VERMONT

Vermont Health Care Innovation Project

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Disability Awareness Briefs:

*INTRODUCTION TO DISABILITY AWARENESS**

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OVERVIEW OF DISABILITY AWARENESS BRIEFS

The purpose of this Disability Awareness packet is to provide an overview of the essential information necessary for providers to deliver effective and quality care for individuals with disabilities. The packet contains the following six Disability Awareness Briefs:

- **Introduction to Disability Awareness**
- **Disability Competency for Providers**
- **Disability Competency for Care Management Practitioners**
- **Cultural Competency**
- **Accessibility**
- **Universal Design**

The Briefs are intended to serve as foundational documents for the development of more targeted materials for specific audiences and purposes (e.g., provider educational brochures, training modules). They provide basic information that will facilitate:

- A general understanding of health, wellness, and care issues for individuals with disabilities;
- Familiarity with provider practices that improve quality health care, services and supports; and methods to reduce communication, attitudinal and structural barriers*;*

* 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.

- Appreciation of the organizational capacities that can support best practices for providing care for individuals with disabilities;
- Awareness of key skills and behaviors necessary to promote good communication and rapport between providers and individuals with disabilities and to enhance provision of quality care; and
- Awareness of the supports, structures, systems, and values that an organization needs in order to support disability and culturally-competent care.

Each Brief focuses on a specific topic and, with the exception of the Brief on Disability Competency for Care Management Practitioners which contains some overlapping information, effort has been made to ensure that the information in each Brief is not redundant with that provided in one of the other five Briefs. However, the information in this Introduction and each of the five Awareness Briefs is inter-dependent. As such, **this Introduction and the five topical Briefs should be considered together in order to inclusively address the health care needs of individuals with disabilities.**

In addition, the information in these Briefs should serve as an introduction, but not as a substitute, for more in-depth education and experience necessary to become familiar with best practices in each area. Each Brief contains endnotes with links to key resources to facilitate more in-depth exploration of the content that is presented.

Please note that 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, the content is inclusive rather than exclusive.

WHAT IS DISABILITY?

The Americans with Disabilities Act[1] defines the term "disability" with respect to an individual as:

- a physical or mental impairment that substantially limits one or more major life activities of the individual –major life activities include, but are not limited to: caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working;

- a record of such an impairment; or
- being regarded as having such an impairment.[2]

Disability is a natural part of the living process. A disability is not something that a person “has,” but it is something that occurs when the person, their functional limitation or difference, and the environment interact. Health disparities and environmental factors (e.g., physical environment, culture, attitudes, economics, and policies that shape our life experiences) also affect an individual’s ability to obtain needed services and supports.[3,4,5]

Individuals with disabilities include children, adults of all ages, individuals with vision or hearing loss, as well as individuals with physical, mental health, developmental, or intellectual disabilities.[6,7] Not all disabilities are apparent; these types of disabilities are often referred to as “hidden” or “invisible” disabilities. Some examples include low vision, a seizure disorder, hearing loss, a cognitive disability, a brain injury, autism, a mental health disorder, or a health condition.[8]

Individuals with disabilities are often thought of as a similar group, but in fact each type of disability has unique characteristics that require specific strategies to ensure quality care and well-being. It is best practice to focus on a person’s strengths, talents, individuality and maximization of function rather than on a medical diagnosis or perception of a lack of ability. Furthermore, while there are disability-specific categories (e.g., mobility, sensory, mental health, cognitive), it is important to recognize that each individual’s experience of their disability is unique to that person, and their care must be approached differently based on the individual’s specific strengths, values, preferences and needs

Note: A number of different terms are used to refer to individuals with disabilities within the context of health care and services delivery (e.g., patient, client, consumer, member, recipients). Each of these terms can have different meanings and implications for various audiences, and it is clear that no single term is preferred by, and perhaps even acceptable to, everyone. As such, these Briefs use the term “individual” due to its universal meaning and applicability across all settings.

In addition, because family members often serve as a primary support for an individual with disabilities, they have been referenced throughout these Briefs. However, family members should only be included in activities related to the care of adults with disabilities when the adult has expressed the desire and has given permission for the family member’s involvement.

WHY IS DISABILITY AWARENESS IMPORTANT?

An estimated one in five Vermonters has a disability.[9] **As a group, individuals with disabilities fare far worse than their nondisabled counterparts across a broad range of health indicators and social determinants of health.**[10,11,12,13] They also experience significant barriers to health care when compared with individuals who do not have disabilities.[14,15]

Disability is now understood to be more than a physical, cognitive, or emotional condition. Effective care must address the full range of barriers, including environmental, architectural, logistical, societal, and cultural, that impact the health of disabled individuals as much as their biologic impairments. Disability competent care can help prevent unnecessary emergency-room visits, costly case mismanagement, and dangerous secondary medical conditions,[16] as well as support the individual's overall well-being and quality of life.

Individuals with disabilities frequently struggle to find providers who are sensitive to their needs.[17] Health care facilities or offices may not be accessible or have the equipment needed to serve individuals with disabilities. Also, individuals can be embarrassed because their disability requires them to obtain additional assistance from staff, requiring them to surrender some of their independence and privacy. Sometimes, staff may not know how to assist an individual with a disability, causing frustration for both the individual and the staff member. From the providers' perspective, limitations in the physical environment, such as the lack of appropriate equipment, may cause them to forgo procedures for individuals with disabilities that would otherwise be commonplace. As a result, individuals with disabilities may only pursue medical care for emergency or acute conditions,[18] or they may not access other services and supports that can increase their health and quality of life, including primary and preventive care.

Limited provider knowledge and understanding about disabilities and poor accessibility can pose significant barriers that prevent individuals with disabilities from receiving appropriate and effective treatment, services and supports.[19,20,21] Expanding providers' knowledge, improving communication between individuals and providers, and ensuring access to information and services are highly critical to the delivery of quality care to individuals with disabilities.

Implementation of the strategies presented in these Briefs will not be as effective without an organizational commitment to provide disability and culturally-competent care. Organizational governance, leadership, policies, procedures, structures and

resources all should reflect awareness of the needs of individuals with disabilities and support providers and staff to implement practices to meet those needs.[22]

OVERARCHING CONCEPTS ABOUT MEDICAL CARE AND DISABILITY AWARENESS [23]

- **Individuals with disabilities require the same quality of medical service and preventive care** as individuals without disabilities, but the former may be underserved and receive less than quality care.
- **Defining "health" as the absence of disability or chronic illness negatively affects individuals with disabilities.** Many lead active, fulfilling lives, which include employment, parenting, sexual relationships, and community involvement.
- While a disability doesn't necessarily imply illness, some disabilities may lower the threshold to secondary conditions. **Preventive care and early intervention can reduce complications.**
- **It is imperative to listen attentively to individuals with disabilities** in order to understand their background and functional needs, and avoid assumptions about disability.
- **Many individuals with disabilities have expertise** in living with their disabilities and managing any related health conditions. This expertise should be sought out and respected. Others, particularly newly disabled individuals, may need information, education and support to become active partners in managing their health and disability-related services.
- A **team approach** works best to accommodate complex medical and support needs and to provide care coordination across specialists and relevant organizations (e.g., schools, community providers, therapists, tc.).
- Barriers to receiving quality health care include **physical/architectural barriers, communication barriers, attitudinal barriers, environmental and transportation barriers, and social/economic barriers**. Understanding these barriers and obtaining accessibility training is helpful for both medical and support staff.

- **People with multiple disabilities or medical conditions, or both a physical disability and a mental health condition, often find it more difficult to navigate the health care system.** When people with mental health conditions act outside of the social norm, they may face additional barriers to obtaining health care services.

- The **Americans with Disabilities Act requires that medical facilities and care practitioners** provide access to health care services for individuals with disabilities. The law requires **reasonable accommodations,** (i.e., those that are **readily achievable** and do not present an **undue hardship** on the facility. It is important to know about and provide accommodations for all types of disabilities.

- **Advanced planning** by providers to ensure individuals' access to care can save time and improve the quality of care.

- **Health care providers should check accessibility** when referring individuals to diagnostic testing and specialty clinics.

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[1] The American with Disabilities Act (ADA) is a federal civil rights law passed in 1990 to eliminate discrimination against individuals with disabilities in employment, state and local government, public accommodations, commercial facilities, transportation and telecommunication. The Vermont Human Rights Commission is the state agency responsible for enforcing compliance with the ADA.

[2] *The Americans with Disabilities Act of 1990 and Revised ADA Regulations Implementing Title II and Title III.* United States Department of Justice; March 15, 2011. Available at: http://www.ada.gov/2010_regs.htm

[3] *International Classification of Functioning, Disability and Health.* World Health Organization. Geneva, Switzerland: World Health Organization; 2001.Available at: http://www.who.int/classifications/icf/en/

[4] *Individuals with Disabilities as an Unrecognized Health Disparity Population.* Gloria L. Krahn, PhD, MPH, Deborah Klein Walker, EdD, and Rosaly Correa-De-Araujo, MD, PhD. American Journal of Public Health, April 2015. Available at http://ajph.aphapublications.org/doi/full/10.2105/AJPH.2014.302182

[5] *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

[6] *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: https://www.resourcesforintegratedcare.com/sites/default/files/Disability-Competent%20Care%20Self%20Assessment%20Tool_508%20Compliant.pdf

[7] The US Department of Health and Human Services has established the following data standards for defining disability: deafness or serious difficulty in hearing (all ages); blindness or serious difficulty in seeing (all ages); serious difficulty in concentrating, remembering, or making decisions because of a physical, mental, or emotional condition (5 years or older); serious difficulty walking or climbing stairs (5 years or older); difficulty dressing or bathing (5 years or older); or difficulty doing errands alone (e.g., visiting a doctor's office or shopping) because of a physical, mental, or emotional condition (15 years or older). US Department of Health and Human Services. Final data collection standards for race, ethnicity, primary language, sex, and disability status required by section 4302 of the Affordable Care Act, October 31, 2011.
[8] *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
[9] *How many individuals have disabilities?* Centers for Disease Control and Prevention: Atlanta, GA. Available at: http://www.cdc.gov/ncbddd/documents/Disability%20tip%20sheet%20_PHPa_1.pdf
[10] *Closing the Gap: A National Blueprint to Improve the Health of Individuals with Mental Retardation: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation.* US Department of Health and Human Services. Rockville, MD: US Department of Health and Human Services; 2002. Available at: http://www.nichd.nih.gov/publications/pubs/closingthegap/Pages/index.aspx
[11] *The Surgeon General's Call to Action to Improve the Health and Wellness of Individuals with Disabilities.* US Department of Health and Human Services. Rockville, MD: US Department of Health and Human Services; 2005. Available at: http://www.ncbi.nlm.nih.gov/books/NBK44667/
[12] *World Report on Disability,* World Health Organization. Geneva, Switzerland; 2011. Available at: http://www.who.int/disabilities/world_report/2011/report.pdf.
[13] For example, adults with disabilities are 3 times more likely to have heart disease, stroke, diabetes, or cancer than adults without disabilities. http://www.cdc.gov/vitalsigns/disabilities/
[14] *CDC Grand Rounds: Public Health Practices to Include Individuals with Disabilities.* Centers for Disease Control and Prevention: Atlanta, GA; August 30, 2013. Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6234a3.htm?s_cid=mm6234a3_w
[15] *CDC Vital Signs: Adults with Disabilities*. Centers for Disease Control and Prevention: Atlanta, GA; May, 2014. Available at: http://www.cdc.gov/vitalsigns/disabilities/
[16] *A Training Curriculum on Improving Access and Quality of Care for Individuals with Disabilities.* World Institute on Disability, Berkeley, CA; 2011. Available at: http://wid.org/publications/access-to-medical-care-training-tools-for-health-care-providers-disabled-individuals-and-advocates-on-culturally-competent-care-and-compliance-with-disability-law/
[17] *ibid.*
[18] *Removing Barriers to Health Care.* North Carolina Office on Disability and Health: Chapel Hill, NC; 2007. Available at: http://fpg.unc.edu/sites/fpg.unc.edu/files/resources/other-resources/NCODH_RemovingBarriersToHealthCare.pdf
[19] *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
[20] *The Current State of Health Care for Individuals with Disabilities.* National Council on Disabilities; 2009. Available at: http://www.ncd.gov/publications/2009/Sept302009#Professional

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

[22] *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: https://www.resourcesforintegratedcare.com/sites/default/files/Disability-Competent%20Care%20Self%20Assessment%20Tool_508%20Compliant.pdf

[23] *A Training Curriculum on Improving Access and Quality of Care for Individuals with Disabilities.* World Institute on Disability. Berkeley, CA; 2011; pages 13-14. Available at: http://wid.org/publications/access-to-medical-care-training-tools-for-health-care-providers-disabled-individuals-and-advocates-on-culturally-competent-care-and-compliance-with-disability-law/

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