Disability Awareness Brief:

*DISABILITY COMPETENCY FOR CARE MANAGEMENT PRACTITIONERS**

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 Care Management Practitioners 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.[1] 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.[2]

Examples of Disability Competency include promoting integrated, accessible care;

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comfortably and respectfully communicating with individuals with disabilities and their families; understanding the values, interests and needs of individuals with disabilities; 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.[3,4]

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).[5,6]

WHAT IS INTEGRATED CARE MANAGEMENT? [7]

Integrated Care Management (ICM) is a person-centered, evidence-based model for the provision of active and responsive coordination and support for the individual and his or her care needs across providers, settings and time. The individual's preferences, values, and goals are the central drivers of care. ICM uses a collaborative partnership with the individual and the care team to address the interests and needs of the individual, not just one aspect of his or her condition. ICM is especially useful for individuals with disabilities who need multiple services and supports to address their disability-related needs, health conditions, and access to primary and preventive services.

One key element of the ICM model is the Care Management Practitioner who serves as the individual's primary point of contact across all of his or her primary, acute, medication, mental health, substance abuse, developmental, and long term care services and support needs. In addition, the Care Management Practitioner is responsible for assessment, planning, identification of service resources, service facilitation, and advocacy to meet an individual's needs, including at times of transition. It is essential that the practioner work with the individual to determine how much care coordination is helpful and how it can best be provided.

ICM is not a profession in itself, but an area of practice within one's profession. Care Management Practitioners can have a wide variety of education, training, and experience. As such, in this Brief the term "Care Management Practitioners" refers to any person whose core job responsibility is to perform the ICM roles described in this Brief, regardless of degree or job title. This can include but is not limited to graduate trained, licensed and/or certified professionals; direct care staff with on the job training

and experience; individuals such as nurses, social workers, therapists, addiction and mental health counselors; those working directly with elders and individuals with disabilities; community health workers; peer support specialists and recovery coaches; and staff whose job titles include case manager, care manager, care coordinator, service coordinator, etc.

Another key element of the ICM model is the Integrated Care Team (ICT) which is comprised of the individual, selected health care, service and support professionals, as well as chosen family members, advocates, or peer support providers. The Team shares collective responsibility for the development and execution of the individual's plan of care as well as the health and well-being of the individual. This requires health care professionals to collaborate across disciplines and care settings and engage in a meaningful partnership with the individual. This integrated, team-based care management for individuals is quite different from traditional case management, and requires a unique set of skills. As such, ICT members must be disability-competent and may need to develop new capabilities in person-directed care, interdisciplinary collaboration, and team-based care.

It also is important that health care practices and community organizations have leadership, workflows and clinical / service operations that promote the provision of integrated person and family-centered care.

WHY IS IT IMPORTANT THAT CARE MANAGEMENT PRACTITIONERS HAVE DISABILITY COMPETENCY?

Effective ICM requires that Care Management Practitioners who support individuals with disabilities have the knowledge and skills necessary to provide service coordination and support to people with diverse disabilities, social and economic backgrounds, and life experiences.

The effects of living with a disability reflect a complex interplay among individual, interpersonal, institutional, community, and societal factors. Many individuals with disabilities and their families require services from multiple providers and are looking for improved access to a continuum of services that will help maintain health and independence, while addressing changing personal, health and disability related needs and concerns. Yet in many health care and service delivery systems, health care treatment and support services for individuals with disabilities may be fragmented. In addition, youth and elders with disabilities many need different levels of support as they navigate the chasm between pediatric, adult, and aging services. Understanding the

unique needs, values and preferences of an individual with a disability and aligning social services and supports with health care delivery is critical to the individual's health and well-being.

INDICATORS OF DISABILITY COMPETENCY:

Following are examples of disability competency within care organizations that support ICM, and competencies (knowledge and skills/behaviors) for Care Management Practitioners that serve individuals with disabilities.

Note: These competencies are not meant to be comprehensive in that they do not reflect all competencies that are essential for the provision of ICM nor many of the basic or specialty competencies required by specific disciplines. Rather the intent of this Brief is to highlight competencies that are specifically related to the effective delivery of ICM for supporting individuals with disabilities.

ORGANIZATIONAL CHARACTERISTICS:

- A culture focused on providing population-based, whole-individual, person-centered care.
- Teaching and supporting whole health self-management and recovery approaches and self-directed service options.
- Organizational ability to determine the types of staff expertise needed to deliver ICM for individuals with disabilities.
- Organizational awareness of the complexity of home and community-based long term care services and supports.
- Advocating for and fostering the use of peer support approaches and peer support providers as a component of care delivery.
- Commitment to providing continuity of care/services and a stable, positive relationship with the individual's Care Management Practitioner.

KNOWLEDGE FOR SUPPORTING INDIVIDUALS WITH DISABILITIES:

- Familiarity with the information provided in the five other VHCIP Disability Awareness Briefs: Introduction, Disability Competency for Providers, Cultural Competency, Accessibility, and Universal Design.
- Knowledge of socio-economic indicators of health, including generational poverty, health literacy, etc. and their impact on overall health status and well-being.

- Knowledge of quality of life issues often associated with chronic conditions, disabilities or other functional limitations.
- Understanding of the concept of "dignity of risk" and its application in practice (i.e., the right of individuals to choose to take some risk in engaging in life experiences, even if that choice is not one recommended by a care professional.
- Familiarity with the specialized community services, community resource and advocacy networks, and peer support opportunities available to individuals with disabilities.
- Knowledge of eligibility requirements for accessing Vermont Medicaid specialized programs, services and supports for individuals with disabilities (e.g., Choices for Care, Community Rehabilitation and Treatment, services for children with Severe Emotional Disturbances, Developmental Disability Services, Traumatic Brain Injury Services).
- Knowledge of screening tools and assessments available to identify an individual's needs and strengths across primary, acute, medication, mental health, substance abuse, developmental, and long term care services and supports.
- Familiarity with entitlement programs such as Medicare and Medicaid, Veterans' Administration, SSD, SSI, and their eligibility requirements.
- Knowledge of the available social services that may benefit an individual's health and well-being, including housing, nutrition assistance, employment counseling and supports, transportation, language and literacy training, legal and financial services, and/or other supports that aid individuals with day-to-day living and optimal functioning.
- Knowledge of federal and state laws, policies and standards including but not limited to:
    - Americans with Disabilities Act of 1990
    - National Standards for Culturally and Linguistically Appropriate Services (CLAS) in Health and Health Care of 2013
    - Complaint and Grievance Procedures
    - Abuse and Critical Incident Reporting
    - Acceptable Use of Medicaid Funds
    - Specific Vermont Specialized Program Regulations and Guidelines (e.g., Services Funding Guidelines, Quality Guidelines, Self-Management Guidelines)

SKILLS AND BEHAVIORS OF CARE MANAGEMENT PRACTITIONERS FOR SUPPORTING INDIVIDUALS WITH DISABILITIES:

The following presents major domains of competency for Care Management Practitioners, descriptions of the domains, and examples of the unique skills and behaviors that exemplify each of the domains when supporting individuals with disabilities.

Person-Centered Care: *The ability to engage, communicate effectively with, and take direction from the individual in decisions affecting the design, delivery and evaluation of care management activities and service delivery, including honoring and respecting the individual's choices to take some risk in engaging in life experiences (i.e., the concept of "dignity of risk").*

Examples include:
- Seeing the individual as a whole person with hopes, values, preferences and strengths as well as limitations.
- Honoring self-determination, which is the basic right of all people to have as much control as they desire over the aspects in life that are important to them.
- Recognizing that the individual is not a passive recipient of care, but should create, direct and participate in their care plan and services to the fullest extent possible.
- Informing the individual and their family members of available self-directed service options and related supports.
- Using the individual's preferred mode of communication.
- Adapting communication to meet the individual's needs for receiving information, and reflecting back information to ensure that the individual has been accurately understood.
- Supporting the individual to understand the concept of "dignity of risk", to explore areas of possible risks in his or her life, and allow flexibility in negotiating risks based on their potential for harm vs. growth and improved quality of life.
- As appropriate, advocating within the care setting for the role of the individual and his or her chosen family members in care decisions.
- As appropriate, representing the point of view of individuals when they are unable to participate in discussions.
- Where applicable, including the person's legal guardian or agent in accordance with that individual's legal responsibility.
- Adhering to and respecting all policies regarding the rights, anonymity, and confidentiality of individuals with disabilities, and ensuring that they are fully informed of their rights and protections.

- Being careful when discussing sensitive or potentially stigmatized issues related to the individual's disabilities.

Screenings and Needs Assessment: *The ability to conduct or arrange for brief, evidence-based and disability specific screenings and assessments in a timely manner and to conduct or arrange for more detailed assessments when indicated.*

Examples include:
- Detecting signs of abuse, neglect, domestic violence, and other trauma in individuals across the lifespan.
- Assuring that evidence-based and developmentally appropriate screenings occur, as indicated (e.g., screens for cognitive impairment, common mental health problems, behaviors that compromise health, risk related to self-harm or harm to others, impairments in functional self-care, abuse, neglect and domestic violence).
- Assisting the individual in obtaining relevant assessments in order to develop an appropriate care plan and/or to access Medicaid specialized service programs.
- Following up as needed to ensure in-depth assessments are conducted for more specialized needs (e.g., severe and persistent mental illness, long-term care).
- Ensuring that the assessment process occurs whenever a significant change occurs that alters the services and supports needed or their availability.

Care Planning: *The ability to utilize information from assessments and from the individual and their family members to develop a comprehensive care plan that includes all of the individual's needs, goals, and interventions to address them.*

Examples include:
- Creating integrated care plans in consultation with the individual, family members, other providers, and other people identified by the individual as part of the care team.
- Ensuring the individual's short and long-term goals and preferences are addressed in care planning.
- Utilizing information from the needs assessments across primary, acute, mental health, substance abuse, developmental, medication and long term care service and support settings to develop a comprehensive integrated care plan.
- Incorporating the individual's culture, language and disability-related needs in care planning to identify effective social services and supports.
- Identifying the individual's informal support systems/networks in relation to functional and safety needs, and inclusion in the care plan as appropriate.

- Addressing the challenges, risks, and rewards inherent in the individual's choices and working with the individual to define the risks that are real and tolerable to be included in the care plan.

Integrated Care Coordination: *The ability to ensure that an individual's care is integrated across all settings; that needed information is routinely exchanged among individuals, family members, and providers; and that relevant parties are informed of changes in an individual's health, functional or situational status to ensure responsive and high quality services.*

Examples include:
- Coordinating the individual's care across primary, acute, mental health, substance abuse, developmental, medication, and long term care service and support settings by referring, educating, negotiating, and mediating with the individual and formal and informal providers in order to meet care plan goals.
- Linking multiple health care providers and community services to meet the individual's needs.
- Creating and convening person-centered interdisciplinary care teams for individuals with complex needs as necessary to ensure the individuals' needs are met.
- Explaining to the individual and family the roles and responsibilities of each team member and how they will work together to provide services and support to the individual in meeting his or her care plan goals.
- Educating members of the team about the individual's characteristics, healthcare needs, health behaviors, disability-specific needs and views toward illness and treatment due to cultural influences or personal preferences.
- Linking the individual and family members with resources, including but not limited to specialty health care, rehabilitation and social services, peer support, legal and advocacy services, financial assistance, and transportation; and following up to ensure that effective connections have been made.
- Maintaining working relationships with the individual's primary care provider and other team members, especially in situations where the individual is mainly served by a specialist.

Routine Support for and Collaboration with the Individual Receiving Services:
The ability to serve as the individual's single point of contact across all of his/her service and support needs, and to provide on-going information and assistance to individuals to ensure they have the supports necessary to maintain well-being.

Examples include:

- Serving as the individual's single point of contact across his or her primary, acute, mental health, substance abuse, developmental, medication, and long term care service and support needs.
- Maintaining regular contact with the individual, his or her caregivers and service providers.
- Understanding the individual's living environment to assure basic necessities are available (e.g., food, heat, running water) and to identify need for accommodations (e.g., inaccessible entrance, bathroom or sleeping area).
- Understanding the nature of the individual's family and social support system and other socio-economic resources that have an impact on his or her health and well-being.
- Ensuring the individual has accessible information about his or her health care conditions, prevention, available treatments, self-management, peer support and recovery (where appropriate).
- Ensuring that all services are adapted to the individual's language, cultural norms, and personal preferences, and that accommodations (physical, cognitive, cultural, and other) are in place to support active participation in care planning, receipt of quality services and positive health and social outcomes.
- Ensuring the individual receives services in the least restrictive and most appropriate setting in accordance with their needs and preferences.
- Recognizing self-neglecting behaviors and offer intervention, when such behaviors jeopardize the person's wellbeing; this may include a referral to Vermont Adult Protective Services.
- Monitoring the delivery of formal and informal services and supports to ensure that services are being provided as planned, the individual's identified needs are being met, and that his or her goals are being pursued.

Support During Care Transitions: *The ability to work across multiple settings in times of individual crisis, change in health status, change in age, or change in socio-economic factors (e.g., housing, financial resources, informal supports) to support a seamless and effective outcome for the individual.*

Examples include:

- For facility-based transitions, contacting facility case managers/discharge planners to assist with the transition in care and follow up after discharge to ensure that all aspects of the plan of care are in place and the individual's ongoing needs are met.

- Managing non-facility-based transitions (e.g., changes in health status or socio-economic factors) through home visits to ensure the individual's medication, living skills, social supports, and functional and behavioral health needs are addressed.
- Supporting the individual in transition planning and in accessing needed services as he or she transitions across age-specific service delivery systems (e.g., from pediatric to adult care, and from adult to elder care).

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[1] *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.

[2] *Introducing the Universalization Principle.* Smith OM: Children's Voice. March/April 2011. Available at: http://www.cwla.org/childrens-voice/

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[5] *ibid*

[6] *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

[7] The information in the remaining sections of this Brief was obtained or adapted from the following sources:

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  Healthcare Improvement; May 22, 2013. Available at:
  https://www.resourcesforintegratedcare.com/sites/default/files/Disability-
  Competent%20Care%20Self%20Assessment%20Tool_508%20Compliant.pdf

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