences for a person with a mental illness who discloses or reports sexual victimization? How can a service provider help? *See page C5.7.*

West Virginia Resources/Services for Persons with Mental Illnesses

STATE MENTAL HEALTH AGENCY

Division for Adult Mental Health
Bureau for Behavioral Health and Health Facilities
Department of Health and Human Resources
Phone: 304-558-0627
Fax: 304-558-1008
E-mail: obhs@wvdhhr.org
Internet: www.wvdhhr.org/bhhf/adultmh.asp

The Division for Adult Mental Health provides information about admission, care, treatment, release and patient follow-up in public or private psychiatric residential facilities in West Virginia.

STATE SUBSTANCE ABUSE AGENCY

Division of Alcoholism and Drug Abuse
Bureau for Behavioral Services and Health Facilities
Department of Health and Human Resources
Phone: 304-558-0627
Fax: 304-558-1008
E-mail: obhs@wvdhhr.org
Internet: http://www.wvdhhr.org/bhhf/ada.asp

The Division of Alcoholism and Drug Abuse provides information about the treatment and care of substance abuse disorders in West Virginia.

ADVOCACY

NAMI West Virginia
Phone: 304-342-0497
Toll-free: 800-598-5653
Fax: 304-342-0499
E-mail: namiwv@aol.com
Internet: www.namiwv.org

The National Alliance on Mental Illness (NAMI) maintains a helpline for information on mental illnesses and referrals to local groups. Local self-help groups have support and advocacy components and offer education and information about community services for families and individuals.

FAMILY SUPPORT

Mountain State Parents, Children and Adolescent Network
Phone: 304-233-5399
Toll-free: 800-244-5385
Fax: 304-233-3847
E-mail: ttoothman@mspcan.org
Internet: www.mspcan.org

This statewide, family-run organization provides support and information to families of children and adolescents with serious emotional disorders.

STATE PROTECTION AND ADVOCACY AGENCY

West Virginia Advocates, Inc.
Litton Building, Fourth Floor
Phone: 304-346-0847 (TDD)
Toll-free: 800-950-5250 (Nationwide/TDD)
Fax: 304-346-0867
Internet: www.wvadvocates.org

Spanish language assistance available.

West Virginia Advocates, Inc. is the federally mandated protection and advocacy agency for the rights of people with disabilities in West Virginia. It provides advocacy services and investigates reports of abuse and neglect that arise during the transportation or admission to facilities that care for or treat individuals with disabilities, during residency in them or within 90 days after discharge from them.

INVESTIGATION OF FRAUD AND MISTREATMENT

WV Medicaid Fraud Control Unit (MFCU)
Office of Inspector General, Department of Health and Human Resources
Phone: 304-558-1858
Fax: 304-558-3498
Tipline: 888-372-8398
Internet: http://www.wvdhhr.org/oig/mfcu/

The MFCU investigates complaints of alleged fraud and mistreatment of patients in facilities receiving payment from medical programs of the state.

ADVOCACY

West Virginia Mental Health Consumers' Association
Phone: 304-345-7312
Toll-free: 800-598-8847
Fax: 304-414-2416
Internet: www.wvmhca.org

Statewide consumer organizations are run by and for consumers of mental health services and promote consumer empowerment. They provide information about mental health and other support services at the state level and are active in addressing and advocating for mental health system issues.

LOCAL SOURCES OF INFORMATION

Also consider local resources. Your area mental health center and other branches of city or county government may be able to help. For example, your local board of education office might have information about help for children and the agency for the aging might know about services for senior citizens. Also, family physicians or area hospitals may be able to make referrals. For legal advice, contact the local bar association or go to www.findlegalhelp.org. The library and telephone yellow pages may offer applicable resource lists.

National/Regional Resources for Persons with Mental Illnesses

Centers for Medicare and Medicaid Services (CMS)
Phone: 410-786-3000
Toll-free: 877-267-2323
TDD: 866-226-1819
E-mail: question@CMS.gov
Internet: www.CMS.gov

CMS, a component of the U.S. Department of Health and Human Services, addresses patient complaints about treatment facilities that receive Medicare and Medicaid funding (e.g., see its Beneficiary Complaint Response Program). Concerns may also be shared with staff at West Virginia's regional office for CMS:

Philadelphia Regional Office (Region 3)
Centers for Medicare and Medicaid Services
Phone: 215-861-4140
Fax: 215-861-4140
Internet: www.CMS.gov/RegionalOffices/04_RO3.asp

National Mental Health Consumers' Self-Help Clearinghouse
Phone: 215-751-1810
Toll-free: 800-553-4KEY (539)
Fax: 215-636-6312
E-mail: info@mhselfhelp.org
Internet: www.mhselfhelp.org

This clearinghouse promotes and helps to develop consumer-run self-help groups across the country. Technical assistance and materials are available on such topics as organizing groups, fundraising, leadership development, incorporating, public relations, advocacy and networking.

Consumer Organization and Networking Technical Assistance Center (CONTAC)
Phone: 304-345-7312
Toll-free: 888-825-TECH (8324)
Fax: 304-345-7303
E-mail: usacontac@contac.org
Internet: www.contac.org

CONTAC is a resource center for consumers/survivors and consumer-run organizations. Services and products include informational materials, on-site training and skill-building curricula, electronic and other communication capabilities, networking, and customized activities promoting self-help, recovery, leadership, business management and empowerment.

Mental Health America Resource Center
Phone: 703-684-7722
Toll-free: 800-969-6642
TDD: 800-433-5959
Fax: 703-684-5968
E-mail: infoctr@nmha.org
Internet: www.nmha.org

Mental Health America (formerly the National Mental Health Association) maintains a referral and information center and can help you locate local chapters. These local groups have information about community services and engage in national and state level advocacy.

National Empowerment Center
Phone: 978-685-1494
Toll-free: 800-769-3728
Fax: 978-681-6426
E-mail: info4@power2u.org
Internet: www.power2u.org

This center, run by mental health consumers, carries a message of recovery, empowerment, hope and healing to people who have been diagnosed with a mental illness. It provides information and referrals to consumer resources and offers technical assistance to individuals and groups involved in consumer empowerment activities.

ADDITIONAL NATIONAL ONLINE RESOURCES

National Alliance on Mental Illness (NAMI)
www.nami.org

National Institute of Mental Health (NIMH)
www.nimh.nih.gov

National Suicide Prevention Lifeline (24 hour)
www.suicidepreventionlifeline.org
1-800-273-TALK (8255)
Calls are routed to the nearest crisis center in a national network of more than 140 crisis centers.

Substance Abuse and Mental Health Services Administration (SAMHSA)
www.samhsa.gov

Part 2: DISCUSSION

Projected Time for Discussion
2 hours

Purpose and Outcomes

This discussion is designed to help participants apply the information presented in *Part 1: Core Knowledge* of this module to their work with sexual violence victims. It could be incorporated into forums such as agency staff meetings as well as volunteer meetings or trainings. Anticipated discussion outcomes include skill building and increased understanding of service providers' roles in working with sexual violence victims who have mental illnesses.

Refer to the learning objectives at the beginning of this module for specific outcomes for this module.

Planning

- Ensure that the meeting is held at an accessible location. Ask participants prior to the meeting if they need any accommodations—if so, work with them to secure accommodations.
- Select a facilitator. The facilitator should have expertise in responding to persons with mental illnesses who are also victims of sexual violence.
- Participants and the facilitator should review *Part 1: Core Knowledge* of this module before the discussion, as well as *Disabilities 101. Tips for Communicating with Persons with Disabilities*.
- Bring the following supplies and materials to the meeting: flipcharts and colored markers, sufficient copies of participant materials, office supplies (tape, pens, paper, etc.) and a clock/watch to monitor time. Optional items include name badges and table tents.

Suggested Activities and Questions

1. **Invite participants to identify discussion ground rules to promote open communication.** Utilize the following principles: *(10 minutes)*

- An environment of mutual respect and trust is optimal. Everyone should feel comfortable expressing their opinions and feelings about the scenarios. There are no right or wrong responses, only different approaches.
- Avoid personalized comments that are negative as they can lead to defensiveness and confrontation among participants and ultimately may shut down dialogue. The purpose of the role play scenarios is to provide an opportunity to practice new skills and obtain constructive feedback.
- Be clear about what information discussed during this meeting is confidential and what the expectations are for confidentiality in the context of this partnership.

2. Invite participants to share their general experiences in working persons with mental illnesses, as well as with sexual violence victims with mental illnesses. *(15 minutes)*

a. What are common issues and challenges?

b. What unique issues and challenges arise when interacting with victims with specific mental illnesses?

c. Does your agency have in-house expertise on mental health issues and/or partnerships in the community? Describe.

d. What additional actions or resources would be helpful to improve your agency's capacity to effectively serve these victims?

3. Have participants break into small groups and assign each group one or more of the scenarios below. **Ask each group to consider the issues and challenges specific to that scenario and then outline how they would respond to that victim** (what they would say, discuss, share and ask). Remember the focus is on the initial response during intake or crisis intervention. Be careful not to step beyond your professional role within your agency. Each small group should select a recorder to take notes and a reporter to report back to the large group. (10 to 15 minutes per scenario; time will vary depend on how may scenarios each group reviews)

Scenario 1

A 23-year old woman was sexually assaulted by her pastor, whom she was seeing regularly to talk about her severe anxiety. Her fears are "smothering her"—she can't stop thinking that she will have an anxiety attack and die if she sees the pastor again, that she will get AIDS and die, that she will have to face the humiliation of a sexually transmitted infection, that she will become pregnant, that the congregation will rally behind the pastor and ostracize her, that the pastor's wife will think she was trying to seduce him, that her parents will literally die of embarrassment, etc. What do you do to help?

Scenario 2

A 15-year-old male calls you and discloses that he woke up in the middle of the night last evening to find his step-father fondling his penis. He is humiliated by what happened and says that he wants to kill his step-father and will do so if tries to touch him again. Although he wants to leave home, he feels he must stay there to protect his sister from his step-father. He admits that since the attack, he has tried to calm himself by taking more anti-depression medication than he is prescribed. He also has been cutting himself and obsessively washing to rid himself of the" feeling of his step-father's touch," to the point where his skin is raw and bleeding. He refuses to tell you his name, the step-father's name or where he lives. What do you do to help?

Scenario 3

A 30-year old woman with chronic depression discloses a history of child and adult sexual victimization. She has sporadically sought mental health treatment and frequently stops taking her anti-depression medications due to negative side effects. She self-medicates with alcohol. She has a great sense of humor, which helps her cope, especially when she sees her 45-year-old brother who sexually abused her throughout her childhood. She has never confronted him or disclosed his abuse to any family member; he maintains power over her by constantly putting her down. She worries about whether he has abused other children. She is a frequent caller to your agency (so you are aware of her circumstances), reaching out when she has flashbacks, bouts of self-loathing, interactions with her brother, or is intoxicated. She often feels suicidal. What do you do to help?

Scenario 4

A 50-year-old man tells you he has been fired from his job after he disclosed to his supervisor that "ever since he had that 'problem with the IRS' a few years ago, tax auditors have blackmailed him to perform oral sex on them, threatening to start an IRS investigation on him unless he meets their demands." Ultimately, he lost his job because he refused mental health treatment (and still does not want it). He reported the incidences to law enforcement, but they "didn't believe him." His family and friends have "abandoned" him because they "think he is crazy" and he is now close to losing his home. He is desperate for someone to believe him and do something about "the blackmail by the IRS." What can you do to help?

4. As a large group, **facilitate a review and discussion of issues, challenges and appropriate responses for each scenario**. Ask a reporter from each assigned group to report back and then use the below "scenario considerations" to help guide discussions. *(10 minutes per scenario, for a total of 40 minutes)*

Scenario 1: Considerations

Validate the victim for seeking help. Help her calm down as needed so she can engage in a conversation with you. Ask what assistance she would like from you/your agency, briefly explaining your agency's services and limitations. If it was a recent assault, let her know that she can go to the local hospital for a sexual assault forensic medical examination to address her concerns about her health (e.g., get emergency contraception to prevent pregnancy and preventative treatment for sexually transmitted infections) and have evidence gathered. Discuss her options to report to law enforcement. Aid her in understanding that she is experiencing common reactions to being sexually assaulted, but her reactions may be more intense and intrusive due to her anxiety. Ask her what she has done in the past to get through these feelings and help her plan how she will use these and other tactics to deal with her current concerns. If she is at a point that she can discern her anxiety from reality, talk with her about replacing her fears with facts (e.g., it is unlikely she would die from an anxiety attack, that she will contract AIDS or a sexually transmitted infection or die from these conditions, or become pregnant). Discuss with her that sexual assault is always the fault of the perpetrator; nothing she did provoked his assault. Help her prepare for the reality that some people may make assumptions about what happened, not wanting to consider that they misplaced their trust in the pastor. She can't control what other people think, just how she deals with their opinions. Help her plan how she wants to deal with these situations, including identifying who she can turn to for support.

Scenario 2: Considerations

Validate the victim for seeking help and ask what assistance he would like from you/your agency, briefly explaining your agency's services and limitations. Share with him the common feelings that victims of sexual violence experience, such as humiliation, pain and fear, and let him know the abuse was not his fault and that he can heal from it. Let him know that, like him, some victims self-medicate and self-mutilate to divert emotional pain. Some obsessively try to wash the touch of the perpetrator off of their bodies. Discuss with him healthier options available for dealing with these feelings. Talk with him about his safety and that of his sister and his options for protection, as well as potential consequences of retaliation against the offender—and help him develop a plan for safety if he permits. Help him identify persons whom he can turn to for support (e.g., a counselor, teacher, relative, friend, etc.). Explain what will happen if he reports the abuse to Child Protective Services (CPS) or law enforcement and provide him with the contact information. Let him know he and his sister deserve to be safe from his step-father and that you would like to make a report if he would provide you with the pertinent contact information (even though he may refuse to provide it). Explain that he can also go to the local hospital to address any health concerns (e.g., if he gets an infection from the obsessive washing).

Scenario 3: Considerations

This scenario deviates from the others in that the victim has previously disclosed sexual violence to your agency, but she frequently calls in crisis. Trauma caused by sexual victimization is rarely a one-time event, but rather can be repeatedly triggered throughout one's lifetime. Depression intensifies traumatic reactions for this victim. Each crisis call from a frequent caller needs to be treated as a new crisis requiring the development of a new action plan (even if the plan ends up being similar for each crisis).

Validate her for seeking help (she already is aware of your agency's services) and focus on providing crisis intervention to help her deal with her suicidal thoughts, self-loathing and fears produced by the flashbacks. Ask her if she is actively planning to kill herself and has the means (if so, seek immediate emergency assistance). Ask

her about her drug/alcohol use. Help her determine how she will get through the current crisis, reminding her that she has gotten through crises before and can again. Aid her in developing a plan to become more stable (this plan may include her contacting her mental health provider to discuss medications and crisis needs). Encourage her to call again if she is in crisis, as well as to interact with and seek help from her support system (her counselor, doctor, a support group, friends, etc.).

Scenario 4: Considerations

Regardless of whether the events the man describes actually happened or are a hallucination/distortion of reality, you can validate him for seeking help and let him know you understand he believes the sexual violence occurred. Ask what assistance he would like from you/your agency, briefly explaining your agency's services and limitations. Assure him that by contacting law enforcement he has warned the community about this problem. It may be useful if a law enforcement detective explains to him why his case was closed/what evidence was lacking (offer to connect him with the law enforcement agency). Ask him what he would like to do to deal with this trauma in his life. Offer to help him explore his options and make a plan for rebuilding a support system, his emotional health, financial stability, housing, etc. You can offer information about available counseling and mental health services (e.g., he might be more receptive to ongoing therapy or a support group than psychiatric care). Recognize, however, that he may not be able to have a rational discussion about what he is experiencing, whether or not he has a mental illness.

5. **Closing.** Ask participants what they learned from this module and how they will apply the lessons learned to their practice settings. *(10 minutes)*

Funding was provided by Grant No. 2006-FW-AX-K001 awarded by the Office on Violence Against Women, U.S. Department of Justice. The opinions, findings, conclusions and recommendations expressed in this module are those of the authors and do not necessarily reflect the views of the U.S. Department of Justice, Office on Violence Against Women.

[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]Paragraph drawn from National Alliance on Mental Illness (NAMI), *Mental illness facts* (Arlington, VA, accessed May 12, 2010), through http://www.nami.org/. Note that all 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.

[3]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 are often referred to as female. Note, however, that this reference to female victims does not imply that most persons who have mental illnesses are women—statistics on gender vary depending on the type of mental illness. Discussion of these statistics is beyond the scope of this module.

[4]Paragraph drawn from NAMI.

[5]Drawn in part from WebMD, *Types of mental illness* (2009), http://www.webmd.com/mental-health/mental-health-types-illness.

[6]Another publication that is sometimes referred to classify mental illnesses is the International classification of diseases by the World Health Organization.

[7]In addition to mental illness, the *DSM* classification system speaks to other mental disabilities. For instance, it identifies autism and intellectual disabilities (also referred to as mental retardation) as forms of developmental disabilities, not mental illnesses. Autism affects brain functioning; it may impact communication and social skills, and can cause extreme sensitivity to physical contact (as cited in Autism Defined Net, Autism defined (2010), http://autismdefined.net/). An intellectual disability is characterized by a significantly below-average score on a test of mental ability or intelligence and limited daily living skills (as cited in NAMI; and Centers for Disease Control and Prevention, *Intellectual disabilities* (Atlanta, GE, 2005), http://www.cdc.gov/ncbddd/dd/ddmr.htm).

[8]R. Kessler, W. Chiu, O. Demler & E. Walters, Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Co-morbidity Survey replication, *Arch Gen Psychiatry* 62(6) (2005), 617-27. Note that the term "mental disabilities" in this article is inclusive of more conditions than just mental illnesses.

[9]Kessler, Chiu, Demler & Walters.

[10]P. Tjaden & N. Thoennes, *Prevalence, incidence and consequences of the violence against women: Findings from the National Violence Against Women Survey* (Washington, DC: National Institute of Justice and Altanta, GE: Centers for Disease Control and Prevention, 1998), http://www.ncjrs.gov/pdffiles/172837.pdf.

[11]L. Goodman, M. Salyers, K. Mueser, S. Rosenberg, M. Swartz, S. Essock, et al., Recent victimization in women and men with severe mental illness: Prevalence and correlates, *Journal of Traumatic Stress,* 14(4) (2001), 615-632. As cited in Kentucky Association of Sexual Assault Programs, Recognizing Sexual Victimization of Persons with Disabilities (2007), http://kyasap.brinkster.net/Portals/0/pdfs/pro%20guide%20pages/RecognizDisabilPg14.pdf.

[12]A. Clayton, Sexual abuse and mental health sequelae, *Primary Psychiatry* (2010), http://www.primarypsychiatry.com/aspx/articledetail.aspx?articleid=682. This article provides information about multiple studies that support this statement, as well as additional comments of the author.

[13]J. Coverdale & S. Turbott, Sexual and physical abuse of chronically ill psychiatric outpatients compared with a matched sample of medical outpatients, *Journal of Nervous and Mental Disease,* 188(7) (2000), 440-445; S. Friedman, L. Smith, D. Fogel, et al., The incidence and influence of early traumatic life events in patients with panic disorder: A comparison with other psychiatric outpatients, *Journal of Anxiety Disorders,* 16(3) (2002), 259-272; and S. Dinwiddie, A. Health, M. Dunne, et al., Early sexual abuse and lifetime psychopathology: A co-twin–control study, *Psychological Medicine,* 30(1) (2000), 41-52.As cited in Clayton.

[14]For more information on the following symptoms and behaviors, see the *Diagnostic and statistical manual of mental disorders* (DSM) by the American Psychiatric Association.

[15]With the exception of the last sentence, drawn from Mental Health America, Factsheet: *Dissociation and dissociative disorders* (Alexandria, VA, 2010), http://www.nmha.org/go/dissociation.

[16]For more on sexual violence and substance abuse, see Wisconsin Coalition Against Sexual Assault, *Sexual violence and substance abuse, information sheet series* (Madison, WI: 2000), http://www.prandicenter.org/Resources/sexual%20assault%20and%20substance.pdf.

[17]For example, the risk for persons who have experienced a major depressive episode is about 4 percent more than for the general population; almost 15 percent more for those who have had a manic episode; and about 10 percent more for those who have schizophrenia. From the National Institute of Mental Health, as cited in National Drug Intelligence Center, *Drug abuse and mental illness fast facts* (Johnstown, PA: U.S. Department of Justice, 2004), http://www.justice.gov/ndic/pubs7/7343/index.htm.

[18]M. Gliatto & A. Rai, Evaluation and treatment of patients with suicidal ideation, *American Family Physician* (1999), http://www.aafp.org/afp/990315ap/1500.html.

[19]E. Moscicki, Identification of suicide risk factors using epidemiologic studies, Psychiatric Clinics of North America, 20 (1997), 499-517. As cited in Gliatto & Rai.

[20]Gliatto & Rai.

[21]C. Rich, D. Young & R. Fowler, San Diego suicide study. I. Young vs. old subjects, *Archives of General Psychiatry,* 43 (1986), 577-82; and Moscicki. As cited in Gliatto & Rai.

[22]Gliatto & Rai.

[23]Mayo Foundation for Medical Education and Research, *Suicide: What to do when someone is suicidal* (2010), http://www.mayoclinic.com/health/suicide/MH00058.

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 *Sexual 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 *Sexual 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 pages C6.4–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.

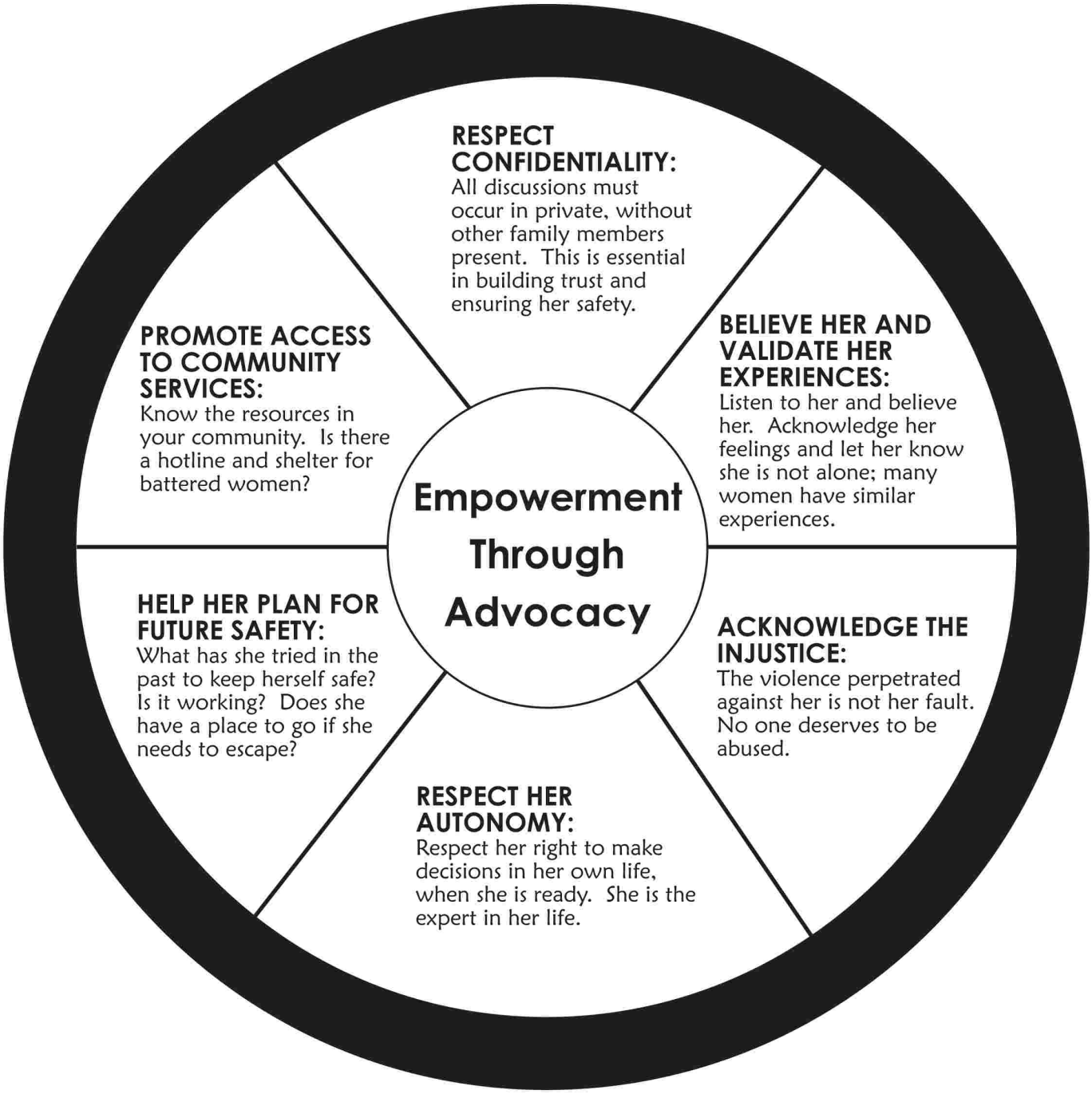
[21]C. Parsons, *The dignity of risk: Challenges of moving* on (paper presented in 2007 at the Mental Health Services Conference in Melbourne, Australia).

[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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Guardianship and Conservatorship

This module offers a basic overview on working with adults who have or may need a guardian and/or conservator to make personal and/or financial decisions on their behalf, and includes West Virginia laws pertaining to guardianship and conservatorship.[1]

Key Points

- *If an adult in West Virginia lacks the ability to make personal and/or financial decisions, it may be determined by the court that they are a "protected person"* and need a guardian and/or conservator to be appointed to make these decisions on their behalf. A *guardian* is a person appointed by the circuit court who is responsible for the personal affairs of a protected person. A conservator is a person appointed by the circuit court who is responsible for managing the estate and financial affairs of a protected person. The terms and conditions of the court order of appointment will indicate the scope and limitations of the guardianship/conservatorship.
- *In order for a guardian or conservator to be appointed, a petition must be filed in circuit court* in the county where the potentially protected person resides. Any interested person may file this petition. A hearing is scheduled within 60 days of the petition being filed.
- *Based upon information presented during the hearing, the court determines* if the individual is to be considered a protected person; the person's limitations; development of the person's maximum self-reliance and independence; whether a guardian and/or conservator should be appointed; the type of guardian and/or conservator and specific areas of protection, management and assistance to be granted; the suitability of the proposed guardian and/or conservator; and the length and other terms and conditions of the order. Prior to appointment, the guardian/conservator must complete mandatory training. The court monitors the appointment through periodic reports by the guardian/conservator. *This process is intended to pursue the least intrusive type of appointment necessary to meet the person's needs.*
- *Providers should view guardians/conservators as partners in assisting clients to meet their self-identified needs* (according to the terms and conditions of their appointment), unless there is reason to think otherwise.
- *If providers suspect abuse or neglect of a protected person by their guardian/conservator,* they are required to report their suspicions to their local Department of Health and Human Resources (DHHR) or the statewide hotline at 800-352-6513. If they suspect a crime has been committed against a protected person, they should call local law enforcement. If they think a protected person is in imminent danger, they should call 911. If they suspect a guardian/conservator is not acting in a protected person's best interest, they can contact the circuit court that appointed the guardian/conservator or a private attorney for information on options. In cases in which DHHR is the appointed guardian, service providers can also contact their local DHHR.
- *If a client has a guardian/conservator, service providers must clarify the terms and conditions of the appointment.* Service providers need this information before making decisions to release client information to a guardian/conservator. They also must consider whether they need the permission of the guardian/conservator to release client information to other providers or to provide specific services to the client.

C7. Guardianship and Conservatorship

Purpose

You received a call last week regarding Beth, a vibrant 26-year-old with a cognitive disability. You arranged to meet with her today. When you go out into your reception area, Beth is there with an older gentleman whom she introduces as her guardian. You want to speak to Beth alone. Legally, can you? What do you do?[2]

The above scenario is one illustration of why it is important for service providers to have general knowledge about guardianship and conservatorship, as they may work with adults with disabilities who have, or may be in need of, a guardian and/or conservator. There are times when adults, due to "mental impairments,"[3] are no longer able to make their own decisions; in some situations, a guardian and/or conservator may be appointed to make decisions on their behalf. The West Virginia Guardianship and Conservatorship Act,[4] originally enacted in 1994, outlines the circumstances under which a guardian and/or conservator may be appropriate, the process for a guardian and/or conservator to be appointed, and the duties and responsibilities of an appointee. The role of the guardian is distinguished from the role of a conservator by the nature of the decisions each is authorized to make. Guardians are authorized to make certain *personal* decisions, while conservators are authorized to make *financial* decisions.

Service providers should be able to connect clients who have questions or needs related to guardianship and conservatorship to the appropriate resources. When clients already have a guardian/conservator, providers need to know how the involvement of a guardian/conservator can potentially impact service delivery and ways to work collaboratively with the guardian/conservator and the client to address the client's self-identified needs. For clients who are sexual assault victims, providers must realize the inherent power that the guardian/conservator has over the dependent person and that this power could be used to manipulate and take advantage of that person. Critical safety issues to consider include the scope of confidentiality of client information and what to do if there are suspicions that a guardian/conservator is mistreating a client or not acting in a client's best interest.[5]

Objectives

Those who complete this module will be able to:

- Understand the differences between guardianship and conservatorship;
- Understand the process and criteria for appointing guardians and conservators, as well as determining their respective duties;
- Describe how to collaborate with clients with disabilities and their guardians and conservators to meet clients' self-identified needs; and
- Discuss potential safety concerns for persons with disabilities who have guardians and conservators.

CORE KNOWLEDGE

What definitions are important to know related to guardianship and conservatorship?[6]

PROTECTED PERSON: An adult individual, 18 years of age or older, who has been found by the circuit court, because of mental impairment, to be unable to receive and evaluate information effectively, or to respond to people, events and environments to such an extent that the individual lacks the capacity to: (a) meet the essential requirements for his or her health, care, safety, habilitation[7] or therapeutic needs without the assistance or

protection of a guardian; OR (b) manage property or financial affairs, or to provide for his or her support or for the support of legal dependents without the assistance or protection of a conservator. This assessment is called a competency evaluation and is performed by the circuit court judge.

GUARDIAN: A person appointed by the circuit court who is responsible for the *personal affairs* of a protected person. Responsibilities of a guardian may include making personal decisions for the protected person such as deciding where the person will live, how meals and daily care will be provided, and how healthcare will be provided.

Guardianship may be full or limited. A limited guardian has only those responsibilities for the personal affairs of a protected person as specified in the order of appointment. A limited guardianship generally occurs when the court determines that a protected person needs a guardian for a specific purpose, but is capable of addressing some of the essential requirements for her or his health, care or safety. The court can also appoint a temporary guardian if it finds that an immediate need exists—the temporary guardian has only those powers and duties specifically set forth in the order of appointment and only for a limited time.[8]

CONSERVATOR: A person appointed by the circuit court to be responsible for managing the *estate and financial affairs* of a protected person. Conservator responsibilities may include controlling the protected person's assets, paying bills and managing property.[9] Like guardianship, conservatorship may be full or limited, as well as temporary.[10]

FYI *The West Virginia Social Services Manual, Guardianship Services* indicates that incompetence is a legal determination that individuals lack the ability to understand the nature and effects of their acts and, as a result, are unable to manage their business affairs or are unable to care for their physical well-being, thereby resulting in substantial risk of harm.[11]

What are the responsibilities of a guardian/conservator?

In order for a guardian/conservator to be appointed, a petition requesting this type of appointment must be filed with the circuit court (see pages *C7.4–C7.5*). If, during the guardianship/conservatorship hearing, the court determines that the adult meets the definition of a "protected person" under the Guardianship and Conservatorship Act, a guardian/conservator may be appointed to assist the protected person with her/his decisions. The court determines the specific terms and conditions of the appointment—it is the responsibility of the guardian or conservator to honor those terms and conditions. As noted earlier, the authority of the guardian/conservator may extend to all personal/financial decisions affecting the protected person or may be limited in scope or duration. *The court typically pursues the least intrusive type of appointment necessary to meet the individual's needs. The appointment should promote the protected person's self-reliance and independence.*[12]

To determine the responsibilities of a guardian/conservator for a particular individual, it is necessary to review the order of appointment for that individual. Note, however, that in addition to the specific terms and conditions of their appointment, the state code outlines general mandated requirements and responsibilities both for guardians and conservators. For details, refer to *WVC§44A-3-1 through 3–10*.

FYI **A guardian/conservator is entitled to reasonable compensation** as allowed by the court from the protected person's estate. However, the frequency and amount of compensation must be approved by the court.

Who is qualified to serve as a guardian or conservator?

Any adult may be appointed by the court to serve as a guardian and/or conservator, provided that the court determines that the individual is capable of providing a suitable program of guardianship and/or conservatorship for the protected person. Frequently the same person is appointed as guardian and conservator. However, the court can appoint different people to fill these positions if it is determined that it would be in the protected

person's best interests.[13] Also, the court may, after determining it to be in the best interest of the protected person, appoint co-guardians, co-conservators or both.[14]

In the event that a family member, friend or other qualified person is not available to be appointed by the court, the law specifies other agencies and entities the court can designate to assume these responsibilities. Examples of these agencies include the West Virginia Department of Health and Human Resources (DHHR), Adult Protective Services (APS), and certain state licensed non-profit entities. DHHR may be appointed to serve as a guardian in instances where no one else is equally or better qualified, but this agency is not allowed by law to be a conservator. When there is no one else equally or better qualified to serve as conservator, the sheriff of the county where the petition was filed may be appointed.[15]

NOTE: Persons employed by or affiliated with any public agency, entity or facility (including nursing home employees) that is providing substantial services or financial assistance to a protected person are not eligible to serve as a guardian or conservator to that person.

FYI Persons being considered by a court for appointment as a guardian and/or conservator are required to provide information regarding any crime other than traffic offenses for which they were convicted. The court or mental hygiene commissioner also may order a background check to be conducted by the state police or county sheriff. The court will then consider this information in determining a person's fitness to be appointed as a guardian/conservator.

There are no specific educational requirements in order to be considered for appointment as a guardian/conservator. It is only necessary that persons being considered demonstrate that they are capable of performing the duties of guardianship or conservatorship.

What is the process for determining the need for and extent of guardianship and/or conservatorship?

This section discusses filing a petition to appoint a guardian/conservator, the initial hearing, mandatory training for guardians/conservators and the order of appointment.

FILING A PETITION: In general, the process begins when someone makes an official request (files a petition) to the circuit court to appoint a guardian/conservator for a potentially protected person. There is a $110 filing fee (some jurisdictions waive this cost when DHHR is the petitioner).[16] The petition must be filed with the circuit court clerk in the county where the potentially protected person resides, unless the person has been admitted to a health care or correctional facility in another county. In this situation, the petition should be filed in the county where the facility is located.

Any interested person may file a petition to request the appointment of a guardian/conservator. Individuals specifically identified in the state code as persons who may file include: the potentially protected person; a person who is responsible for that individual's care/custody; the facility providing care to the individual; a person the potentially protected individual has nominated to serve as guardian/conservator; DHHR; or any other interested person. When it is believed a guardian/conservator is needed and no one is available or willing to file the petition, DHHR may file.

A petition to appoint a guardian/conservator must contain the following information:

- Petitioner's name, address and relationship to the potentially protected person;
- Potentially protected person's name, address, gender, race, height and eye color;
- Names and addresses of the potentially protected person's nearest known living relatives;
- Name and address of any individual or facility who is responsible for the potentially protected person's care or custody and a detailed list of things they do for the person's benefit;
- Name and address of the potentially protected person's living will or medical power of attorney representative or appointed healthcare surrogate, and a detailed list of things they do for the person's benefit (copies of these documents should be attached to the petition if available);
- Name, address and phone number of the petitioner's attorney;
- If the potentially protected person will be able to attend the hearing and, if not, why;
- Extent of guardianship/conservatorship requested, reasons why and specific areas of protection or assistance requested;
- Name and address of the guardian/conservator the petitioner proposes;
- If the proposed guardian/conservator is an individual, the petition should include the proposed guardian's/conservator's address, age, occupation and relationship to the potentially protected person (it should also include the same information for the individual the potentially protected person has nominated as guardian/conservator, if different from the one being proposed by the petitioner);
- Name and address of any current guardian/conservator already acting on the potentially protected person's behalf;
- The names and criminal histories of any individual proposed, nominated or acting as a guardian/conservator, as listed on this form, who has ever been convicted of a criminal offense other than a traffic offense;
- An evaluation report by a licensed physician or psychologist documenting the nature, type and extent of the protected person's incapacity (its primary purpose is to provide evidence as to whether an individual meets the definition of protected person under the law and the scope of protection and assistance needed[17]); and
- A statement of financial resources, for conservatorship only (listing the protected person's social security number, approximate value of real and personal property and the anticipated annual income and other receipts[18]).

FYI See http://www.state.wv.us/wvsca/rules/conservator/gcindex.htm for **links to forms used in guardian/conservator cases** in state circuit courts. Forms are also available at local circuit court clerks' offices.

INITIAL HEARING: A hearing is scheduled by the circuit court within 60 days of the petition being filed. The potentially protected person (and caregiver as appropriate) will receive a notice of the date, time and place of the hearing, a copy of the petition and a copy of the doctor's evaluation not less than 14 days before the hearing.[19] The court will appoint legal counsel for the person, taking into consideration the person's preferences if they are known.[20]

It is the responsibility of the court to determine, based on the information presented during the hearing:

- If the individual is to be considered a protected person under the law;
- The limitations of the protected person;
- The development of the person's maximum self-reliance and independence and the availability of less restrictive alternatives, including the extent to which it is necessary to protect the person from neglect, exploitation or abuse;
- Whether a guardian and/or conservator should be appointed;
- The type of guardian and/or conservator and specific areas of protection, management and assistance to be granted;
- The suitability of the proposed guardian and/or conservator; and
- The length and other terms and conditions of the order.

FYI Note that a court finding that persons only exercised poor judgment in caring for themselves/their property is not enough to qualify them as protected persons.[21]

It is the appointed legal counsel's role to determine whether a guardian and/or conservator is needed, tailor the guardian's/conservator's role to the person's specific needs, ensure that the individual with the greatest interest in the potentially protected person is appointed guardian/conservator and ensure that proper living arrangements and placement are considered. Legal counsel should also ensure that any bond required by the court is adequate—posting of bonds is at the court's discretion and *usually not required* of a guardian,[22] but typically *is required* of a conservator.[23] The bond provides a way for the court to safeguard the protected person's assets—the court's order of appointment will indicate the amount and type of bond, if applicable.[24]

The appointed legal counsel should interview the potentially protected person to determine the person's needs and wishes, conduct an investigation to determine if a guardian/conservator is needed, and make recommendations as to who would be the best guardian/conservator for the person and what would be suitable living arrangements/placement.[25]

MANDATORY TRAINING: Any guardian/conservator named at the conclusion of the petition hearing is typically required to complete mandated training (coordinated by the WV Court of Appeals) within 30 days of the court's determination . Upon completion, the court can issue the order of appointment.[26]

ORDER OF APPOINTMENT: Once the court has determined that a guardian/conservator is necessary and a guardian/conservator has been appointed, the appointed individual is charged with the responsibility of acting in accordance with the specific terms and conditions established by the court.

How can service providers collaborate with clients with disabilities and their guardians/conservators to meet the clients' self-identified needs?

Some examples of simple steps that service providers can take:

- To the extent possible, speak directly with clients, rather than to or through their guardian/conservator. Encourage them to do the same with you.
- Endeavor to find out what clients need (as opposed to what their guardians/conservators want) and base services provided on those needs to the extent possible. If appropriate (e.g., if clients have the capacity/comfort

(See the other Disability 101 modules for ways to enhance your interactions with victims with disabilities.)

What are potential safety concerns for persons with disabilities who have guardians/conservators?

The vast majority of guardians and conservators act in the best interests of the persons they are appointed to care for and protect (as per the terms and conditions of their court appointments) and are not abusive to them. However, persons with disabilities are particularly vulnerable to being manipulate and taken advantage of by less conscientious guardians/conservators because of the power guardians/conserva may have over them and their personal affairs. (See Sexual Violence 101. Sexual Victimization of Persons with D Prevalence and Risk Factors and Sexual Violence 101. Indicators of Sexual Violence.)

Service providers should take action if they suspect persons with disabilities are being abused or neglected by their guardians/conservators. If providers suspect abuse or neglect of a protected person by a guardian/conservator, they are required to report their suspicions to their local DHHR (go to http://www.wvdhhr.org/ to find contact information) or the statewide DHHR 24-hour hotline at 800-352-6513. If they suspect a crime has been committed against a protected person by a guardian/conservator (e.g physical/sexual assault or theft), they should contact local law enforcement. If they think a protected person is in imminent danger, they should call 911 for immediate assistance. (See Sexual Violence 101. Mandatory Rep and Sexual Violence 101. Crisis Intervention.)

Service providers may suspect a guardian/conservator is not acting in a protected personÕs best interest. Guardians/conservators are subject to the jurisdiction of the circuit court that appointed them. They can be removed for not acting in the protected personÕs best interests or not following court terms and conditions. (One way the courts monitor compliance with terms and conditions is by requiring periodic reports from guardians/conservators.) Guardianships and conservatorships can be modified for a number of reasons including a change in the protected personÕs medical status or financial circumstances. Guardians and conserv can also be removed or limited in their duties if they become incapacitated in some way themselves. Legal acti to remove a guardian and conservator is a serious step that may be appropriate in some cases.[27] For informati on what clients can do in these instances, contact the circuit court that appointed the guardian/conservator (fo contact information see http://www.state.wv.us/wvsca/circuits/map.htm) or an attorney (for referrals, contact Legal Aid of West Virginia at www.lawv.net or 866-255-4370). In cases in which DHHR is appointed the guardia service providers can also contact their local DHHR for more information on options for protected persons.

Service providers may be unclear about whether client information is confidential when a client is a protected person and has a guardian/conservator. The extent of confidentiality of client information will depend on the terms and conditions of the guardianship/conservatorship. In the case of full guardianship, the guardian is most likely able to access client information. If the guardianship is limited, an many are as courts strive to place protected persons in the least restrictive environment possible, client informatio may be protected to some extent from the guardian. Those who are conservators only should not have access to client information unless it involves the clientÕs finances.

To clarify whether client information is confidential, providers must find out if clients with disabilities have guardians/conservators and the terms and conditions of their appointments. They can ask clients during their initial contact if they have a guardian/conservator (in many cases, a client will share this information freely or i may be evident because a guardian/conservator or someone who knows that there is a guardian/conservator may call/come in for services with the client). If they answer affirmatively, providers should take the next step to ask clients or those accompanying them about the terms and conditions of the guardianship/conservatorshi In addition to asking about terms and conditions, providers should request to see a certified copy of the court

order appointing the guardian/conservator. Alternatively, they can seek to access the court order through the circuit court in which the guardianship/conservatorship was petitioned. Although documents related to a guardianship/conservatorship proceeding are not considered public records, the protected person and her/his attorney may inspect or copy the file and others may petition the court for permission to inspect/copy the file. Upon good cause shown, the court/mental hygiene commissioner may grant another party this permission.

Providers need information about the terms and conditions of a guardianship/conservatorship before making a decision to release that client's information to a guardian/conservator. They also must consider whether they need the permission of the guardian/conservator to release information to other providers or to provide specific services to the client (e.g., non-acute medical care, intake services, mental health counseling and transportation). If providers have questions about confidentiality in these cases, they or their agencies can seek legal advice. (See *Sexual Violence 101. Confidentiality.*)

Questions to consider:

1. What has your overall experience been in interacting with clients with disabilities who have a guardian/conservator, and more specifically, with sexual assault victims with disabilities who have a guardian/conservator?
2. Does your agency have any policies/procedures that guide your interactions with clients and their guardian/conservator?
3. What are the challenges of working with clients who have a guardian/conservator? Is meeting a client's self-identified needs problematic? How does the involvement of the guardian/conservator impact service delivery?

These questions can be considered by individual readers and/or discussed among agency employees and with representatives from partnering agencies.

Test Your Knowledge

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

1. According to the WV Guardianship and Conservatorship Act, what is a protected person? What is a guardian? What is a conservator? *See pages C7.2–C7.3.*
2. What are the responsibilities of a guardian and a conservator? *See page C7.3.*
3. Are guardians/conservators compensated for carrying out their appointed duties? *See page C7.3.*
4. Who is qualified to serve as a guardian or conservator? *See pages C7.3– C7.4.*
5. In what situations is DHHR appointed to serve as guardian and the county sheriff appointed to serve as conservator for a protected person? *See page C7.4.*
6. Who may file a petition to request the appointment of a guardian and/or conservator? Where is the petition filed? Is there a fee for filing the petition? *See page C7.4.*
7. What information does a petitioner need to provide about the potentially protected person? *See page C7.5.*
8. What does the court seek to determine during the initial hearing? *See pages C7.5–C7.6.*

9. What are some examples of how service providers can collaborate with clients with disabilities and their guardians/conservators to meet the clients' self-identified needs? *See pages C7.6–C7.7.*

10. What should providers do if they suspect abuse or neglect of a protected person by their guardian/conservator? If they suspect a crime has been committed against a protected person by their guardian/conservator? If they think a protected person is in imminent danger? If they suspect a guardian/conservator is not acting in a protected person's best interest? *See page C7.8.*

11. How do service providers determine if a client's information is confidential when a client is a protected person and has a guardian/conservator? *See pages C7.8–C7.9.*

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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.

[2]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 are often referred to as female.

[3]Note that some legal terms used in the state law on guardianship and conservatorship—"mental impairment" for example (*West Virginia Code, Chapter* 44A. 1-4 or *WVC§44A-1-4*)—may seem outdated. (See *Disabilities 101. Person First Language.*) We use this term here solely to reflect the definition of a potential "protected person" under the law.

[4]See *West Virginia Code, Chapter 44A (WVC§44A), West Virginia Guardianship and Conservatorship Act,* http://www.legis.state.wv.us/WVCODE/Code.cfm?chap=44A&art=1. 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. WV Department of Health and Human Resources, Social services manual, guardianship services, was also referred to during this module's development.

[5]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.

[6]The definitions are drawn from *WVC§44A-1-4*.

[7]"Habilitation needs" in this context means the person's needs related to being able to function in society.

[8]West Virginia guardian and conservator handbook, A guide for court-appointed guardians and conservators, 2.

[9]*WVC§44A-1-8(k)*: A conservator shall not be appointed when the protected person's total assets are worth less than two thousand dollars or the protected person's income is: (1) from the Social Security Administration and a representative payee has been appointed to act in the best interest of the individual; (2) from Medicaid and the only income distributed to the individual is the personal account allotment; or (3) less than 50 dollars per month or 600 dollars per year. In these instances, the guardian, representative payee or health care facility, if there is no other person or entity, shall manage the personal care account or assets.

[10]*West Virginia guardian and conservator handbook, A guide for court-appointed guardians and conservators,* 2.

[11]WV Department of Health and Human Resources, 1.

[12]WV Department of Health and Human Resources, 1.

[13]Last two lines in paragraph, Appalachian Legal Aid, *Guardianship/conservatorship:What do I need to know* (Charleston, WV), http://www.wvlegalservices.org/guardcon.pdf.

[14]*WVC§44A-1-8(b).*

[15]Appalachian Legal Aid.

[16]*West Virginia guardian and conservator handbook,* 4. The fee was $110 as of the 2010 writing of this module. If a guardian/conservator is appointed by the court, filing fees may be reimbursed to the individual who filed from the protected person's estate, if funds are available.

[17]*West Virginia guardian and conservator handbook,* 20. The court, for good cause shown, may grant leave to file the petition without an evaluation report. However, it must order that the appropriate assessment and a report be prepared and filed.

[18]*West Virginia guardian and conservator handbook,* 20.

[19]*Guardianship/conservatorship:What do I need to know.*

[20]Paragraph from *Guardianship/conservatorship:What do I need to know*.

[21]*Guardianship/conservatorship:What do I need to know.*

[22]*WVC§44A-1-9*.

[23]*Unless the conservator is a bank or trust company.West Virginia guardian and conservator handbook,* 10.

[24]*West Virginia guardian and conservator handbook,* 10–11, as drawn from WVC§44A-1-9. In making the determination about the amount of a bond, the court considers: the value of the estate, annual income and other receipts that are within the conservator's control; the extent to which the estate has been deposited under an arrangement that requires a court order for removal; whether an order has been entered that waives the requirement that accountings be filed or that the accountings be presented less frequently than once a year; the extent to which income and receipts are paid directly to a facility responsible for the protected person's care and protection; the extent to which the income and receipts are from state or federal programs that require periodic accountings; whether a guardian has been appointed, and if so, whether the guardian has presented reports as required, and whether the conservator was appointed pursuant to a nomination which requested that bond be waived.

[25]Above two paragraphs from *Guardianship/conservatorship:What do I need to know.*

[26]*WVC§44A-1-10* and *West Virginia guardian and conservator handbook,* 6 and 10.

[27]Paragraph from Washington State Department of Social and Health Services, *Guardianship basics—Frequently asked questions,* http://www.aasa.dshs.wa.gov/pubinfo/legal/guardianship.htm.