



Disability-Competent Care Self-Assessment Tool

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Purpose

The Disability-Competent Care Self-Assessment Tool (DCCAT) is designed to assist health plans and health systems in evaluating their ability to meet the needs of adults with disabilities or functional limitations. Health plans and health systems can use the DCCAT to help them identify strategic opportunities for improving their disability competency. This tool primarily focuses on meeting the needs of persons with functional limitations, however, disability-competent care (DCC) is applicable to all individuals with disabilities because its intent is to remove barriers to timely health care.

Serving Persons with Functional Limitations

Health plan and health system processes and procedures are often designed to meet the needs of the general population, which may result in difficulties meeting the needs of persons with disabilities. People with disabilities are a diverse group, including children, adults of all ages, and people with vision or hearing loss, and their limitations may be the result of physical, mental health, developmental, or intellectual disabilities. Consequently, persons with disabilities are more likely to experience difficulties or delays in receiving care. They often experience unfavorable outcomes and are less likely to receive recommended care and health screenings (e.g., for breast cancer, colorectal cancer, or diabetes).¹ Health plans and health systems may need to provide extra support to providers to ensure they can adequately meet the needs of persons with disabilities.

Disability-Competent Care

Rather than focusing on a diagnosis — such as spinal cord injury, multiple sclerosis, or mental illness — DCC focuses on providing care and supports for maximum function and addressing the barriers to integrated, accessible care. Meeting the needs of this population requires special attention to an individual's expectations of independence and autonomy, as well as his or her participation in work, school, and community or social activities.

Disability-competent care focuses on providing care and support for maximum function while preventing or eliminating barriers to integrated, accessible care.

The DCC model requires health care professionals to collaborate across disciplines and care settings and engage in a meaningful partnership with the participant. DCC is participant-centered and focused on achieving and supporting maximum function. To achieve this aim, health care professionals may need to develop new capabilities in teamwork, interdisciplinary collaboration, and participant-directed care.

The interdisciplinary team (IDT) supports this initiative by maintaining health, wellness, and life as the participant chooses in the community. The IDT focuses on reducing avoidable illnesses through

¹ Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress: Social Risk Factors and Performance under Medicare's Value Based Purchasing Programs. Retrieved from <https://aspe.hhs.gov/pdf-report/report-congress-social-risk-factors-and-performance-under-medicare-value-based-purchasing-programs>

prevention and providing timely access to medical care, equipment, and home and community supports. Therefore, the IDT is structured to respond to the participant's physical and clinical needs while also considering their emotional, social, intellectual, and spiritual needs.

Core Values of the DCC Model

Applying the DCC model requires an understanding and appreciation of the three core values, which are supported by seven functional area pillars.

- A. **Participant-centered approach** recognizes the participant's, preferences, goals and choices that provide the foundation for his or her individualized plan of care (IPC).
- B. **Respect for the participant's choice** and the dignity of risk, which honors and respects the participant's choices even if they are inconsistent with health care recommendations.
- C. **Elimination of medical or institutional bias** that may interfere with addressing the individual's choices, unique abilities, limitations, and preferences for social and community participation.

Seven Pillars of the DCC Model

Applying the DCC model requires an understanding of the model's seven pillars. Each DCC component represents a standalone pillar. Together, these pillars form the foundational structure of the DCC model.

- 1. **Understanding DCC and disabilities** within the population being served
- 2. Focusing on **participant engagement** and implementing participant-centered care
- 3. Ensuring participants have **access** at all phases of health care delivery and community participation
- 4. Developing and integrating responsive **primary care**
- 5. Identifying key **care coordination** needs across the full spectrum of services, including transitions and leveraging community supports
- 6. Establishing flexible **long-term services and supports (LTSS)** so participants have the resources needed to function in the community
- 7. Integrating **behavioral health** services to ensure participants receive the full continuum of coordinated care

How to Use the Tool

This self-assessment is designed to facilitate a candid analysis of current practices and processes within the organization. Establishing DCC within a health plan or health system may impact the entire organization – from direct care delivery to business operations. As such, all key areas in the organization should be represented in the completion of the Tool.

Individuals working in the health plan or health system will be asked to evaluate each element, as described below. The accompanying *Evaluation Results Form* will help summarize results and identify strengths and prioritize opportunities for improvement. Guidance on how to use the DCCAT and the *Evaluation Results Form* can be found in the *DCCAT User Guide*.

Pillar 1: Understanding DCC and Living with a Disability

The DCC model focuses on the individual needs of the participant, respecting the participant's choices, and eliminating medical and institutional bias when providing care. DCC is a participant-centered model, delivered by an interdisciplinary team (IDT), focusing on supporting individuals to achieve maximum function. The model intentionally places a high emphasis on the treatment of the participant as a whole person instead of solely focusing on the participant's disability (clinical diagnosis). This concept is integral throughout the DCC model and represents a key difference in both practice and application when compared to the medical model.

Understanding each participant's unique disability and its functional impact is a preliminary, but crucial, step in putting the DCC model to practice. The IDT aims to understand each participant's unique disabilities and their functional impact on the participant. DCC requires that providers and plans understand: the participant's experience of their disability; the clinical diagnosis of the disability; and the functional limitations that individuals with disability may experience.

1.1 Do staff understand the following core value of the DCC model: participant-centered care?

The DCC model requires identifying and honoring the participant's preferences, goals and choices as these provide the foundation for the participant's IPC. Staff should understand the importance of recognizing individual participants' needs and providing participant-centered care.

1.2 Do staff understand the following core value of the DCC model: participant choice?

Participant choice recognizes the importance of the dignity of risk, which entails honoring and respecting the participant's choices even if they are inconsistent with health care recommendations. Staff should understand the role dignity of risk plays in providing participant-centered care.

1.3 Do staff understand the following core value of the DCC model: elimination of medical or institutional bias?

Medical, institutional and individual biases often impede the ability of providers and plans to address the participant as a whole. Staff should recognize and work to eliminate these potential sources of bias when providing care.

1.4 Do staff understand the following basic tenet of the DCC model: team-based care?

The DCC model is delivered by an IDT, composed of proficiencies in primary care, nursing, social work, and behavioral health. Care coordination across this spectrum of services is key to providing team-based care for the participant.

1.5 Do staff understand the following basic tenet of the DCC model: focus on health?

The DCC model focuses on supporting individuals to achieve maximum function and acknowledging the preference of participants to live in the community as they choose.

1.6 Do staff understand the following basic tenet of the DCC model: viewing each participant as an individual?

The DCC model recognizes and treats each individual as a unique person, not just as a diagnosis or condition.

1.7 Do staff understand the following basic tenet of the DCC model: addressing the comprehensive needs of the participant?

The DCC model is designed to respond to the participant's physical and clinical needs while also considering their emotional, social, intellectual and spiritual desires.

1.8 Is there an organizational commitment to incorporate the lived experience of individuals with disabilities into the delivery of care?

Disability-competent organizations can incorporate the lived experience of participants by consulting consumer advisory boards and focus groups, conducting telephone surveys, and employing persons with disabilities throughout the organization.

1.9 Do staff conduct initial face-to-face assessments with all participants, and at least annually or upon significant change in status thereafter?

The best way to provide participant-centered care is to know the individual. Meeting the participant in person provides the opportunity to establish a relationship based on trust and respect. Staff should therefore strive to conduct an initial face-to-face assessment with all participants, preferably in their home environment. This allows the IDT to better inform the assessment results and care plan by understanding how the participant is functioning. Due to large numbers of new participants, many plans and providers utilize an initial screening process, the most common of which is a risk assessment, to prioritize those most in need of timely care. The participants demonstrating a high-level of need are prioritized for in-person assessments. See **Pillar 2** for additional information regarding assessment.

1.10 Does the assessment include a component to evaluate the participant's understanding and acceptance of their disability?

A participant's functional status is seldom stable; whether they have a new, evolving, or progressive disability. Therefore, it is important to evaluate the participant's understanding and acceptance of their disability to gauge their level of resiliency. The concept of resiliency refers to the ability to incorporate the changes that are occurring in an individual's life into their self-image. Higher resiliency will better enable the participant to accept and adapt to their disability status and to develop increasing self-awareness. An accurate measure of resilience allows the participant and care team to develop realistic and achievable goals.

1.11 Are the priorities, goals and choices of the participant identified and documented during the assessment?

The initial and all subsequent assessments provide an opportunity to engage the participant in a discussion of their priorities, goals and preferences. A participant may have difficulty identifying or asserting his or her preferences, so the IDT must consistently seek his or her perspective and preferences. If a participant's decision is inconsistent with the IDT's recommendation, the participant's choice should be respected while the IDT continues to educate and advocate for recommended options.

1.12 Is the IPC derived directly from the assessment, with the involvement and consent of the participant?

The assessment provides the information for the discussion and development of the IPC and subsequent service plans. An IPC should outline the goals and priorities identified with the participant during the assessment, and the care needed to accomplish those goals.

1.13 Does the assessment identify the barriers that interfere with accessing needed care?

Individuals with disabilities may face a variety of barriers that prevent them from accessing care. The participant's preferences, as well as their health care, living, working and social environments need to be considered to help them maneuver barriers to care. For example, if a participant needs to undergo a mammogram, the participant should be referred to a provider with accessible equipment for the screening.

Pillar 2: Participant Engagement

Participant engagement requires a person-centered approach to care and an understanding of their individual experience living with a disability. Participant-centered care is based on the recognition that the participant is the primary source for defining care goals and needs, rather than a passive recipient of medical care. This requires cultivating a relationship with the participant, seeing them as a unique person with hopes and preferences, and recognizing the participant generally knows how to best use available resources. Inherent in participant-centered care planning is the concept of the dignity of risk, which honors and respects the participant's choices even if they are inconsistent with the recommendation(s) of the interdisciplinary team (IDT). It requires an understanding of the concept of self-direction and the roles of care partners, guardians, representative payee and other support and advocacy representatives in the planning of care.

Participant engagement requires actively listening to the participant's stories and experiences, properly assessing and reviewing the complete history of the participant, documenting this information, and relating all necessary information to necessary parties.

- **Participant Engagement:** The participant's choices, preferences, and goals provide a foundation for his or her individualized plan of care (IPC). A relationship based on trust and respect between the participant and his or her care team is necessary to ensure decisions remain participant-centered.
- **Assessment:** The initial and regularly revised assessment of the participant's care needs and goals is an interactive process, with the outcome being a comprehensive IPC.
- **Individualized Plan of Care:** The IPC is the guiding document that identifies all the care, services, and supports for each participant. It is a living document, referenced and revised over time, depending on the needs and goals of the participant.
- **Care Partners:** Persons with disabilities are often in need of support services from relatives, partners, friends, and community members. Care partners reflect this partnership. It is important to inquire and attend to the needs of the participant and their primary care partners to help maintain healthy and supportive relationships.

Participant Engagement

The participant's choices, preferences, and goals provide a foundation for his or her IPC. A relationship based on trust and respect between the participant and his or her care team is necessary to ensure decisions remain participant-centered.

2.1 Do participants play an active role in their own assessment and care planning?

Participants who are actively engaged in the care planning process are more likely to assume responsibility for their health and health care. To encourage participants to take an active role, the IDT should gather meaningful participant input throughout the process. Participants commonly need to be oriented to the care planning process, and provided support or coaching as needed. This support may be provided by a member of the IDT, peer coaches or other individuals who are familiar with the assessment and care planning process.

2.2 Does the care management staff develop an individualized, professional relationship with the participant, showing respect for the participant's preferences and choices?

Developing a trust-based relationship is necessary in a participant-centered approach to care and can promote the participant's self-advocacy skills. Such a relationship requires a discussion of the participant's goals, values, and preferences for their care, ideally through a face-to-face interaction. A preliminary "get to know you" meeting can help establish a relationship so that the subsequent meeting can focus on the full assessment and care plan development.

2.3 Does the IDT know and appreciate the participant's personal, social and health history?

Understanding the participant's personal background (e.g. cultural, religious, and educational) as well as their health history is key to fully understanding their perspective and needs. The IDT should actively listen to participants and seek to understand their personal stories, experiences, and health history.

2.4 Are participants (and identified family and/or friends) involved in care planning and implementation to promote a participant-centered focus?

Health plans and systems that provide DCC have multiple ways to engage participants in the care planning and to seek their views and ideas.

Assessment

The initial and regularly revised assessment of the participant's care needs and goals is an interactive process, resulting in a comprehensive IPC.

2.5 Is a health risk assessment completed upon first contact with the participant?

Health risk assessments (HRAs) provide the IDT with a sense of issues and any urgent risks to address. Many IDTs use these tools to prioritize the scheduling of initial comprehensive assessments and assignment of teams with specific competencies.

2.6 Is the initial assessment conducted face-to-face?

Disability-competent organizations have found that a key lever to establishing a trusting and respectful relationship between the participant and his or her IDT is having the opportunity to meet in person. It is especially important to conduct the initial assessment face-to-face to help establish the relationship.

2.7 Does the participant have the option of including other individuals (family and/or friends) in the assessment process?

Participants may wish to include other individuals such as family members, caregivers, friends, community supports, or other health and wellness professionals such as therapists, fitness coaches and massage therapists. Participants should be aware of the opportunity to include other individuals in the assessment process.

2.8 Are at least a portion of the initial assessment and the periodic reassessments conducted in the participant's living environment?

Meeting in the participant's living environment often helps the participant feel safe, comfortable, and in control. This also provides the IDT an opportunity to see first-hand how the participant lives, to understand and assess their level of function within the home environment, and to identify opportunities to increase independence and safety in daily functioning. Some participants may opt to initially meet their IDT outside their home. In this case, the IDT should work to gain the trust of the participant so they can be welcomed into the participant's home in the future to see how he or she functions in that environment.

2.9 Are the initial assessments attended, or reviewed by all members of the core IDT?

The core staff composition of the IDT should be a primary care provider (PCP), nurse, social worker, and behavioral health professional. Some health plans also view the participant as a member of the IDT. It is important for all members of the participant's IDT to be involved in the assessments and reassessments, for each discipline brings a different set of skills and knowledge. While not all IDT members may conduct the assessment in person, they need to be involved in the IDT team review and discussion upon completion.

2.10 Do initial assessments include input from a rehabilitation professional?

If the participant has functional limitations, he or she should receive a rehabilitation assessment to identify individual rehabilitation needs. This should be conducted during the initial assessment as well as during reassessments if the participant's needs or function change.

2.11 Does the IDT annually assess how well each participant understands his or her rights and consumer protections?

As the IDT becomes familiar with the participant, it is important to assess the participant's understanding of consumer protections and their ability to express their rights. This is commonly conducted as part of the reassessment. Consumer protections and rights that the participant should be aware of include privacy, dignity, respect, independence; freedom from abuse, neglect, exploitation, coercion, and restraint; and other human and legal rights.

2.12 Is the initial assessment comprehensive and multidimensional, incorporating all aspects of the participant's life?

The initial assessment should cover all areas of the participant's life, including, but not limited to, the following:

- Participant strengths, goals, and priorities
- Demographic, contact, financial, and eligibility information
- Level of education attained, and employment/volunteer status
- Social activities and community participation
- Functional abilities (activities of daily living [ADL], instrumental activities of daily living [IADL], physical therapy and occupational therapy assessments)
- Medical diagnoses
- Utilization history
- Health-related services (including behavioral management, exercises, medications, equipment, skilled nursing, rehabilitation therapies, long term services and supports [LTSS]) and all current providers
- Behavioral health screening
- Communication needs
- Access needs (language, comprehension and disability-related modifications)
- Nutrition (food access, preparation, diet, etc.)
- Home and community environment, safety, accessibility, and health risks
- Formal, informal, and social supports
- Review of other assessments, with the permission of the participant

2.13 Does the assessment process identify additional expertise needed for the participant's IDT?

To provide comprehensive care, the IDT must incorporate the expertise of other clinicians or care providers as needed. This may include rehabilitation therapists, behavioral health providers, dietitians, peers, or specialists (such as palliative care providers). The assessment should help to identify the need for these additional care providers and whether their support is required on an ongoing or consulting basis.

2.14 Are the IDT staff prepared to assess the participant's capacity to express and assert their needs?

Some participants will be very clear about what they need and want, while others may be unable to express these needs. The IDT must be able to identify strategies to compensate accordingly. If necessary, the IDT should encourage participants to involve care partners or to receive training to optimally identify and advocate for their needs and preferences.

Individualized Plan of Care

The IPC is the guiding document that identifies all the care, services, and supports for each participant. It is a living document, referenced and revised over time, depending on the needs and goals of the participant.

2.15 Are the participant's life and care goals, action steps to meet those goals, and proposed interventions documented in the IPC?

IDT members need to be prepared to guide participants in identifying their personal goals, including their medical, social, and other goals. The IDT should then document these goals in the participant's IPC, along with the action steps and interventions necessary to achieve those goals.

2.16 Does the IPC contain specific documentation on what care and support services are to be provided, by whom, and when?

Accountability and timeframes for support services should be built into the IPC. This includes documenting the type of support services that are needed, as well as who will be providing those services and when they should be provided.

2.17 Does the IPC contain documentation of all formal care partners and supports needed?

The IPC should document all relevant partners and supports. This may include: primary and acute care, behavioral health services, rehabilitation therapists, home care, transportation, personal care, housing with support services, care requested/specified by specialist physicians, pre-employment training and employment supports, and other long-term support services.

2.18 Do IDT members ensure that participants understand and feel free to accept, negotiate, modify, or appeal components of, or changes to their IPC?

Staff should be trained to work with participants to address any concerns they have regarding their care. Disability-competent organizations provide their staff with coaching to be sensitive to any participant disagreement or resistance to care needs and goals specified in the IPC.

2.19 Are potential ethical conflicts formally reviewed to ensure participant independence and self-determination?

It is common for differing opinions and preferences to arise among the participant, IDT, and care providers around what is perceived as being 'in the best interest' of the participant. These differences can be more stark when participant choice and financial constraints are also considered. Disability-competent organizations should have policies and procedures (e.g., ethics committees) in place to review any differences and potential ethical conflicts.

2.20 Do participants and all members of the IDT have full access to the initial assessment, IPC and any subsequent changes or updates?

The initial assessment and the IPC need to be accessible so the participant and all authorized providers can reference them as needed. Ideally, the assessment and IPC should be available electronically to the participant and all authorized providers (including those providing after-hours care). A paper version can serve as a substitute, although this will make it more difficult to maintain updates and automated reminders.

2.21 Does the IPC identify any specific communication or care needs of the participant?

As the central care document, it is important for the IPC to clearly identify any communication or unique care needs of the participant. These may include, but are not limited to, needs related to the participant's hearing, seeing, learning, language, ethnic or cultural preferences, cognition, comprehension or memory.

2.22 Does the IPC include strategies to address any identified health risks?

A risk management plan is an integral component of the IPC, helping to guide the participant, their family members and care partners to reduce health risks. An assessment of the participant's living environment may help to identify any risks. The IPC should then document strategies to address any identified health risks, such as counseling to manage stress, or establishing a smoking cessation program, and assess the participant's readiness to address these risks.

2.23 Does the IPC include an emergency or crisis management plan?

A crisis management plan identifies what to do in the case of any form of crisis, such as a caregiver not showing up, a behavioral health issue, or a family crisis. The IPC should clearly document the crisis management plan for easy reference by the participant or authorized care providers.

Care Partners

Persons with disabilities are often in need of support services from relatives, partners, friends, and community members. Care partners reflect this partnership, and are commonly referred to as informal care supports. It is important to inquire and attend to the needs of the participant and their primary care partners to help maintain healthy and supportive relationships.

2.24 Does the IDT routinely inquire about whether the participant has, or wishes to have, an ongoing care partner?

The support of a care partner may help the participant increase their level of functioning and independence. The IDT should learn about who the participant views as their care partner. If a care partner has not already been identified, it may be helpful to discuss how the participant may find such an individual and the ways in which a care partner may be of assistance. For participants with complex care needs, cognitive limitations or even confusion, a care partner can accompany the participant to medical appointments, coach the participant to ask questions during the appointment, assist with following the IPC, and provide support while the participant is accessing care.

- 2.25 Is the IDT aware of what needs are being met through the participant's informal care partners, and what services are provided through more formal provisions of care by hired workers?

Relatives, partners, and friends often serve as informal care partners. Participants may benefit from the support of these informal care partners for a short-term, long-term, or indefinite period of time; or they may rely more on formal, paid care partners. The IDT should be aware of the types of services that the participant may be receiving, including whether they are receiving support primarily through informal or formal care partners.

- 2.26 Is there a means of communication established between the IDT and the identified care partner(s), if appropriate and desired?

Given the care partner's role in supporting the participant's care, it can be helpful to have an established method of communication between the care partner and the IDT. The presence of a care partner ought to be noted in the participant's IPC along with documentation regarding the nature and means for communication between the IDT and care partner.

- 2.27 Are care partners offered training to prepare them for their support role?

It is important to evaluate the care partner's ability and interest in serving in this particular role. If needed, training should be provided to individuals in the care partner role. While this type of training is often informal, it may include specific education regarding preventive strategies and identification of warning signs.

- 2.28 Are care partners noted as part of the medical record?

Including the participant's care partner in their medical record will enhance care coordination as these partners are often helpful sources of information and support. It is important that this information is routinely verified and updated in the medical record.

- 2.29 Are care partners a part of the participant's IPC?

The participant may designate informal care partners to be involved in IDT-related communications and assessments. Care partners are helpful sources of information on the participant's day-to-day physical and mental status, and are commonly able to help ascertain the participant's functional, mental, and emotional capacities and needs. Care partners who are not local may need to be included in the decision-making process and should be incorporated as appropriate.

- 2.30 Do IDT staff regularly consult the participant regarding options to share protected health care information with specific care partners?

It is crucial to obtain the participant's permission prior to sharing health information with family and non-family care partners. The participant should be informed of their options regarding the sharing of their protected health information and they should specify what information may be shared with their care partners.

- 2.31 Are IDT staff trained to watch for, and report, problematic care partner relationships, such as abuse, neglect, and exploitation?

IDT staff should be able to identify potentially problematic interactions and relationships between the participant and his or her care partner. Staff should also be knowledgeable and comfortable with respectfully addressing concerns with the participant and others as appropriate.

- 2.32 Are staff aware of respite care resources and, when appropriate, do they share the information with the participant and their care partners?

Respite care is the planned provision of a short period of rest or relief for care partners who routinely provide supportive services to a participant. It may help the care partner avoid burnout and continue providing services for a longer period of time, enabling the participant to remain in a less restrictive care setting. Respite care may be provided by paid home health aides or personal care assistants in the home, or the participant may temporarily receive care in a setting outside of their primary residence. IDT staff should be aware of options for respite care, and inform the participant and care partners of these options when appropriate.

Pillar 3: Access

Persons with disabilities must be able to access care and supports. Access competency requires recognizing the barriers and complexities of living with disabilities, learning from participants, and paying attention to details.

Barriers include negative attitudes or stereotypes held by key providers; practice procedures that hinder the proper provision of care; inadequate physical and medical equipment access; poor communication; and insufficient navigation and coordination within the provider system. Removing barriers will enable participants and providers alike to realize desired health outcome(s) and quality of life.

Attitudinal Access

Attitudinal barriers to care include stereotypical perceptions and biases toward individuals with disabilities.

- 3.1 Are key providers aware of and prepared to address internalized biases and attitudes towards persons with disabilities across their staff and in their own practices?

Attitudinal access requires providers to see the participant as a fully capable adult with age-related hopes, dreams and aspirations. However, key providers may find attitudinal issues difficult to identify and address as they are generally culturally based and engrained, and may include speaking “down” to participants, or making assumptions about them. The interdisciplinary team (IDT) and other key providers, such as specialists and community-based providers, should actively seek to identify their own biases towards individuals with disabilities and work towards addressing them in their practice.

Process Modifications

Procedural access issues include scheduling and appointment duration. Organizations and staff understand that planning ahead can provide access to care by removing disruptions, long wait times, and delays.

3.2 Does the IDT seek or confirm access needs prior to appointments?

Identifying the participant's access needs prior to their appointment will allow the IDT to make any necessary process modifications in advance. When scheduling appointments, the IDT should ask participants to identify any specific access needs for the appointment, keeping in mind that the participant's needs may vary from day-to-day, based on their current health status and other changes.

3.3 Is there a place in the participant's EHR (electronic health record) to document modification needs?

Documenting the participant's access needs in the EHR will allow the IDT to easily reference them and arrange for necessary modifications in advance of the participant's appointments. This information should be documented in a consistent location and routinely updated.

3.4 Are there procedures in place to ensure this information is referenced and addressed before and during each appointment?

Referencing any documented access needs in advance of each appointment and addressing these needs during the appointment will allow staff to conduct the visit more efficiently and make the appointment more comfortable for the participant. While procedures for reviewing any access needs may be common in a health plan or primary care clinic, coordinators and referral agents need to ensure this information is also communicated when a participant uses an external provider.

Physical Access

Physical access includes overall accessibility, building access, and equipment and medical access. Disability-Competent Care involves ensuring the participant can access the setting - to get to, into, and use the provider office.

3.5 Is the building location accessible?

The care setting should be housed in an environment that is accessible to all participants. This includes ensuring that elements such as parking lots, paths of travel, and building entrances are easily accessible or include necessary modifications. This is best achieved by completing a physical access survey of providers' offices by trained surveyors. Such surveys include, but are not limited to: directional signage, accessible pathways, parking, building exterior and interior, office reception areas, restroom, exam rooms, exam tables and scales and other medical equipment.

3.6 Is the setting accessible?

Many practices are located in large health care settings or office buildings. Modifications should be made to ensure the participant can maneuver within the setting to access the

provider office. This may require an assessment of elevators, pathways, signage, and other potential access issues that may pose barriers to participants when trying to access the provider office.

3.7 Is the provider office accessible?

Primary care practices and other health care providers should have accessible offices, which includes a reception area with space for a wheelchair user, a reception window or desk at wheelchair height, and accessible hallways and restrooms.

3.8 Is the equipment used for the participant's care accessible?

Accessible medical equipment such as scales, exam tables and lift equipment should be available to provide comprehensive care for participants with functional limitations. If resources are limited, one exam room can be designated as disability-competent, instead of updating all exam rooms with appropriate equipment. Disability-competent organizations should assess and document the availability of accessible equipment at sites of care that can be used by participants with disabilities.

3.9 Are alternative sites identified and available if a primary care provider's equipment is not accessible?

Providers commonly refer a participant to an alternative site of care for accessible equipment if this is not available in the primary care office, such as a wheelchair scale. This requires a network of ancillary providers who have the equipment necessary to accommodate the needs of participants with disabilities.

Communication Access

Communication access modifications include auditory, visual, comprehension and expression, and memory. This requires assessing cognitive and intellectual capabilities and those with limited language proficiency in receiving, understanding and using health information.

3.10 Are practices in place to identify, document, and meet participants' communication needs?

Participant communication needs should be identified and documented to ensure availability of any necessary modifications. Longer appointment times may be necessary when working with participants with intellectual, speech or hearing disabilities. Additionally, the following may be required to meet a participant's needs:

- Methods for remote communication (telephone, text or email) for making or confirming appointments, sharing test results, and other needs
- Assistance completing forms
- Sign language interpretation
- Language interpreters
- Oral interpretation, such as lip and tactile reading
- Assistive listening devices
- Computer-assisted real-time transcript

- Reader devices
- Letter, picture, or translator boards
- Printed materials in alternative formats, such as electronic audio, pictures or large print approaches

3.11 Are the participant's communication needs documented and routinely updated in the participant's health record?

All staff should have quick access to information regarding the communication needs of the participant. This information is commonly included on an opening page of health records. It is important to routinely verify and update this information to ensure its accuracy.

3.12 Are printed materials available in alternative formats?

Printed materials should be available in alternative formats and offered to participants if needed. Alternative formats include:

- Audio recording
- Braille
- Large print
- Electronic text/CD/flash drive/e-mail provided in advance if necessary

3.13 Is important information available in alternative formats upon request?

To meet a participant's communication needs, the following information should be available in alternative formats:

- Contracts, benefits, rights, informed consent, permission for treatment
- Provider directory
- Medication information (dose, instructions for administration, side effects, food or drug interactions)
- Admission, discharge procedures and reports
- Follow-up care instructions, treatment, therapies, other recovery directions
- Health education information

3.14 Are options offered for remote communication with the participant?

To facilitate remote communication, disability-competent organizations should offer some of the following options:

- Email
- Text messaging
- Speech-to-speech telephone
- Use or relay services (i.e. TTY, video relay service)

- Online provider portal

Programmatic Access

Programmatic barriers to care include aspects of how the provider's office operates and the availability of physician and allied health professional expertise regarding the provision of health care.

3.15 Is there an IDT staff member designated to support the participant in accessing the social and financial services and support they require?

Program access refers to informing and supporting the participant in accessing needed social and financial services and support, such as transportation services and food stamps, housing, and legal advocacy. This is commonly done by the long term services and supports (LTSS) specialist or social worker on the IDT, who has access to the following information:

- What services are available
- Who provides the service
- How to obtain authorization for the service
- How to arrange for the service
- How to access the service

Pillar 4: Primary Care

Delivering DCC in a primary care setting is a collaborative effort. It involves a participant-centered approach and primary care as part of the interdisciplinary team (IDT). Particularly for participants with disabilities, primary care involves maintaining health, preventing or managing common secondary complications, preventing avoidable hospitalizations, and establishing transition protocols to mitigate difficult changes.

Delivery of Care

The timeliness of primary care is often the key factor in reducing emergency department and inpatient utilization and costs. A key to capturing this opportunity is the availability of primary care and the communication between the primary care provider and the IDT.

4.1 Is there a standard practice of providing all participants with an annual primary care visit?

The standard of care for this population is a minimum of an annual primary care visit. The primary care visit should include, but is not limited to, the following:

- Health and physical examination
- Medication review
- Care Plan review
- Review of recent history and identification of prevention strategies for the future

- Discussion of advance directives

- 4.2 Is a primary care provider who has access to the participant's current medical information (e.g. electronic health record [EHR]) available for consultation and intervention 24 hours a day?

DCC requires the availability of a primary care provider to respond to newly emerging episodes of care to capture preventable emergency room use or inpatient admissions. The provider should have access to the participant's EHR so they can diagnosis and initiate treatment, and connect with the participant's IDT. Some disability-competent organizations have opted to hire or contract with primary care providers who agree to make home visits and take calls from participants.

- 4.3 Are participants specifically coached as to when and how they ought to access their primary care provider?

Disability-competent organizations encourage participants to call their primary care provider upon first indication of a health problem or illness so that plans can be made to ensure the appropriate level of care. Participants should be educated about when it would be appropriate to contact their primary care provider and how they can contact the provider in such instances.

- 4.4 Do all primary care practices have access on site, or through timely and accessible referral, to diagnostic tests, including x-ray and laboratory testing, either in-house or through referral?

Participants should have timely access to diagnostic tests. If accessible diagnostic tests are not available onsite, primary care providers should have easy access to a list of preferred disability-competent ancillary providers to whom they can refer the participant.

- 4.5 Do all primary practices have procedures in place to provide for the access and process needs of persons with disabilities?

Persons with disabilities often present with functional and cognitive limitations that require alternative processes and systems to meet their needs. Primary care practices serving persons with disabilities should have specialized office-based practice procedures such as longer appointments, additional time for dressing/undressing, and additional time for communication.

- 4.6 Are all staff in the primary care practice trained in specialized procedures and practices to meet the needs of persons with disabilities?

Providing adequate primary care services starts with the scheduling of the appointment and continues through the appointment checkout. Therefore, all staff involved with the participant should be trained to support the needs of the participants they serve.

- 4.7 Are primary care providers' schedules flexible enough to provide same-day episodic care assessment and clinical management?

Providers' schedules should include enough flexibility to allow them to address newly emerging episodes when needed. Disability-competent organizations commonly augment

clinic-based primary care provider services by having nurse practitioners available for home visits or consultations. This approach is optimal assuming the participant is able to obtain transportation.

- 4.8 Are there alternative means to providing care if primary care is not available or accessible, due to transportation, in a timely manner?

Primary care providers can meet this need through a variety of approaches. A common alternative is having a skilled nurse make the home visit and consult with the primary care provider telephonically to assess the urgency of intervention. Alternatively, the health plan or primary care practice can have a nurse practitioner or another professionally licensed individual (able to diagnose and treat participants) available to make home visits.

- 4.9 If primary care is not co-located with the IDT, is there an established means of communication between the primary care physician and the rest of the IDT?

Ongoing communication among members of the IDT is essential for DCC and requires special attention when a participant engages external providers (such as a specialist or rehabilitation therapist) in addition to his or her IDT. Primary care and other members of the IDT should maintain regular means of communication to ensure sharing of assessment information and care management follow-up regarding treatment plans and referrals.

- 4.10 Are there strategies in place to ensure integration of primary care and behavioral health, as well as close collaboration between primary care, behavioral health, and long term services and supports (LTSS) providers?

Effective DCC requires integration of behavioral health with primary care and LTSS. Integration can take many forms such as co-location, integrated or full access to the EHR by behavioral health providers, or regular participation in care team meetings involving communication of urgent issues. Some disability-competent organizations contract with crisis intervention providers who can respond to participants with behavioral health needs at all times, including the provision of home-based services and emergency accessible transportation. This referral information should be documented in the health record for quick reference.

Preventive Care and Health Education

Health and wellness are important to people with disabilities. It is important not to assume secondary conditions such as physical decline, illness, pain, weight gain, or other conditions are inevitable when living with a disability.

- 4.11 Do primary care providers administer recommended vaccinations?

Persons with disabilities are at higher risk of acquiring preventable illnesses, such as pneumonia and influenza. Thus it is important that primary care providers ensure they receive the recommended vaccinations. Providers need to be especially vigilant regarding the provision of annual and other recommended vaccinations for persons with disabilities.

4.12 Do primary care providers follow clinical protocols for routine preventive care and the identification and treatment of key secondary conditions related to a participant's disability?

Disability-competent organizations should have clinical protocols for the identification and treatment of common secondary conditions related to living with a functional disability. Examples of such conditions include skin breakdown, urinary tract infections, upper respiratory infections, bowel impaction, and depression.

4.13 Do primary care providers have care guidelines to prevent secondary complications of disability?

Prevention of secondary complications is critical for DCC. At a minimum, care guidelines should be referenced for the following complications:

- Pressure ulcers
- Pneumonia
- Upper respiratory infections
- Urinary tract infections
- Stool impaction
- Shingles
- Hepatitis C
- Loss of bone density

These guidelines are in addition to standard guidelines based on age and chronic conditions.

4.14 Do primary care providers have guidance on how to tailor care protocols or interventions for the management of chronic conditions for people with disabilities?

Traditional protocols and practices for management of chronic conditions are applicable to this population, but must be tailored to each participant to factor in their other needs, medications, functional status, and available supports. Primary care providers should be educated on how to tailor protocols and practices in an appropriate manner.

4.15 Are participants and care partners (when appropriate) provided with health promotion and self-care direction and education specific to the participant?

Participants should be educated on strategies for health promotion and self-care, including the importance of physical activity, to help them manage their health. Towards this end, the IPC ought to include a health and wellness plan, which should include information on the following:

- Accessing primary care
- Routine health prevention services
- Management of conditions associated with existing disability and chronic conditions
- Prevention of secondary conditions of disability

- Participant and caregiver education for self-care for chronic conditions

4.16 Are participants receiving dental services as recommended?

Obtaining dental care and cleaning is often difficult for persons with disabilities due to access barriers, limited financial resources, and a need for professionals experienced in providing dental care to those with motoric and spasticity challenges. Lack of dental services can result in avoidable emergency room (ER) utilization and secondary conditions. It is therefore important to ensure participants are referred to accessible dental services. Disability-competent organizations should identify schools and community health centers that may provide dental services for persons with disabilities.

Screenings

Participants with disabilities have a higher risk of chronic conditions and illnesses, many of which are related to living with a disability. Health screenings are the gateway to health resources, including medical care, social support groups and health promotion interventions.

4.17 Are participants with mobility limitations screened for osteoporosis?

Persons with mobility limitations, especially women, are at greater risk for developing osteoporosis as they age. It is therefore important to ensure these participants receive proper screening.

4.18 Are all participants provided recommended cancer screenings?

Persons with disabilities are at the same risk for cancer as the non-disabled population, but persons with disabilities may receive delayed screenings which can result in further progression of the cancer before it is identified. Participants should receive routine cancer screenings. The IDT should ensure that facilities can accommodate a participant's unique physical, communication, and social barriers. Access barriers are especially important considerations for equipment intense interventions like mammograms, OBGYN visits and colonoscopies.

4.19 Are providers and facilities requesting necessary information from participants to enable them to prepare for the screening?

For persons with disabilities, many screening protocols are especially challenging due to preparation requirements and the need for additional supports. The IDT should address these issues when referrals are made. The IDT may choose to send a care partner with the participant to provide assistance during the screening (e.g. physical transfers).

4.20 Does the IDT have access to information regarding the accessibility of providers, offices and equipment needed to administer the screening?

Participants often require referrals to an alternative provider or care setting to receive screenings (e.g. cancer). To facilitate screenings for the participant, the IDT should be aware of which providers have the capability and the necessary equipment to administer accessible screenings

Pain Assessment and Management

Participants with disabilities report pain at rates greater than those without disabilities. Whether pain is a direct result of their disability or functional limitations or due to an acute situation, the pain needs to be assessed and treated appropriately.

- 4.21 Does the primary care provider (PCP) include an assessment of the participant's experience of pain during the initial and subsequent assessments?

It is important to assess each participant's experience of pain, and the impact of the pain on their functioning. Besides quantifying the level of pain (using the standard 10-point scale), it is just as important to understand the participant's perception of how it impacts all areas of their functioning, relationships and community participation.

- 4.22 If the presence of pain is identified, is there a specific care plan developed with the participant to treat and/or manage the pain?

If the participant is experiencing pain, the PCP should work with the participant to develop a plan to address the pain. Even if the pain is inconsistent, it is important to identify strategies with the participant to help them manage the pain when it arises.

- 4.23 Does the PCP have access to a pain specialist either through consult or referral if the initial effort to address the participant's pain is not successful?

It may be necessary to refer the participant to a pain specialist if the initial treatment plan did not manage the pain. Though most pain specialists have worked with persons with functional limitations, it is important to ensure the referred pain specialist has the necessary experience working with the specific disability of the participant. This is especially important when working with persons with communication limitations and intellectual and developmental disabilities.

Sexual Health

The topic of sexual activity is often avoided by providers when working with participants with disabilities. Individuals with disabilities have the same sexual needs and desires as the non-disabled, keeping in mind that some individuals meet these needs in unexpected ways. Additionally, providers need to be aware of the signs of sexual abuse and where to seek further information if needed.

- 4.24 Is there a section of the comprehensive assessment where the participant's sexual history is obtained?

As with the non-disabled population, it is important to obtain a sexual history to identify risks, educational needs and preventive services.

- 4.25 Are participants routinely screened for being at risk for a sexually transmitted disease, and provided testing if indicated?

Participants may be unaware of their risks for a sexually transmitted disease, and can benefit from an open and trust-based discussion. If routine screening identifies a need for further testing, the participant should be provided or referred to accessible testing.

4.26 Are staff prepared to provide the participants with sexual health information in a non-judgmental manner?

As with the non-disabled population, it is important for the provider to provide information on sexual health to the participant. This is commonly a sensitive subject for both the participant and the provider requiring a level of trust that may take time to develop.

Primary Care Network

Providing disability-competent primary care to participants may involve developing a network of external providers for primary care services. Identifying a disability champion among the physicians and office management may help to ensure that the needs of participants with disabilities are met throughout their interaction with the health system.

4.27 Does your organization assess the disability competency of primary care providers?

A first step in preparing to meet the needs of persons with disabilities is to assess the capacity, competency and engagement of your primary care providers to serve the population. Ensure staff understand what disability means, the different types of disability, and the issues of importance to participants with disabilities.

4.28 When involving external primary care practices, are there strategies to help them establish or strengthen their disability competency and awareness?

Disability-competent organizations may have a checklist of the physical access elements needed to provide care to those with a disability (e.g., ramps, scales, accessible entry points) as well as guidance for staff related to enhancing in-person and telephonic communication (for participants with speech, hearing, cognition or language disabilities), and scheduling strategies to manage participant appointments. Health plans and health systems often provide training for their external primary care practices related to routine and preventive care for persons with disabilities.

4.29 Is there a mechanism to track the performance of external primary care providers and share the information with the providers?

Performance measurement ensures quality for participants and the development of improvement efforts and best practices. Performance measurements for external primary care providers and practices can take shape through the use of reports focusing on outcomes of care as well as care planning functions such as timeliness, appropriateness, continuity of care, and medication management.

4.30 Do primary care practices have access to a network of medical sub-specialists who are experienced in providing care for people with disabilities?

A network of specialists is essential to providing comprehensive and coordinated care for people with disabilities. Maintain a list of preferred disability-competent sub-specialists and make it available online or in a centrally accessible record. Sub-specialists include, but are not limited to:

- Neurologist
- Physiatrist

- Dermatologist
- Infectious disease specialist
- Urologist
- Gastroenterologist
- Pain management specialist
- Behavioral health specialist (including psychiatry, mental health and substance dependency treatment specialists)

4.31 Is there a routinely updated directory of primary care practices?

Maintaining an up-to-date directory of primary care practices allows participants to make informed decisions regarding their source of care and support. Ideally, this directory should include information regarding the provider’s disability competency in relation to access and delivery of care.

4.32 Are the participant’s modification needs documented and routinely updated in the participant’s health record?

Recognize the modifications required by a participant to reduce barriers to access. This information is commonly the opening page or “face sheet” of the participant’s electronic medical record.

Pillar 5: Care Coordination

Following initial assessments and the development of the individualized plan of care (IPC) in collaboration with the participant, care coordination implements and manages the IPC and oversight of the participant’s health and well-being. Care coordination involves frequently monitoring the participant’s medical and psychosocial conditions, maintaining a relationship based on trust with the participant, and including the participant’s perspective in care planning.

Composition of Interdisciplinary Team (IDT)

The core care team is composed of staff with competencies in primary care delivery, nursing, behavioral health, and social work or community-based service supports.

5.1 Are the competencies of primary care, nursing, long term services and supports (LTSS) and behavioral health (as needed) represented on the IDT?

Ensure that the full complement of competencies are involved in the assessment process and available upon request and on an ongoing basis as needed.

5.2 Are all providers on the IDT trained and experienced in providing disability-competent care?

Members of the IDT need to be experienced, or willing to gain experience, working with persons with disabilities in order to understand the needs and preferences of participants. Extensive training programs for new staff are recommended to teach disability sensitivity, awareness, and competencies related to their specific area of practice. Ongoing training

should also be provided based on feedback from the participants and providers and outcomes data.

5.3 Is the participant’s primary language, and ethnic/cultural background considered in assigning specific members of the IDT?

While this is not always feasible, having IDT members with the knowledge and understanding of a participant’s cultural background facilitates communication and gives way to increased trust between participants and their IDT. Some providers hire community health workers or community resources for this purpose.

5.4 Do all IDT members understand their individual roles and responsibilities?

While the IDT collectively shares responsibility for the health and well-being of each participant and their IPC, each member of the IDT practices within their scope of competency, minimizing redundancy and utilizing support staff when appropriate. Clearly identifying roles and responsibilities ensures accountability in addressing the needs of participants.

5.5 Is one member of each participant’s IDT designated as the “lead”?

It is imperative that one team member have final responsibility and accountability for both the IDT and the IPC. Some disability-competent organizations choose to routinely have the team lead assigned to a specific role, such as the nurse, while others vary the lead based on the unique needs or preferences of the participant.

5.6 Are external health care professionals and specialists available to the IDT to address the specific needs of each participant?

Additional professionals may include sub-specialty providers, such as speech therapists, occupational therapists, physical therapists, durable medical equipment providers, nutritionists and pharmacists.

5.7 Is the participant able to designate a family member or a close friend to be involved in IDT-related communications?

When a participant specifies a family member or another person to be involved in IDT communications, this must be documented in the IPC and communicated to all IDT members to ensure consistent follow-through.

Communications within the IDT

Operating in close communication with participants and external providers, the IDT is responsible for ensuring that participants receive the care and support needed to achieve their goals and maximize their independence.

5.8 Does the IDT meet weekly or bi-weekly, at a minimum, to discuss relevant participant updates, new assessments, and reassessment reviews?

Utilize structured agendas to ensure productive use of team meeting time. Meetings can be in-person or virtual. While most participants are only discussed periodically, protocols should

be in place to ensure: 1) review of any participant in acute care and/or medically unstable state; 2) review of any participant in transition; 3) discussion of any participant change in health status; 4) review of new participants; and 5) routine, prescheduled reviews or assessments.

- 5.9 If a participant maintains a relationship with an external primary care provider, is there a designated IDT member who serves as the point of contact with the external provider?

Some participants may have a primary care provider who is not actively involved on the participant's IDT. If this is the case, designate a nurse or other member of the IDT to be responsible for communicating with the external primary care provider.

- 5.10 Is the IDT able to communicate, either in person or virtually, within one working day if the participant's needs or situation changes?

The timeframe of the response will vary depending on the urgency of the situation. The IDT staff should maintain flexibility on their daily schedules to be able to address emerging or newly developing concerns.

- 5.11 Is the assessment and IPC available to anyone providing after- hours coverage?

Information on each participant's IPC should be recorded in an electronic health record (EHR) or on paper.

- 5.12 Are participants specifically coached as to when and how to reach out for care management support?

As part of the initial and subsequent assessments and care planning process, review with the participant when and how to obtain care management support. For example, if the participant has a history of urinary tract infections, they should be trained to watch their urine output and call the care coordinator if urine appearance becomes abnormal.

IPC Implementation, Management, and Monitoring

Ongoing monitoring and review of the IPC is needed to ensure the plans are effective and being followed, that preventive strategies are in place, and that revisions are made based on the participant's changing needs.

- 5.13 Do IDT members identify the frequency and type of contact each participant wants and requires?

IDT members should take note of the contact preferences of participants. These encounters should be scheduled and entered into the EHR to provide IDT members with timely reminders for outreach and follow-ups.

- 5.14 Are IDT members alerted when a participant has a change in health status or care needs that affects the IPC?

Methods such as instant messaging should be used to alert IDT members to urgent issues, needs or changes in the care plan, IPC review dates, changes in medications, routine reviews, and utilization information.

- 5.15 Is the IDT provided with clear criteria for guidance as to when a change in a participant's health status or condition requires a change to their IPC?

The criteria may include hospitalizations or changes in living arrangements as well as newly emerging episodes of illness or change in function. Members of the IDT should know the process for incorporating a change in health status into a participant's IPC.

- 5.16 Is the IDT provided with timely reminders to guide their work with each participant as specified in the IPC?

Implement methods such as electronic reminders to alert IDT members of outstanding items in a participant's IPC that require attention.

Allocation of Care Management and Services

Participants need varying levels of care management support and assistance. The allocation methodology should be derived from the assessments and noted in the IPC.

- 5.17 Is there a process for determining the nature and amount of specific care management required by each participant?

Consider the following elements when assessing care management needs:

- Desire and ability to self-manage
- Behavioral health issues, including substance abuse and dependency
- Comprehension, including memory limitation and cognitive abilities
- Availability of home- and family-based supports
- History of inpatient (hospital, skilled nursing facility, behavioral health) and emergency department utilization
- Number of chronic conditions
- Risk for secondary complications of disability

- 5.18 Are participant expectations and preferences a routine part of the assessment process for determining the nature, amount and means of care management support provided by the IDT or other designated person(s)?

Discuss the frequency and nature of care management to be provided as part of the assessment process so that the participant's expectations are identified, discussed, and incorporated in the care plan. For example, a participant's preference for bi-weekly encounters should be incorporated into the plans for care management support.

- 5.19 Does the IDT review and discuss the participant's expectations in terms of care management during all reassessments to ensure he or she receives the level, nature, and timeliness of care management he or she desires and requires?

Encourage participants to communicate the care, supports, and services they feel are lacking and encourage participants to give feedback to the IDT on whether or not expectations are met.

Transitions

Transitions refers to a changes in the participant's life that can affect their care, including changes in care settings, providers, medications, financial, housing, legal, and employment status, and other changes that can affect the participant's ability to function in the community of their choice. All transitions require attentiveness by the IDT to identify and oversee the change and ensure the safety of the participant.

5.20 Is a transition plan developed and implemented for all significant participant changes (move to different county, change of care providers, etc.)?

Significant changes include all transitions that involve more than one component of the participant's ability to function. The IDT should ensure all care transitions are well documented and that all aspects of any transition, such as assistance with moving or home modifications are addressed.

5.21 Are there protocols to assist IDT members in managing key types of transitions?

Provide protocols for different types of transitions and use a checklist of actions required for all types of transitions or several checklists for different types of transitions.

5.22 Do all participant transitions have an IDT member identified as responsible for ensuring successful completion and timely follow-up?

Transitions generally involve many persons completing numerous steps. Therefore, it is important to assign one person to follow-up and ensure success of the transition. For example, if the transition involves changes in medications, an IDT member may be responsible for medication reconciliation or coaching the participant regarding signs and symptoms to bring to the attention of the IDT, while another schedules follow-up appointments, another arranges transportation, and another arranges for home-based care.

5.23 Does a significant change in the participant's functional capacity trigger consideration of a potential change in care and transition plan?

IDT staff should record and address any changes in a participant's functional capacity. A need to increase the type, amount, or location of care may necessitate the development of a transition plan.

5.24 Is the participant's current living situation re-evaluated prior to planning a long-term transition to a higher level of care?

The participant and support persons may see the loss of function as a need to transition to a higher level of care, without realizing that additional supports can be implemented without requiring a transition. Create a procedure to conduct a review of such situations through an individual or committee not involved with the participant or their IDT.

5.25 Are peer support and counseling services available to participants considering or undertaking a care transition process?

The IDT should make a list of resources available to the participant for peer support and other self-help or community supports. Examples include local centers for independent living and transitions counseling offices.

Tailoring Services and Supports

The IPC specifies the individualized services and supports that are reflective of the participant's preferences and services needed to achieve his or her goals and should be modified as appropriate.

5.26 Are traditional services/supports substituted with alternative services when appropriate, regardless of whether they are specifically defined as "covered services"?

Consider all alternatives and assess the long-term benefit of providing the service/support, participant preference, and cost-effectiveness. Examples include alternative transportation services, air conditioners, equipment loan programs, support groups, acupuncture, and moving services. Participants are often the best source of creative, cost-effective alternatives.

5.27 Is the IDT provided with clear guidelines to base their care authorizations?

A central part of the DCC model includes giving the IDT flexibility to modify the care or service based on the participant's needs. Disability-competent organizations provide their staff with specific criteria or guidelines to facilitate the care authorization process when the care is to be modified. Clear guidelines help to facilitate this process and can reduce wait times for needed care.

5.28 Does the IDT have the authority to modify the means of care delivery based on the unique context of the individual or a specific change in condition (either temporary or long-term)?

Allow the IDT to alter the scope, intensity, and frequency of care delivery, supports, and services when warranted. Resource allocation authorization is the responsibility of the IDT. The criteria used for service authorization should be explained to participants and relevant providers.

Health Record

A comprehensive health record is composed of many elements, including assessments, the IPC, medication lists, referrals and authorizations, care management notes, and other information important to the care and support of the participant.

5.29 Is all information (e.g., medical, medications, social, financial) for each participant documented, maintained, and updated within an EHR or, at a minimum, available via a paper document?

The participant's health record should be available via electronic means. If this is not possible, the health record should be available to the participant and all providers via paper, fax, or email. Access to this information by those providing 24/7 coverage is essential.

5.30 If an EHR is maintained, is it interoperable with EHRs of key providers involved in the participant's care?

An electronic or paper document should be shared with all providers involved in the participant's care. When possible, the EHR should incorporate the medical records, care management activities, and service plans, from all providers and settings engaged in the participant's care.

5.31 Does the participant have the ability to access key components of his or her health record?

At a minimum, the participant should be able to review key components of his or her health record during or after visits with a primary care provider or other IDT team member.

5.32 Is an IDT member or support person specifically identified to manage, update, and disseminate each participant's EHR assessment, IPC, and updates to appropriate providers as discussed with the participant?

This person is typically a clinical office-based team assistant or support person available during working hours to facilitate communications to ensure all involved providers are kept up to date.

5.33 Is there a means to quickly access, communicate, and disseminate key participant information, especially for anyone providing after-hours coverage?

Disability-competent organizations commonly provide key participant information in the participant's opening page of the EHR to ensure quick access and efficient communication of participant information.

5.34 Is utilization data from the EHR or claims routinely reviewed by the IDT to identify areas for clinical intervention and quality or process improvement?

It is very helpful to have real-time administrative data from emergency department visits and inpatient hospital admissions (including diagnostic information) to identify needs for transition management, potentially preventable admissions or conditions that are open to participant education. Additionally, real-time pharmaceutical data is useful to identify a change in condition, track adherence, and enhance medication reconciliation.

5.35 Is pertinent quality and utilization data routinely provided to external providers to identify opportunities for improvement?

Data on participant costs, emergency department visits, specialty referrals, behavioral health services, pharmaceuticals, and inpatient hospital admissions can be used to create management reports that serve as a source of feedback and opportunities to coach providers. Reports reflecting the provider's performance related to their participants provide an opportunity to identify promising practices and areas for improvement.

Medication Management

Persons with disabilities commonly take multiple medications. Comprehensive medication monitoring and management is of particular importance in this population.

- 5.36 Are all participant medications documented and reviewed at assessment, reassessment, upon transitions, and when there is a significant change in condition?

Most disability-competent organizations include a review of medications during all visits with each participant. Regular (monthly or more frequent) reports from the pharmacy are the best means of obtaining information for the purpose of medication management. Some programs routinely bring medication fill reports to all visits with a participant's primary care provider and specialists.

- 5.37 Is a consulting clinical pharmacist available to the IDT to assess and address potentially problematic prescribing?

Disability-competent organizations often develop criteria regarding when to engage clinical pharmacists. Some may decide to do this on an annual basis while others opt to engage them if the participant is on a defined number of medications (it is common for participants to be prescribed 10 to 15 medications from multiple physicians), or upon the use of anti-psychotics or opioids. The primary care provider on the IDT assumes responsibility for ensuring the medications are reviewed and managed.

- 5.38 Is the participant's primary care provider, if not a member of the IDT, informed when another provider orders a medication change or addition?

Disability-competent organizations typically build these notifications into care management software, along with regularly updated medication fill reports.

- 5.39 Are participants and their caregivers trained in medication administration, if needed?

The participant's ability to manage his or her medication regime should be assessed and the tools needed for self-management (such as medication cases or bubble-wrapped dosing) should be provided to both the participant and any care partners involved in supporting the participant's care. Participants must be informed of side effects and warning signs of each medication.

Advance Directives

Completing and honoring advance directives is an interactive process between the participant and his or her IDT. DCC requires the ability to discuss advance directives and end-of-life care issues with participants with respect, sensitivity, and awareness.

- 5.40 Are participants routinely asked to consider developing advance directives?

Most disability-competent organizations include a question or section regarding advance directives in the initial and recurring assessments. If the participant is interested in developing an advanced directive, it should become an element on the IPC.

- 5.41 Are staff trained in coaching participants on advance directives and end-of-life care decisions?

Disability-competent organizations can establish training for staff on how to effectively coach participants on advance directives and end-of-life care decisions, as well as on disability and cultural sensitivity, awareness, and respect.

5.42 Are participants offered counseling or assistance in completing their advance directives?

A member of the IDT who has a trusting relationship with the participant should offer counseling and assistance with completion of advance directives. Establishing trust in the process is important to ensure that the participant can voice concerns and incorporate their preferences into their advance directives.

5.43 Are all completed advance directives reviewed by the IDT and revisited at least annually with each participant?

Any changes in the participant's advance directive needs to be noted in their health record and accessible to those providing care.

Pillar 6: Flexible Long-Term Services and Supports

LTSS provide assistance for participants with disabilities to fully integrate and function in the community as they choose. There are three foundational domains of community living: 1) social connectedness and relationships, 2) meaningful activity, and 3) resources and settings to facilitate inclusion. Integrating LTSS into the participant's individualized plan of care (IPC) facilitates the transition from a traditional medical model to a person-centered model, while encouraging social connectivity, in accordance with personal preferences.

LTSS includes home health supports, transportation, personal care attendants, behavioral health, and nursing facility services. In addition to these paid services, it is important to appreciate and promote the use of informal community service options that may be low-fee or no-fee such as community education or recreation centers, health clubs, and religious activities.

LTSS Services, Capacity, and Network

A full range of available supports and community resources is required to fully meet the needs of participants with disabilities.

6.1 Are the needs and options of individual home and community-based supports identified as a part of the assessment and care planning process?

Respect for the participant's preferences, regarding all dimensions of community participation need to be explored as part of the assessment and care planning process.

6.2 Are participants able to maintain existing relationships with LTSS providers if desired?

Where situations arise that involve either a physical or environmental change, the participant's established providers should be incorporated into planning. Maintaining existing relationships with LTSS providers ensures coordination of care and information symmetry among providers.

6.3 Is there adequate network capacity to ensure the participant has access to the full range of needed LTSS?

It is possible that members of an interdisciplinary team (IDT) are not up to date on all available provider options and tend to use those with which they are most familiar. It is

important for the team to explore existing or new providers on an ongoing basis. This includes education and training of potential providers, the development of relationships with team members, and training to know how and when to best access community resources.

6.4 Is there capacity to develop specific services not readily available in the community that are needed for an individual's IPC?

If no known resources exist for a needed service component, IDT members are encouraged to advocate, influence or develop options with community providers/partners to meet the unmet service need.

Long-Term Services, Supported Living, and Personal Assistance

There are a range of support systems and services for participants with disabilities. The IDT is responsible for presenting the available options and working with the participant and external agencies to develop a support system that works best for the participant and their care goals.

6.5 Are assessments completed on the functional needs of all participants requiring community-based services and supports?

The provision of personal care assistant (PCA) services are based on functional assessments (such as activities of daily living [ADLs] and instrumental activities of daily living [IADLs]) and are specified in a care plan. The provider must be specifically trained in the care required on an individual basis, unless the participant is able to provide the training independently.

6.6 Are participants informed of and prepared to choose housing or supported living options, taking into consideration affordability, availability, physical accessibility, and preferences based on need?

There are situations where the combination of physical accessibility, affordability, and the ability to meet specific needs do not align. It is important that the participant is informed of all aspects in choosing the living/housing component and the availability of the other options. A participant may choose to forgo a service option (PCA flexibility in scheduling due to location) to obtain desired autonomy and privacy in a housing unit.

6.7 Do individualized assessments incorporate the values of the participant-centered approach, respect for the participant's choice, and elimination of medical or institutional bias?

As the IDT communicates with the participant and their self-identified supports, it is important to explicitly explore these core values, as many persons with disabilities do not know their options or that they can make these decisions.

6.8 Does the IDT help participants explore all possible options for living in the setting of their choice?

It is essential that the participant is informed of the options available for their input and prioritization. IDT members can take into account the preferences of participants to provide similar and feasible living arrangements.

- 6.9 Are participants given a choice of community supports and service providers (e.g., personal care assistance, home care, independent living center, adult day programs, behavior supports)?

Participant choice is integral to providing participant-centered care as it builds self-determination for the participant and establishes respect between the participant and providers. Provider agencies may offer a continuum of services which can be beneficial for continuity of care and communication among the individual service providers. Alternatively, a participant may want to choose a PCA from one agency but have their behavior support from another.

- 6.10 Are participants able to maintain access to established or preferred service providers if desired?

Various settings may have preferred providers of services and it is important that participants are informed and given a choice of alternative providers if desired.

- 6.11 Does the participant have a choice of providers and care settings?

The provision of choice is important to participant-centered care, however, participants should be informed that choosing a housing site may limit their control over other elements of their care, such as individual staff or scheduling of staff hours.

- 6.12 Is there a specified transition plan developed prior to a change in service or model of care, as well as between care settings?

As part of a transition, planning must include communication between current and future providers regarding care and support needs and strategies related to reducing health risks.

- 6.13 Is the participant's IPC, as related to home-based care, available to the community service providers (and other care partners, as appropriate) to direct the delivery of their care on a daily basis?

It is essential that the participant's care plan is available to service providers as indicated by the IDT and participant to ensure adequate coordination and provision of care.

- 6.14 Are participants informed of and given a choice between an agency model (where the agency is the employer of record and handles all human resources functions) and a self-directed model (where the participants assumes responsibility for those functions) for their home-based support(s), and informed of the advantages and limitations of each?

Participants commonly face trade-offs when choosing between the agency and self-directed models. Choices may be limited if a participant chooses to live in a supported living environment that provides services on a per diem or monthly basis.

- 6.15 Does the self-directed option allow participants to be responsible for hiring, firing, training, and supervising personal assistance workers?

Participants can choose as much responsibility as they want for staffing components and the degree of assistance they receive from a community-based organization (CBO) support planner. The self-directed option allows the participant to choose whether they want full

control to hire or fire personal assistance workers. If participants do not prefer the self-directed option, they can delegate such functions to another person or entity.

6.16 Is a fiscal intermediary or co-employment agency available to support the employer functions of the participant, if needed?

A fiscal intermediary or co-employment agency provides for the financial and human resource management of the delivery of the LTSS plan. These tasks are complex and their management can go beyond the knowledge of the participant. Responsibilities of these entities may include background checks, employment-related paperwork, service payments, and employment taxes.

6.17 Is skills training and support provided for participants choosing the self-directed option?

The IDT or a CBO helps the participant understand the self-directed option, person-centered planning, and how to develop a LTSS plan. This plan helps participants address all aspects of implementing, monitoring and problem solving.

6.18 Are participants offered the choice to use an agency for physical assistance services?

When participants use an agency for physical assistance services, the agency hires, trains, and employs the staff. The agency is also the employer of record and handles all human resources (HR) responsibilities.

6.19 Does the participant have an opportunity to train the direct care workers regarding their unique needs and preferences?

Participant involvement in the training of direct care workers contributes to increased accountability and participants' engagement in their own care. In addition, participant involvement encourages workers to look to the participant for direction and discussion on tasks to be addressed. Though an agency has responsibility for the staffing, there can still be opportunities for the participant to train staff regarding their individual preferences of how and when tasks are accomplished.

6.20 Are direct care workers and/or their supervisors included in interactions with the IDT if identified in the IPC?

Direct care workers generally have more interaction with the participant than anyone else and their feedback is highly useful for the IDT. They are in a good position to provide information regarding care needs or changes and to support the participant in interactions with the IDT.

Vocational, Social, and Recreational Support

Vocational supports for work, whether volunteer or paid, as well as social and recreational activities are an integral component of an individual's health, wellness, and independence.

6.21 Are vocational activity and support routinely explored in the participant's assessment?

Avocation and vocational activities promote community participation, socialization, engagement and purpose. The exploration and identification of options for vocational

activities should be explored in the participant's assessment and may sometimes be referred to an outside agency, such as a vocational rehabilitation services center.

6.22 Are participants assisted in accessing information and services to obtain and maintain employment?

Participants can often benefit from ongoing support, even if intermittent, to retain work positions. An alteration to job tasks and changes in the living environment can affect the participant's daily routine. Therefore, staff should assist participants in obtaining and maintaining employment by providing resources such as job listings or directing participants to individuals who can provide career assistance.

6.23 Are the participant's support needs for avocation or vocational activity included in care plans?

Once avocation and vocational activity needs are explored during the assessment, the preferences for them should be included in the care plan. These supports may include ADL supports needed during the day, such as toileting and eating. Assistance may include activity of daily living tasks such as clothing management, transfers, and communication and situational support with job tasks.

6.24 Do staff assess the participant's engagement in community activities and endeavors to support participation as they prefer?

DCC incorporates an assessment of the individual's community participation and works to build upon the participant's interests when identifying options and plans to support this participation. Staff should engage participants in discussion regarding the community activities they are engaged in and whether the activities are meeting their preferences.

6.25 Are participants assisted in accessing resources and information regarding social and recreational activities of their choosing?

Participants should be provided options to choose social and recreational activities of their interests and not be expected to accept or be limited to what might be known or familiar to the IDT members.

6.26 Are participants offered personal assistance services during these activities if needed?

Staff should offer resources for personal assistance services such as ADL supports needed during the activity, such as clothing management, transfers, toileting, eating, communication or other situational support.

6.27 Are social and recreational activities and support needs incorporated in the participant's IPC?

The participant's chosen activities and the support needed to access and participate as fully as desired in these activities should be delineated in the IPC.

Mobility Equipment, Home Modifications, and Supplies

DCC includes the ability to respond to equipment needs in a timely manner. Equipment failure or breakdowns may impair a participant's safety, ability to function, and puts them at risk for health complications such as skin breakdown, depression, missed school or training, loss of work hours and social activities.

6.28 Are participants assessed to identify service and equipment needs to maximize independence?

Many disability-competent organizations have occupational, physical, and speech therapists perform home- and community-based functional assessments as well as participant education and training for functional and effective use of equipment.

6.29 Do participants have access to customized equipment and equipment modifications based on their needs and goals as described in the IPC?

Examples of equipment and modifications include:

- Wheelchairs, scooters, and walkers
- Wheelchair seating and positioning supports
- Communication equipment
- Respiratory equipment
- Accessible vans and lifts
- Bathroom grab bars and doorway widening
- Ramps

6.30 Is there an adequate network of equipment providers to ensure timely access to needed services?

While larger pieces of equipment (such as wheelchairs and communication devices) are commonly available through only one vendor, routine supplies and some repairs are provided by a range of providers. Due to the importance of equipment and supplies, many participants may have preferred providers who are best able to meet their individual needs due to familiarity to these needs, stocking of supplies, and quick response.

6.31 Are repair requests for durable medical equipment addressed in a timely manner so as not to disrupt or limit the daily functioning of the participant?

Timeliness of repairs needs to be carefully prioritized depending on the equipment (e.g., respirator and cushioning malfunctions and other essential health items versus a cooking or hygiene aide), the participant's health and safety, and overall ability to function in daily activities. Many disability-competent plans provide their participants and IDTs with a list of well-prepared and available vendors.

6.32 Are alternative loaner options in place for all essential equipment and supplies?

Ensure access to loaner equipment (such as wheelchairs) and same-day delivery of necessary supplies. It may be best to provide a manual back-up wheelchair for all participants who routinely use a power chair, and other backups for life-dependent devices like respirators. Additionally, plans for extended power outages need to be in place, which are especially critical for those using life sustaining equipment such as ventilators and suction machines.

6.33 Is there a review process for consideration of items that facilitate functional independence but are not a specified benefit or service?

Ideally, resource allocation resides with the IDT and the participant, and they assess the benefit versus cost. For example, providing grab bars in the bath, or a means for a participant to drain her own leg-bag can reduce daily reliance on PCAs. Disability-competent organizations commonly have a policy in place to guide the IDT in making these decisions.

Transportation

Accessible public transportation may be a cost-effective option for routine or social travel, while individualized and supported transportation may be required for medical appointments or care.

6.34 Are the specific transportation requirements of the participant identified as part of the initial assessment?

The assessment includes the participant's physical as well as communication and cognitive requirements. The participant's IPC should specify the type of equipment and assistance that is needed while being transported.

6.35 Is there a range of types of transportation services available to participants?

Types of transportation services include:

- Ambulance
- Medical Vans
- Taxi
- Paratransit services
- Accessible public transportation
- Privately owned vehicles
- Bariatric vehicles

6.36 Are there clear policies regarding transportation assistance to health care appointments and other activities?

Disability-competent organizations should establish clear policies for the provision of transportation services, including authorization guidelines, availability, timeliness, payment, related arrangements, and reporting problems.

6.37 Is transportation scheduling support available for participants?

Disability-competent organizations need to ensure participants understand how to access transportation for all needs (daily as well as episodic and urgent). Support for scheduling is often provided by a designated IDT member, by participant services staff, or other support staff.

6.38 Are transportation services available 24/7 to meet urgent needs?

Outside of regular office hours, only ambulance transport is generally available. When ambulances transport wheelchair users, most often they use a gurney, which means the wheelchair user does not have their wheelchair for use in the next setting. Some disability-competent organizations contract with standard medical van transportation companies to be available after-hours to assist with transportation.

6.39 Are transportation providers monitored to ensure safe, dependable, and accessible service?

The best information source on provider performance is often participants themselves. Many disability-competent organizations ask their participants periodically to provide feedback on transportation providers, and routinely review any injuries that occur during transit to identify patterns or need for immediate changes.

Addressing Social Determinants of Health

Complete LTSS requires the ability to support the participant beyond their immediate health care needs, including finances, housing, and legal matters.

6.40 Are IDT staff prepared to support the participant in addressing their financial-related issues?

Participants may receive many types of financial assistance, such as subsidized housing, Medicaid coverage, and Social Security disability payments. Program requirements, such as annual or biannual confirmation of Medicaid eligibility, can disrupt care and financial supports. IDT support that enables the participant to address these issues in a timely manner will improve continuity of care and financial stability.

6.41 Are staff prepared to support the participant in addressing their housing needs?

Access to housing is a significant concern for persons with disabilities, be it financial or physical accessibility. Staff should be prepared to help identify suitable housing – considering location, finances and accessibility – as a participant’s situation changes. This is especially complex following a significant change in the participant’s functional status or upon discharge following an inpatient episode.

6.42 Are staff aware of a range of legal advocacy organizations to support the participant?

Persons with disabilities are commonly caught between differing and often conflicting rules and regulations for the programs upon which they rely, including issues related to guardianship and power of attorney. Though providers cannot be expected to be legal consultants, it is important for the IDT to be aware of available resources, help with identifying and assessing issues, and refer the participant for assistance as needed.

Pillar 7: Behavioral Health

Behavioral health (BH) is an all-encompassing term for what has traditionally been referred to as mental health and substance abuse and dependency. Most behavioral health issues manifest with functional limitations. The co-existence of physical and behavioral health issues is well known and documented. As such, behavioral health care must be integrated with primary care to ensure continuity with the interdisciplinary team (IDT) and the participant's individualized plan of care (IPC), and the effective delivery of services and supports. The field is centered on the recovery model, which focuses on the following dimensions of mental health: 1) health, 2) home, 3) purpose, and 4) community.

Mental Health

Participants with disabilities may be at a greater risk of experiencing mental health issues than the non-disabled populations.

7.1 Are all participants screened for depression and anxiety using standardized tools?

The incidence of depression and anxiety are high among adults living with functional limitations or disabilities. As such, it is imperative the IDT assess each individual, discuss the results with the individual and develop plans accordingly. There are a range of tools that have been developed and validated. For example, the following tools are brief and easy to complete independently by the participants:

- PHQ-9 – for assessment of depression
- GAD-7 – for assessment of anxiety

7.2 Are participants referred to behavioral health services as recommended?

If a behavioral health services need is identified, it is important to ensure that participants are referred to accessible behavioral health services. The IDT, in collaboration with a consulting psychologist or psychiatrist as necessary, should identify organizations that provide behavioral health services for persons with disabilities. The IDT can also help the participant to understand how this service can benefit them in their daily functioning and relationships.

7.3 Is a mental health professional a part of the IDT for each participant with a mental health concern?

A key value of the DCC model is an interdisciplinary team approach to care. Each participant with a mental health concern needs the input and involvement of a mental health professional or specialist (such as a psychiatrist, licensed independent clinical social worker, or licensed psychologist).

7.4 Is a mental health professional or psychiatrist available for consultation for all IDTs on an ongoing basis?

While not all persons with disabilities initially present with a mental health concern, the team may recognize mental health concerns as they become more familiar with participants

over time. As such, it is important for a mental health professional to be readily accessible to the IDT.

7.5 Does the IDT focus on the functional impact of a mental health concern?

A focus on how a participant's mental health affects their overall functioning is critical to their well-being. Limitations such as difficulty communicating, focusing, maintaining familial and social relationships, or accessing community activities have a major impact on an individual's well-being and overall mental health.

7.6 Does the IDT use a 'stepped care' treatment approach when working with participants with varying levels of mental health concerns?

Stepped care treatment is commonly used in medication decisions to minimize side effects and control costs. This approach starts with more informal supports such as addressing social stressors (financial challenges, family conflicts, inconsistent caregivers, housing and other issues). If this first step does not provide relief, the next step is counseling, both formal and informal through support groups. Many participants benefit from a combination of the two steps along with pharmacological support.

7.7 Does the behavioral health network include providers experienced in the recovery model?

Traditionally, treatment has been composed of pharmacology, psychotherapy, and cognitive-behavioral therapy. Increasingly, there is evidence that addressing social determinants of health are of major importance. The recovery model addresses the four dimensions of mental health: 1) health, 2) home, 3) purpose, and 4) community. Peer counselors, support groups and other non-medical supports are central to the recovery model and should be included in the behavioral health network.

7.8 Does the behavioral health network include specialists trained and qualified in serving persons with specialized mental health issues (traditionally referred to as psychosis, eating disorders, impulse control and addiction issues, personality disorders, obsessive-compulsive disorders, and post-traumatic stress disorders)?

Anxiety and depression can be addressed by the IDT, with input from the team's mental health professional. To address additional mental health concerns, it is best to refer to a specialist who possesses experience with the specific concern. The challenge when referring externally for ongoing treatment is coordinating with the IDT. This will require a designated communication agent from the IDT, with permission of the participant, to ensure two-way communication. The IDT will need to keep the external professional up to date with their observations of the impact of the mental health intervention and progress towards identified goals. It is also important for the external specialist to communicate their efforts to the IDT and identify potential concerns for monitoring.

7.9 Does the long term services and supports (LTSS) network include those with experience and expertise in working with persons with mental health disabilities?

Participants with mental health concerns, especially those with more functional impairment, will require LTSS providers experienced in working with the participant's issues. For example, participants with eating disorders will need providers trained to meet

their unique needs regarding eating disorders. This expertise can sometimes be found within an existing LTSS network by an experienced referral specialist. Otherwise, an out-of-network referral will be needed, as a provider that does not understand how to meet the needs of the participant is less likely to be successful.

Behavioral Challenges

Behavior is a form of communication, which may be exhibited with or without the participant's intent. Differentiating these behaviors from substance abuse and dependency is required for proper care.

7.10 Do the initial and subsequent assessments include a behavioral component of the participant's functioning?

Focus on the participant's ability to be behaviorally functional in their home, with family and peers, at work, and in the community. The initial step is to work with the participant and their key supports to identify the behavior and the triggers of the behavior that interfere with their functioning. From there, a plan can be developed to reduce the stimulation and develop alternative responses.

7.11 Is a behavior intervention professional available for the IDT and the providers working with the IDT's participants?

Behavior challenges can be complex and require an understanding of the cause, awareness, and ability of the participant to control and adopt more functional behaviors. Behavioral specialists should serve as a resource to the IDT to supplement the IDT's expertise in assessing the situation, developing a plan, and supporting the participant and others around them to follow through with the plan.

7.12 Are behavioral specialists available as part of the provider network?

While behavioral specialists are needed to support the participant, they may also be needed by the IDT, primary care provider, and other providers supporting a participant.

Substance Use

Substance abuse and dependency involve mind-altering substances, including alcohol and drugs. Understanding the differences and signs are a key part of addressing these issues.

7.13 Are all participants screened for substance abuse?

Screening for substance use should be a part of all initial and subsequent assessments. It is important to normalize the issue with a participant and give them an opportunity to discuss it openly. In practice, the participant may not be comfortable disclosing their use until they have a higher level of trust with their IDT. Over time, the IDT or other providers may recognize signs of use and may need to discuss with the participant at that time.

Standardized tools such as the NIAAA-1 or NIDA-1 may be of use in the screening process.^{2,3}

7.14 If the basic screening indicates follow-up, are participants further assessed for severity of substance use and need for intervention?

If the participant is assessed to be at risk for substance abuse, additional screening should take place. Standardized tools such as the AUDIT or DAST-10 may be of use to further assess the severity of abuse or dependence.^{4,5} Using such tools will give the IDT and participant an opportunity to develop a specific plan based on unique history and drivers.

7.15 Is a “stepped care” approach to addressing substance abuse issues available to help participants with varying levels of readiness and severity of need?

A stepped care approach is useful in working with participants with substance abuse issues. At early stages, education and discussion are beneficial. At more progressive stages, participants may benefit from self-monitored reductions in usage, discussions about self-control, and/or a formal treatment approach.

7.16 Is a substance abuse professional available for the IDTs?

While members of the IDT may have experience working with persons with substance abuse concerns, participants should discuss their assessment with a substance abuse professional to assist with developing a treatment plan.

7.17 Is the concept of ‘resilience’ employed when addressing participants with substance abuse issues (and also applicable when working with those with mental illness)?

The process of recovery is highly personal and is characterized by continual growth and improvement in one’s health and wellness. It may include clinical treatment, medications, faith-based approaches, peer support, family support, self-care, and other approaches.

² National Institute on Alcohol Abuse and Alcoholism. (2017). How to Screen for Heavy Drinking. Retrieved from https://pubs.niaaa.nih.gov/publications/practitioner/pocketguide/pocket_guide5.htm

³ National Institute on Drug Abuse. (2017). The NIDA Quick Screen. Retrieved from https://www.drugabuse.gov/sites/default/files/files/QuickScreen_Updated_2013%281%29.pdf

⁴ National Institute on Drug Abuse. (2017). Alcohol Use Disorders Identification Test (AUDIT). Retrieved from <https://www.drugabuse.gov/sites/default/files/files/AUDIT.pdf>

⁵ National Institute on Drug Abuse. (2017). Drug Abuse Screening Test (DAST-10). Retrieved from <https://www.drugabuse.gov/sites/default/files/dast-10.pdf>