

**Disability Awareness Brief:**  
***DISABILITY COMPETENCY FOR PROVIDERS\****

**June, 2015**

*Note: This is one in a series of six Disability Awareness Briefs: Introduction to Disability Awareness, Disability Competency for Providers, Disability Competency for Care Management Practitioners, Cultural Competency, Accessibility, and Universal Design. This Brief on Disability Competency for Providers should be considered together with the other five documents in order to have the comprehensive, basic information needed to inclusively address the unique health care needs of individuals with disabilities.*

**WHAT IS DISABILITY COMPETENCY?**

Individuals with disabilities are a diverse group of people who share the experience of living with mobility, sensory, mental health, and cognitive limitations or differences that affect their functioning. As a result, they often experience barriers to health care and full participation in their communities. (See Introductory Brief for more complete definition).

Disability Competency is the ability to provide person-centered and appropriate treatment, services, supports and related accommodations to individuals with disabilities while ensuring that the individual's goals, values, interests and preferences inform the design and delivery of care. Disability-competent care recognizes each individual as a whole person, not a diagnosis or condition, and focuses on providing treatment, services and supports that maximize health, function and independence.<sup>1</sup> Disability-competent care also is consistent with the Universalization Principle, which focuses on the value of every individual person and the respect owed to a person that is essential to human dignity.<sup>2</sup>

Examples of Disability Competency include promoting integrated, accessible care; comfortably and respectfully communicating with individuals with disabilities and their families; understanding the values, interests and needs of individuals with disabilities;

\* This document can be made available in alternative formats (e.g., Braille, larger print, audiotape, other languages). Please contact the Vermont Agency of Human Services Central Office at (802) 871-3008.

honoring the individual's central role in all care planning and delivery; encouraging self-advocacy skills of individuals with disabilities and families; and acknowledging the core values of disability culture, including the emphasis on interdependence as well as independence.<sup>3,4</sup>

Also inherent in person-centered disability-competent care is the concept of “dignity of risk”, which honors and respects an individual's choices to take some risk in engaging in life experiences, even if those choices are not recommended by a health care professional (e.g., choosing to live at home instead of in a supervised setting; electing to forego psychotropic medications that have significant side effects).<sup>5,6</sup>

*Note: The issue of communication is divided between two Briefs. This Brief focuses on respectful communication, while the Brief on Accessibility addresses the use of auxiliary, assistive devices and other communication accommodations to support access to services and information.*

#### **WHY IS IT IMPORTANT THAT PROVIDERS HAVE DISABILITY COMPETENCY?**

Individuals with disabilities often experience barriers to preventive and quality health care services, which can lead to poor health status, delayed treatment of chronic illnesses, and failure to prevent secondary conditions or health problems related to a disability. Expanding providers' knowledge about disability and how to interact with individuals who have disabilities is essential to the provision of quality health care.

For example, research indicates that individuals with disabilities may be disproportionately affected by excess weight or obesity; increased risk for diabetes, hypertension, substance abuse, injury, depression, and stress; and receive less frequent preventative screenings compared to individuals without disabilities.<sup>7</sup> Adults with disabilities who do not partake in physical exercise are 50% more likely to have certain chronic diseases; however, less than half of adults with disabilities who visit a doctor are counseled about the benefits of physical exercise even though they are significantly more likely to be physically active if their doctor recommends it.<sup>8</sup> In addition, the stigma of mental health disorders and a lack of proper training in dealing with episodic behaviors prevent some health care professionals from properly treating individuals manifesting mental health problems.

Furthermore, many individuals with disabilities may have low incomes and / or lack easy access to grocery stores or pharmacies which can impact their ability to maintain good nutrition or obtain necessary medications. Lack of access to accessible transportation

also can impact their ability to attend scheduled appointments, Likewise, appropriate options or funding for needed medical services may not be available. Understanding these potential barriers and providing flexible options to address them are important to the provision of effective care for individuals with disabilities.

Unfortunately, most providers receive little training on respectful interaction with individuals with disabilities, disability culture, or the issues that affect disabled individuals and their unique health circumstances. While education and awareness is increasing in some medical communities, including those in Vermont, disability competency is not required in most medical schools, internships or residency programs and it has not been identified as a federal priority for provider training funds. Without training and awareness, health care providers can hold incorrect assumptions and stereotypes about individuals with various disabilities, which can affect every aspect of care and result in inadequate and inappropriate care.<sup>9,10,11</sup>

The State of Vermont is committed to the use of respectful language when referring to people with disabilities, as evidenced by the 2011 Agency of Human Services Report to the Legislature on the Respectful Language Study, and the subsequent passage of Act 096 of 2014 regarding the use of respectful language in the Vermont Statutes.<sup>12,13</sup> In addition, the Vermont Secretary of State recently issued a guide to disability etiquette for communicating with individuals with disabilities.<sup>14</sup>

Please note that these Briefs use the term “provider” to reflect the variety of professionals and staff that are involved in the provision of care, services and supports for individuals with disabilities. This includes, but is not limited to, medical professionals, other clinicians and health care providers, home and community service providers, medical supply providers, and administrative staff within these settings.

In addition, these Briefs were developed with the recognition that there is a wide diversity of provider familiarity regarding their content; as such, the Briefs include basic information that already may be known and / or practiced by some providers. However, because these are foundational documents intended to be used for the development of more targeted educational and training materials, their content is inclusive rather than exclusive.

### **INDICATORS OF DISABILITY COMPETENCY: <sup>15</sup>**

Following are examples of disability competency:

### **ORGANIZATIONAL CHARACTERISTICS:**

- Awareness and sensitivity training for all staff on interacting with individuals with diverse disabilities.
- Awareness and training for staff on how disability may affect the provision of medical treatment for primary and other care.
- Identifying a provider within the organization who is disability-competent and designating that person to provide ongoing oversight and coaching to the organization's providers and other staff.
- Developing a list of disability-competent sub-specialists and other providers that are experienced in serving individuals with disabilities (e.g., by gathering information from individuals with disabilities who are served by the organization) and keeping it in a centrally accessible place.
- Partnering with peer support and disability service organizations.

### **PROVIDER KNOWLEDGE:**

- Subject Matter Expertise:
  - Understanding and practicing person-centered care by honoring and respecting the individual's choices, including a choice to take some risks in engaging in life experiences (i.e., the concept of "dignity of risk").
  - Familiarity with the core values of disability culture, including the emphasis on interdependence as well as independence.
  - Understanding individuals' potential concerns about loss of privacy that comes with accessing treatment and services.
  - Understanding of the developmental stages regarding identity as an individual with a disability in order to have insight into the individual's possible perceptions and struggles.
  - Understanding that individuals with disabilities can lead long, healthy, productive lives.
  - Understanding and being aware of the effects of disability on family and social relationships and functioning.
  - Familiarity with primary disabling conditions and associated medical conditions.
  - Awareness of the potential for earlier onset of common chronic conditions by individuals with disabilities.
  - Recognizing the need for expertise in symptom management related to individuals with disabilities (e.g., an individual with a disability that limits movement may need a different approach to pain management, shortness of breath, or constipation).

- Recognizing that physical problems can be obscured by, or overlooked because of, an individual's mental health condition.
  - Recognizing that mental health conditions can be obscured by physical symptoms or the individual's reluctance to acknowledge them.
  - Understanding the variety of ways that mental illness affects access to medical care.
  - Awareness of the range of treatment options for mental health conditions.
  - Familiarity with legal requirements applicable to health care, including the Americans with Disabilities Act.
  - Knowledge of requirements regarding mandated reporting of abuse; and that the rate of sexual, physical and emotional abuse is higher for individuals with disabilities.
  - Awareness of community resources available to individuals with disabilities and their families, including peer counseling, mutual support groups, independent living services and supports, advocacy organizations, and recreational services.
  - Knowledge of specialized insurance programs for which the individual or family might be eligible (e.g. Medicaid Katie Beckett program).
  - Knowledge of the medical standards to access other public benefit programs and having the skills to write effective medical letters of support.
- Understanding of Common Barriers to Effective Service Provision and Engagement:
    - Recognizing one's own comfort level when working with individuals with disabilities. (If a provider does not believe he or she can appropriately treat, serve or support an individual because of lack of knowledge or biases due to assumptions, emotions or values, a referral may be the best practice.)
    - Understanding the importance of treating individuals with disabilities with respect and dignity.
    - Recognizing the individual as an important source of information.
    - Awareness to treat family members, caregivers, and personal assistants with appreciation and respect, and avoidance of stereotypes of family members as being "saints" or "amazing."
    - Recognizing that individuals with a disability are potentially employed, contributing to their community, a competent parent, an independent individual, and knowledgeable about self-care.
    - Appreciating the importance individuals with disabilities place on preserving function, maintaining their lifestyles, and maximizing independence.

- Recognizing that individuals with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
- Recognizing that individuals with disabilities can and should be physically active.
- Appreciating the sexuality and reproductive health of individuals with disabilities.
- Understanding that many individuals, including those with disabilities, have stronger receptive (understanding) communication skills than expressive skills.
- Appreciating the need to advocate for resources for individuals with disabilities, including having to demonstrate medical necessity for medical services and equipment in requests to insurers, and having to potentially complete multiple layers of documentation in order to obtain funding for services and supports.

#### **PROVIDER SKILLS/BEHAVIORS:**

##### **For all individuals who have a disability:**

- Attitudes, Etiquette and Communication:
  - Treating the individual with dignity and respect.
  - Showing warmth and a positive regard.
  - Calling the individual by his or her first name only when you're extending this familiarity to everyone present, or conversely, retaining the use of titles if that formality is extended to others.
  - Focusing on the individual's abilities rather than disabilities.
  - Using "People First" language that emphasizes the individual not the disability (e.g., "individual with a disability" rather than "disabled individual"), and not referring to the person as their disability (e.g., "person with quadriplegia" rather than "the quadriplegic").
  - Avoiding words that describe disability as a negative experience (e.g., do not say "suffering from", "afflicted with", or "victim of").
  - Avoiding talking to an adult as if he/she were a child.
  - Talking directly to the individual rather than to someone who accompanies him/her, and managing discussions to ensure the individual's participation when a caregiver or family member is involved.
  - Offering assistance to an individual with a disability if it appears it might be helpful, but waiting until the offer is accepted before helping.
  - Listening to any instructions the individual may want to give about the best way to provide assistance.

- Unless a communication barrier is obvious, not assuming one exists unless the individual, a family member or other caregiver tells you about the barrier.
- If a communication barrier is identified, inquiring about how best to communicate, with the recognition that communication needs vary from individual to individual and from situation to situation.
- Providing Effective Care:
  - Asking the individual, their family members, or guardians for suggestions about what to keep in mind when providing services to the individual, noting the solutions in the individual's chart and plan of care, and anticipating those needs prior to the next visit.
  - Allowing additional time for appointments to ensure the ability to effectively communicate and exchange information.
  - Providing educational information to the individual about his or her disability, if needed.
  - Looking beyond an individual's disability and recognizing unrelated acute and chronic care issues and other non-medical factors that may impact his or her health and well-being.
  - Asking adults with disabilities how much physical activity they get each week, reminding them to get regular physical exercise consistent with their abilities, recommending physical activity options that match the specific abilities of each person, and connecting them to resources that can help them be physically active.
  - Partnering with the individual to ensure treatment or care recommendations are accessible, acceptable, and doable.
  - Referring individuals with disabilities to the full range of preventive, reproductive and sexual health care services and, when appropriate, mental health or substance abuse services.
  - Finding out about a specialist's experience or willingness to treat individuals with disabilities before making the referral.
  - Flagging indications of disability-related needs and accommodations in information when making a referral.
  - Completing necessary medical documentation for service or equipment requests in a thorough and timely manner.
  - Promoting and participating in interdisciplinary and collaborative practice, including routine communication with the individual's lead care manager and other care team members (if permission has been granted by the individual) to ensure adherence to care plans and follow up on referrals.

**For individuals who use wheelchairs or have mobility impairments:**

- Shaking hands even when the individual's hand is immobile.
- Sitting at eye level when conversing at length with an individual in a wheelchair.
- Respecting the individual's personal space, including wheelchairs and assistive devices.
- Enabling the individual to keep their crutches, canes, walkers or wheelchairs within reach, unless requested otherwise.
- Not touching, pushing, pulling or otherwise physically interacting with an individual's body or equipment (including wheelchair) unless requested to do so.
- If it is necessary to move an individual's mobility device, never doing so without asking first.
- Not patronizing individuals who use wheelchairs by patting them on the head or talking *about* them rather than *to* them.

**For individuals who are blind or have visual impairments:**

- When offering to assist someone with a vision impairment, allowing the individual to take your arm so that they are guided rather than being propelled or led.
- When greeting an individual with a severe loss of vision, always identifying yourself and others who may be with you.
- Speaking in a normal tone of voice, and letting it be known when the conversation is at an end.
- Announcing your presence and not leaving without letting the individual know.
- Indicating when you move from one place to another.
- Explaining procedures before beginning treatment, and asking if there are any questions.
- Communicating clearly about what is occurring during a physical exam.
- Indicating where to leave clothing and personal items in the exam room, and not moving these without letting the person know.

**For individuals who are Deaf or have a hearing loss:**

- Directly addressing the individual and not a companion or sign-language interpreter.
- Not talking to the individual from a distance or from another room.
- Looking at the individual while speaking and making sure she/he can see your mouth to allow for lip reading.



- Speaking in a normal tone of voice, avoiding exaggerating mouth movements and rapid talk.
- Facing the light source to facilitate lip reading.
- Keeping your hands and food away from your mouth when speaking, not chewing gum, and keeping mustaches and beards well-trimmed.
- Minimizing background noise.

**For individuals who have a speech impairment:**

- Being patient, and not completing sentences for or second-guessing the individual.
- Not pretending to understand what the individual is saying just to be polite, but rather asking them to repeat or write what they are trying to say.
- Allowing sufficient time for the individual to communicate verbally or via a word board or computer display, without pressure to hurry.

**For individuals who have an intellectual / developmental disability or cognitive impairment:**

- Assessing language skills to choose the level of language to use (i.e., talking with someone with a mild communication difficulty is very different than talking with an individual with a moderate or severe communication difficulty).
- Using alternate interviewing/discussion strategies, such as the use of yes/no questioning or visual aids (e.g., presenting information through pictures or simple visual cues).
- Using simple, concrete as opposed to abstract language (e.g., say “Are you upset? Are you sad? Are you happy?” instead of “What are you feeling?”).
- Checking the individual’s understanding of discussions or information provided.
- If needed, giving the individual the same information more than once in different ways.
- Asking the individual to repeat back (if able) in different words what was asked of them to ensure his or her understanding.
- If the individual’s comprehension is very limited, using pictures to ask questions and to convey important information.
- Not second-guessing the individual.
- If the environment is busy with many distractions, moving to a quieter location.
- Working within the individual’s attention span.
- Minimizing time in the waiting room.
- Scheduling several appointments to conduct exams or assessments to minimize the individual’s frustration if the exams / assessments are lengthy.

***For individuals who have a mental health disability:***

- Allowing extra time to perform a comprehensive mental health screening and to discuss underlying concerns.
- Looking beyond behavioral manifestations during a crisis in order to treat the underlying condition or address the triggering event.
- Implementing interventions that focus on improving patient function and well-being, rather than simply symptom reduction.
- Emphasizing recovery and self-management.
- Supporting the individual's medication management, their medication choices, and strategies to address medication side-effects.
- Including crisis planning in the plan of care.
- Using behavioral contracts to promote consensus with the individual regarding goals and plan of care.
- Identifying severity level of the individual's mental health problem in order to triage care.
- If needed, providing timely referral to specialty care to address the mental health disorder, and following-up to ensure that the individual accesses the referred services.
- Supporting an individual while they are awaiting access to specialty mental health services.

<sup>1</sup> *Disability-Competent Care Self-Assessment Tool*. Resources for Integrated Care, a collaboration between the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS), The Lewin Group, and the Institute for Healthcare Improvement; May 22, 2013. Available at:

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<sup>2</sup> *Introducing the Universalization Principle*. Smith OM: Children's Voice. March/April 2011.

Available at: <http://www.cwla.org/childrens-voice/>

<sup>3</sup> *Considering the culture of disability in cultural competence education*. Edey GE, Robey KL: *Academic Medicine*. 2005 Jul;80(7):706-12. Available at:

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<sup>4</sup> *Disability-Competent Care Self-Assessment Tool*. Resources for Integrated Care, a collaboration between the Medicare-Medicaid Coordination Office (MMCO) in the Centers for Medicare & Medicaid Services (CMS), The Lewin Group, and the Institute for Healthcare Improvement; May 22, 2013. Available at:

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<sup>5</sup> *ibid*

<sup>6</sup> *Person-Directed Strengths and Risk Inventory Tool*. New York Office for People with Developmental Disabilities: Albany, NY; 2014. Available at: <http://www.opwdd.ny.gov/node/5521>

<sup>7</sup> *State Strategies for Promoting Wellness and Healthy Lifestyles for People with Disabilities*. Association of State and Territorial Health Officials: Arlington, VA; 2013. Available at: <http://www.astho.org/Wellness-and-Healthy-Lifestyles-for-People-with-Disabilities-Issue-Brief/>.

<sup>8</sup> *Adults with Disabilities: Physical Activity is for Everyone*. Vital signs, Centers for Disease Control and Prevention: Atlanta, GA; May 6, 2014. Available at: <http://www.cdc.gov/vitalsigns/pdf/2014-05-vitalsigns.pdf>

<sup>9</sup> *Disability and Health: Information for Health Care Providers*. Centers for Disease Control and Prevention: Atlanta, GA; April 1, 2014. Available at: <http://www.cdc.gov/ncbddd/disabilityandhealth/hcp.html>

<sup>10</sup> *The Future of Disability in America*. Institute of Medicine. National Academies Press, Washington, DC; 2007. Available at: <https://www.iom.edu/Reports/2007/The-Future-of-Disability-in-America.aspx>

<sup>11</sup> *The Current State of Health Care for People with Disabilities*. National Council on Disabilities; 2009. Available at: <http://www.ncd.gov/publications/2009/Sept302009#Professional>.

<sup>12</sup> *Report to the House Committee on Government Operations House Committee on Human Services, Senate Committee on Government Operations, and Senate Committee on Health and Welfare on the Respectful Language Study*. Doug Racine, Secretary, Agency of Human Services: Williston, VT; December 1, 2011. Available at: <http://www.leg.state.vt.us/reports/2011ExternalReports/273249.pdf>

<sup>13</sup> *No. 96. An act relating to respectful language in the Vermont Statutes Annotated*. Vermont General Assembly, March 21, 2014. Available at: <http://www.leg.state.vt.us/docs/2014/Acts/ACT096.pdf>

<sup>14</sup> *Disability Etiquette: A Guide to respectful Communication*. Condos J. Office of the Vermont Secretary of State: Montpelier, VT; August 2014. Available at: <https://www.sec.state.vt.us/media/601218/Disability-Etiquette-SOS-Brochure-Final-09-17-2014.pdf>

<sup>15</sup> This information was obtained from the following sources:

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