

DISABILITY-COMPETENT CARE SELF-ASSESSMENT TOOL

INTRODUCTION

Purpose

The Disability-Competent Care Self-Assessment Tool was developed to help health plans and health systems evaluate their current ability to meet the needs of adults with functional limitations and to identify strategic opportunities for improvement.

Serving Persons with Functional Limitations

This Tool focuses primarily on persons with functional limitations, however, disability-competent care is appropriate to all individuals with disabilities because its intent is to remove barriers to timely and appropriate health care. People with disabilities are a diverse group, including children, adults of all ages, people with vision or hearing loss, as well as people with physical, mental health, developmental, or intellectual disabilities. They may have limitations in learning, understanding, remembering, reading, speech, or mobility.

Rather than focusing on a diagnosis – such as spinal cord injury, multiple sclerosis, or mental illness – disability-competent care 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.

Rather than focusing on a diagnosis, disability-competent care focuses on providing care and supports for maximum function and addressing the barriers to integrated, accessible care.

Current models of care delivery are not always well suited to addressing the needs of those with functional limitations. Care is typically provided in clinical offices or inpatient settings, which may have physical barriers (e.g., inaccessible routes from parking areas and drop-off points) or inaccessible equipment (e.g., exam tables and scales). Common clinical practices may also impose procedural barriers, including insufficient time allotted for visits (people with functional limitations may need longer appointments to accommodate for the time required for safe transfer and positioning techniques) and lack of flexibility to accommodate the individual when issues such as caregiver availability or transportation requirements cause unpreventable delays. Individuals with disabilities may face both barriers of inconvenience and barriers that prevent optimal care delivery when trying to access the standard of care that individuals without disabilities may take for granted.

How can we best serve people with disabilities?

The Aspirational Model: Disability-Competent Care

Disability-competent care is participant-centered, provided by an interdisciplinary team (IDT), and focused on achieving and supporting maximum function. It is intended to maintain health, wellness, and life in the community as the participant chooses. Disability-competent care recognizes and treats each individual as a whole person, not a diagnosis or condition. The model, therefore, is structured to respond to the participant's physical and clinical needs while considering his or her emotional, social, intellectual, and spiritual needs.

The aspirational model of disability-competent care depends on health care professionals sharing collective responsibility for the execution of the care plan as well as the health and well-being of the participant. This requires health care professionals to collaborate across disciplines and care settings and engage in a meaningful partnership with the participant. To achieve this aim, health care professionals may need to develop new capabilities in teamwork, interdisciplinary collaboration, and participant-directed care.

The aspirational model of disability-competent care described in the Tool is derived from the "lived" experiences of persons with disabilities and over 20 years of experience from the following three programs:

- Community Medical Group/Commonwealth Care Alliance in Massachusetts
- Community Health Partnership in Wisconsin
- Independence Care System in New York

These programs are unique in their integration of Medicare and Medicaid services and funding, encompassing the full range of acute care, primary care, and long-term services and supports. Each organization has evolved in the context of local care practices and resources. Each has also achieved documented success in improving the experience of care, promoting the health of the population served, and reallocating resources to increase care management and primary care support by capturing avoidable episodes of care.

Three Domains of Success in the Aspirational Model

Relational-based Care Management

Participant-centered care is based on the recognition that the participant is not merely a passive recipient of medical care, but rather the primary source for defining care goals and needs. This type of care requires cultivating a relationship with the participant, seeing him or her as a whole person with hopes and preferences, and recognizing that the participant is oftentimes the best steward of resources. Inherent in participant-centered planning of care goals and needs is also the concept of the dignity of risk,¹ which honors and respects the participant's choices even if they are inconsistent with the recommendation of the IDT.

¹ Dignity of risk means the right of individuals to choose to take some risk in engaging in life experiences, even if that choice is not one recommended by a health professional (e.g., choosing to smoke).

Highly Responsive Primary Care

A highly responsive primary care network is critical for timely, ongoing, and accessible care. The provision of primary care is a vital component of disability-competent care, which involves timely access to care in a variety of settings (in a clinical office practice, community, or participant's home) as well as the capacity to assess and address newly emerging symptoms of concern, and the allocation of care and services.

Comprehensive Long-term Services and Supports

Long-term services and supports (LTSS) comprise the range of home- and community-based care services and supports that enable a participant to reside in his or her home and participate in the community. Comprehensive LTSS often involves the identification of functional needs and the prioritization and allocation of resources. This commonly requires investing in resources and equipment to support the health and well-being of the participant, which, in turn, may prevent avoidable episodes of illness or progression of illness.

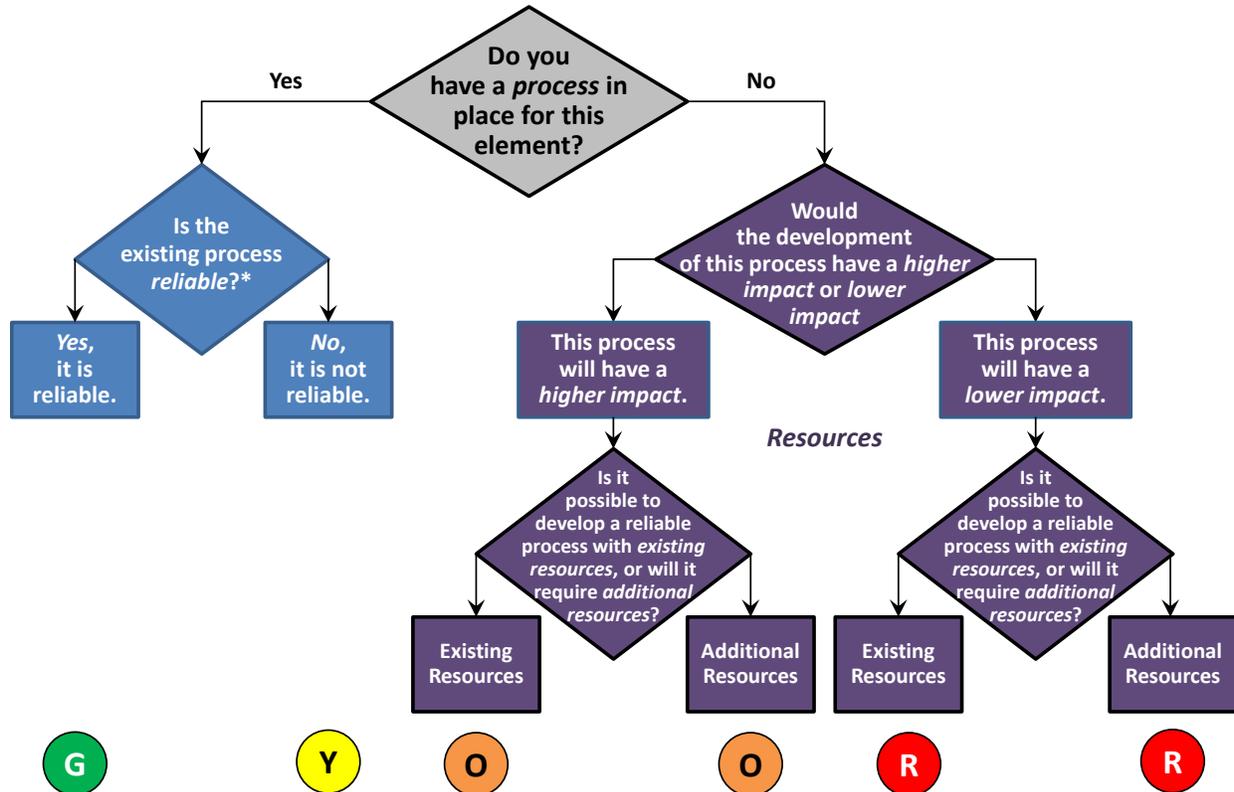
There are a wide range of populations that would benefit from this aspirational model of disability-competent care. How the model is applied will vary based on the population's characteristics, care needs, and care utilization patterns. For guidance on how disability-competent care plans have sought to better understand the populations that they serve, please see *Appendix A: Understanding Your Population*.

How do we use the Tool?

Inherent in the model of disability-competent care is the need to engage the individual in defining their care goals and needs. Establishing disability-competent care within a health plan or health system affects all functional areas of the plan or system, from direct care delivery to contract and payment modifications to management systems to the inclusion of a full range of home- and community-based care options and supports. As such, all key functional areas in the organization should be represented in the completion of the Tool.

Evaluating the Tool

Individuals working in the health plan or health system will be asked to evaluate each element, as described below. Guidance about the results of the evaluation is provided in *Interpreting Your Results*.



*Reliability is defined as a “failure-free operation over time.” In health care, it is feasible to achieve 95% reliability for the majority of care-related processes. One simple way to assess reliability is to predict if five front-line individuals are able to accurately describe the process in the same way. If you are not confident that all five individuals are able to do so, evaluate this process as not reliable.

Each element in the Tool will fall into an Assessment Category (green, yellow, orange, or red) based on your responses. The Assessment Categories are described in *Interpreting Your Results*. An *interactive evaluation grid* is provided so that you can easily identify the Assessment Category for each element based on your responses. A *manual evaluation grid* is also provided for you to print and use as you complete the Tool if you prefer.

THE ASSESSMENT

1 RELATIONAL-BASED CARE MANAGEMENT

Participant-centered care is based on the recognition that the participant is not merely a passive recipient of medical care, but rather the primary source for defining care goals and needs. This type of care requires cultivating a relationship with the participant, seeing him or her as a whole person with hopes and preferences, and recognizing that the participant is oftentimes the best steward of resources. Inherent in participant-centered planning of care goals and needs is also the concept of the dignity of risk, which honors and respects the participant's choices even if they are inconsistent with the recommendation of the IDT.

1.1 Participant-Centered Practice

The participant's choices, preferences, and goals provide a foundation for his or her individualized plan of care (IPC), while respecting his or her dignity of risk. A trusting and respectful relationship between the participant and his or her care team is necessary to ensure decisions remain participant-centered.

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

Participants commonly need support and coaching about the assessment and care planning process. A preliminary "get to know you" meeting can help establish the relationship so that the subsequent meeting can focus on the full assessment and care plan development. This support may be provided by peers or other individuals who are familiar with the assessment and care planning process and understand how it may be daunting and overwhelming.

1.1.2 Does the care management staff develop an individualized, professional relationship with the participant, showing respect for the participant's preferences and for the dignity of risk?

Developing this trusting relationship generally requires an initial face-to-face interaction and includes discussion of the participant's goals, values, and preferences for his or her care.

1.1.3 Are participants (and families or caregivers) involved in program planning and implementation to ensure a participant-centered focus?

Health plans and systems that provide disability-competent care have multiple avenues to engage participants in care planning and to seek their perspectives and ideas. These include consumer advisory boards, new member groups, focus groups, telephone surveys, and employing persons with disabilities throughout the organization.

1.1.4 Do interdisciplinary team (IDT) members consistently respect and accept the decisions and preferences of participants?

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.

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

Disability-competent organizations routinely include this assessment as part of the initial assessment and all reassessments. Staff are trained to be sensitive to any resistance or concerns expressed by the participants and remind them of their rights to disagree.

1.2 Eliminating Medical and Institutional Bias

Medical and institutional bias often impedes providers from addressing the whole individual, including his or her unique abilities, limitations, and preferences for social and community participation. This may require the provision of supports and services needed to function in the participant's preferred living setting.

1.2.1 Does the IDT help participants explore all possible options for living in the least restrictive environment of their choice?

When the participant and his or her IDT determine that the participant's current residential setting is unable to meet his or her needs, the care team identifies and discusses a range of options for settings and levels of care with the participant.

1.2.2 Are participants given a choice of community supports and service providers?

Participants should understand their options for a self-directed model for community supports or a traditional agency/provider model, as well as options for maintaining existing personal care assistant (PCA) relationships. Additionally, having access to a roster of service and support providers with an evaluation of provider performance may help participants make informed decisions.

1.2.3 Is the participant's current living situation re-evaluated prior to planning a permanent transition to a greater level of care?

Many disability-competent organizations have established a re-evaluation process that includes considering if adaptations or additional supports may enable the participant to continue living in his or her current setting. This process seeks to ensure that permanent changes are a choice of last resort.

1.2.4 Are potential ethical conflicts formally reviewed via committee or consultation to ensure participant autonomy and self-determination?

Disability constitutes a significant threat to autonomy because persons living with a disability often need to rely on others to function in their daily lives. Therefore, it is imperative that disability-competent organizations have formal protections in place to ensure that potential ethical conflicts are identified, assessed, and addressed.

1.3 Interdisciplinary Team

Disability-competent care is interdisciplinary team-based care with core competencies in primary care, behavioral health, LTSS, and nursing. Operating in close communication with the participant and external providers, the interdisciplinary team (IDT) is responsible for ensuring the participant receives the care and supports he or she needs to achieve his or her goals and maximize independence.

1.3.1 Composition

1.3.1.1 Are the competencies of primary care, nursing, behavioral health, and LTSS represented on each IDT?

The core care team is composed of staff with competencies in primary care delivery, nursing, behavioral health, and community-based service supports. Primary care practitioners might include physicians, nurse practitioners, or physician assistants. Nursing practitioners might include Advance Practice Nurses, Registered Nurses, or Licensed Practical Nurses. Behavioral health practitioners might include social workers, psychologists, chemical dependency specialists, or other comparably trained practitioners. LTSS practitioners might include social workers, mental health therapists, community health workers, or other comparably trained staff.

1.3.1.2 Are all practitioners on the IDT experienced in providing disability-competent care?

All members of the IDT should either be experienced in working with persons with disabilities or, at a minimum, willing to be trained and coached accordingly. Disability-competent organizations should have extensive training programs for new staff to teach disability sensitivity, awareness, and considerations related to their specific area of practice.

1.3.1.3 Is the participant's primary language, means of communicating, and ethnic/cultural competencies considered in identifying specific members of the IDT?

While this is not always feasible, having IDT members with these competencies can serve to increase the trust between the participant and his or her IDT.

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

While the IDT collectively shares responsibility for the health and wellbeing of each participant, each member of the IDT practices within their scope of competency, minimizing redundancy and utilizing support staff when appropriate.

1.3.1.5 Is one member of each participant's IDT designated as the "lead"?

It is imperative that one individual 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 primary care practitioner), while others choose to vary the designation of lead based on the unique needs and/or preferences of the participant.

1.3.1.6 *Are additional resources or consultants available to the IDT based on the specific needs of each participant?*

Additional resources or consultants may include sub-specialty providers, rehabilitation consultation (OT, PT, Speech Therapy), durable medical equipment, nutritional services, and pharmacy.

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

When a participant specifies a family member or other 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.

1.3.2 Communications

1.3.2.1 *Does the IDT meet weekly to discuss relevant participant updates, new assessments, and reassessment reviews?*

Many disability-competent organizations utilize structured agendas to ensure the productive use of team meeting time. These meetings can be in-person or virtual. While not every participant is discussed every week, triggers are in place to ensure: 1) review of any participant under acute care, 2) review of any participant in transition, 3) discussion of any change in health status, and 4) routine, prescheduled reviews.

1.3.2.2 *Does the IDT ensure that each participant's IPC is reviewed at predetermined intervals?*

Each participant should have his or her IPC reviewed at regular intervals (bi-annually, at a minimum), as well as when a new issue or change in condition emerges.

1.3.2.3 *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 for the external provider?*

Some participants may choose to maintain a primary care provider who is not actively involved on the participant's IDT. If this is the situation, the primary care practitioner on the IDT is often designated to be responsible for communicating with the external primary care provider.

1.3.2.4 *Is the IDT able to meet, either in person or virtually, within 24 to 48 hours if the participant's needs or situation changes?*

The need for timeliness will vary depending on the urgency of the situation. In some disability-competent organizations, IDT members maintain flexibility on their daily schedules to be able to address emerging concerns.

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

At a minimum, information on each participant's IPC should be available via fax or email, but is ideally in the form of a remotely accessible electronic health record (EHR). See section 1.4 for a full description of the assessment(s).

1.4 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. The initial assessment provides a key opportunity for the IDT to establish a relationship with each participant and to build the trust needed for successful, ongoing care and care management.

1.4.1 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.

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

Disability-competent organizations have found that meeting in the participant's living environment often helps him or her feel safe, comfortable, and in control. This also provides the IDT an opportunity to see first-hand where the participant lives, which enables the IDT to 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 in a venue outside the home. If this is the case, the IDT should work to gain the trust of the participant so they can be welcomed into the participant's home to see how he or she functions in this environment.

1.4.3 Are the initial and subsequent assessments attended by all members of the core IDT (see 1.3.1)?

It is important for all members of the participant's IDT to actively participate in the assessments, for each discipline brings a different set of skills and knowledge.

1.4.4 Is the participant able to include other individuals in the assessment process?

Other individuals might include family members, caregivers, friends, community supports, and other clinicians such as fitness coaches and massage therapists.

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

Domains to be assessed include, but are not limited to:

- Participant strengths, goals, and priorities
- Demographic, contact, financial, and eligibility information
- Social activities
- Functional assessment (activities of daily living [ADL], instrumental activities of daily living [IADL], physical therapy, and occupational therapy)
- Medical diagnoses and history
- Behavioral health screening
- Nutrition (food access, preparation, diet, etc.)
- Health-related services (including behavioral management, exercises, medications, equipment use, skilled therapies, rehabilitation therapies) and all current providers
- Long-term services and supports use and all current vendors
- Home and community environment, safety, accessibility, and health risks
- Formal, informal, and social supports
- Community participation, level of education attained, and employment status

1.4.6 Does the assessment process identify additional expertise needed for the participant's care

The IDT should incorporate the expertise of other clinicians or care providers as needed, including rehabilitation therapists, behavioral health providers, dietitians, peers, LTSS providers, or specialists (such as palliative care practitioners), **either on an ongoing or consulting basis?**

1.5 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.

1.5.1 Are the participant's care goals, action steps to meet those goals, and proposed interventions to overcome identified challenges documented in the IPC?

IDT members need to be trained in working with and guiding participants in identifying their personal goals – medical, social, or other (see 1.1.1 above).

1.5.2 Does the IPC contain specific documentation on what care and support services are being provided, by whom, and by when?

Disability-competent organizations ensure that accountability and timeframes are built into the IPC and can serve as triggers for automated reminders to IDT members.

1.5.3 Does the IPC contain documentation of all formal (paid) and informal (unpaid) care and supports needed?

A checklist of such formal and informal providers may include: primary and acute care, preventive care plans, behavioral (mental and chemical) health services, rehabilitation therapists, patient education, 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.

1.5.4 Do IDT members ensure that participants understand and feel empowered to accept, negotiate, modify, or appeal changes made to their IPC?

Disability-competent organizations provide their staff with specific training and coaching to be sensitive to any participant disagreement or resistance of care needs and goals specified in their IPC. Staff are trained to work with participants to ensure concerns are addressed.

1.5.5 Do participants and all members of the IDT have full access (electronically or on paper) to the initial IPC and any subsequent changes or updates?

Ideally the participant's IPC is electronic and available to the participant and all authorized providers (including those providing after-hours care). A paper version can serve as a substitute. The IPC should reside in a "central" location so the participant and all authorized providers can reference it as needed.

1.6 Individualized Plan of Care Oversight and Coordination

Ongoing oversight 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.

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

Many disability-competent organizations use methods such as electronic triggers and signals to alert IDT members to changes to the care plan such as IPC review dates, changes in medications, routine reviews, hospitalizations, etc.

1.6.2 Is the IDT provided with clear criteria as to when a change in a participant's health status or condition requires a revision to his or her IPC?

The criteria may include any hospitalizations or change in living arrangements as well as newly emerging episodes of illness or progression of disease.

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

Many disability-competent organizations use methods such as electronic triggers to remind IDT members of outstanding items in a participant's IPC that require attention.

1.7 Transitions

Transitions include changes between care settings, providers of care, medications as well as financial, housing, legal, employment, and other changes that affect the participant's ability to live independently. Transitions are prime opportunities for potential errors to occur. All transitions require vigilance by the IDT to identify and oversee the change and ensure the safety of the participant.

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

Many disability-competent organizations provide protocols that may be used for different types of transitions. Others may employ a universal checklist of actions required for all types of transitions.

1.7.2 Is a transition plan developed and implemented for all significant participant changes?

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

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

For example, if the transition involves changes in medications, an IDT member may be responsible for providing medication reconciliation or coaching on signs and symptoms to bring to the attention of the IDT, as well as scheduling follow-up contact.

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

The IDT should make a list of resources available to the participant at all times for peer support (such as the local Center for Independent Living) and other counseling services.

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

Any significant change in a participant's functional capacity, as demonstrated by a need to increase the type, amount or location of care, would necessitate the development of a transition plan.

1.8 Tailoring Services and Supports

Specific services and supports listed in the IPC should be derived from the assessments and should be modified as appropriate. The IPC specifies the individualized services and supports that are reflective of the participant's preferences and needs to achieve his or her goals.

1.8.1 Are traditional services/supports substituted with alternative services that might not be considered "covered services" when appropriate?

Disability-competent organizations 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, support groups, acupuncture, and moving services. Additionally, participants are commonly the best source of creative, cost-effective alternatives.

1.8.2 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)?

Disability-competent organizations allow the IDT to alter the scope, intensity, and frequency of care delivery, supports, and services when warranted. Resource allocation authorization resides within the IDT. Furthermore, the criteria used for service authorization is made transparent to participants and relevant providers (see 1.5.5 regarding right to appeal).

1.9 Advance Directives

Completing and honoring advance directives is an interactive process between the participant and his or her IDT. The participant's wishes help determine the course of his or her care and the identification of a proxy helps to ensure his or her wishes are honored in the event of the loss of capacity to make decisions. Disability-competent care requires being able to discuss advance directives and end-of-life care issues with people with disabilities with respect, sensitivity, and awareness.

1.9.1 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.

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

While this is often a sensitive discussion for anyone, it is particularly so for persons living with a disability. Establish training for staff on how to effectively coach participants on advance directives and end-of-life care decisions, as well as on disability sensitivity, awareness, and respect.

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

Disability-competent organizations should ensure participants have disability-competent guidance and assistance in completing advance directives. Due to familiarity, trust, and openness, the participant's primary contact on the IDT may provide this assistance to the participant.

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

Triggers embedded into the IPC may serve as helpful reminders for the IDT to engage participants in advance directive discussions on an annual basis.

1.9.5 Are all completed advance directives documented in the participant's health record for access by all providers, including those providing after-hours care?

Signed copies of advance directives should be sent to the participant's primary care physician (if not a member of the IDT) and the participant's preferred hospital, and should be entered into the EHR.

1.10 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.

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

The following elements should be considered when assessing care management needs:

- Desire and ability to self-manage
- Functional dependencies
- Behavioral health issues, including cognitive disabilities
- Availability of home- and family-based supports
- Social and financial supports
- History of inpatient and emergency department utilization
- Cognitive impairment and abilities
- Number of chronic conditions
- Risk for secondary complications of disability

1.10.2 Are participant expectations and preferences a routine part of the assessment process for determining care management support provided by the IDT or other designated person?

It is important to specifically 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 met.

1.10.3 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 each participant to communicate about the needed care, supports, and services he or she feels are lacking and encourage the participant to give feedback to the IDT on whether or not expectations are met.

1.10.4 Are participants specifically coached as to when and how they may seek and obtain care management support?

Disability-competent organizations encourage participants to call their primary care practitioner upon first indication of illness so that plans can be implemented to ensure the appropriate level of care.

1.11 Care Partners

Care partners (usually unpaid) are friends, relatives, or peers who provide assistance to and coach the participant.

1.11.1 Does the IDT routinely inquire whether participants have, or wish to have, an ongoing care partner who accompanies the participant to medical appointments?

A care partner can provide assistance to the participant who has complex care needs or cognitive limitations, such as accompanying the participant to medical appointments. The care partner can coach the participant to ask questions during the appointment, assist with adherence to the care plan, and provide support while the participant is accessing care.

1.11.2 Is there a means of communication established between the IDT and the identified care partner?

The presence of a care partner ought to be noted in the participant's IPC with documentation regarding the nature and means for communication between the IDT and care partner.

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

This training is usually relatively informal, though it may include specific education regarding preventive strategies and identification of warning signs. Additionally, it is important to evaluate the care partner's ability and interest in serving in this role.

1.12 Health Record

A comprehensive health record is composed of many elements, including assessment(s), the IPC, medication lists, referrals and authorizations, care management notes, and other information as appropriate. The IDT overseeing the overall plan of care is responsible for having and maintaining an electronic health record (EHR) for each participant.

1.12.1 Is all information (e.g., medical, social, medications, financial) for each participant documented, maintained, and updated within an electronic health record or, at a minimum, available via fax or email?

The participant's health record is ideally 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.

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

At a minimum, a paper or electronic document is shared with all providers involved in the participant's care. The ideal is to have an EHR that is able to incorporate the medical records, care management activities, and service plans from all providers and settings engaged in the participant's care.

1.12.3 Does an IDT member or support person specifically manage, update, and disseminate each participant's EHR information 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.

1.12.4 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 front page of the EHR.

1.12.5 Is utilization data in the EHR routinely reviewed by the IDT to identify areas for clinical intervention and quality improvement?

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

1.12.6 Is pertinent clinical 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, pharmaceutical services, 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 experience of a provider's full panel of participants provide an opportunity to identify promising practices and areas for improvement.

1.12.7 Does the participant have the ability to access all components of his or her health record?

At a minimum, the participant should be able to review all components of his or her health record during visits with his or her primary care practitioner.

2 HIGHLY RESPONSIVE PRIMARY CARE

A highly responsive primary care network is critical for timely, ongoing, and accessible care. The provision of primary care is a vital component of disability-competent care, which involves timely access to care in a variety of settings (in a clinical office, community, or participant's home) as well as the capacity to assess and address newly emerging symptoms of concern, and the allocation of care and services.

2.1 Primary Care Network Capacity

The capacity of an organization's primary care network to provide disability competent care should be considered since a significant number of external providers may not be experienced in providing disability competent care.

2.1.1 Does your organization assess the disability competency of provider networks?

When engaging with external primary care practices, many disability-competent organizations designate a lead disability-competent practitioner to provide ongoing oversight and coaching to the external practice and its practitioners.

2.1.2 Are strategies employed to help primary care *practitioners* enhance their disability awareness and competencies?

Disability-competent organizations often provide a provider training program for staff members and may contract with disability-competent organizations to provide in-service training and networking opportunities. Continuing Education Units (CEUs) may also be provided.

2.1.3 When involving external primary care *practices*, are there strategies to help them become more disability-competent and aware?

Disability-competent organizations may provide practices with a checklist on the structural elements needed to provide disability-competent care (e.g., ramps, scales, accessible entry points) as well as guidance for staff related to enhance in-person and telephonic communication (for participants with speech or language impairments).

2.1.4 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 LTSS providers?

Disability-competent care requires integration of behavioral health with primary care and LTSS.² Integration can take many forms, including co-location; integrated or full access to the EHR by behavioral health providers; or regular participation in care team meetings.

2.1.5 Do all primary care practitioners have a network of accessible disability-competent providers for basic diagnostic tests, including x-ray and laboratory testing?

Maintain a list of preferred disability-competent providers and keep the list in a centrally accessible record.

² Finding or training disability-competent behavioral health practitioners is an ongoing challenge in most localities; one strategy is to contract with health plans/providers that co-locate mental health services in primary care clinics or place primary care providers in mental health clinics.

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

Maintain a list of preferred disability-competent sub-specialists and keep it in a centrally accessible record. Sub-specialists include, but are not limited to:

- Neurology
- Physiatry
- Dermatology
- Infectious Disease
- Urology
- Gastroenterology
- Pain Management
- Behavioral Health

2.1.7 Is there a mechanism to track the performance of external primary care practitioners?

Many disability-competent organizations create reports for external primary care practitioners and practices who may only serve a small number of participants with disabilities. These reports focus on outcomes of care as well as care planning functions such as timeliness, appropriateness, continuity of care, and medication management.

2.1.8 Do primary care providers use care guidelines to observe for secondary complications of disability?

Prevention of secondary complications is critical for disability-competent care. Care guidelines for the following should be used:

- Pressure ulcers
- Pneumonia
- Upper respiratory infections
- Urinary tract infections
- Stool impaction

2.2 Availability of Care

The timeliness of primary care is often the key factor in reducing emergency department and inpatient utilization and costs.

2.2.1 Are primary care practitioners available for diagnosis and treatment at all times?

Some disability-competent organizations have opted to hire or contract with primary care physicians who agree to make home visits and take calls from participants. Others have opted to hire or contract with nurse practitioners who make home visits and provide 24/7 coverage while working in partnership with a broader primary care practitioner network.

2.2.2 Are primary care practitioners available to provide care in the community (clinic, urgent care, or place of residence)?

Community- or home-based care is often necessary, as transportation can be difficult to arrange and is a key barrier to accessing timely care.

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

Disability-competent organizations commonly augment clinic-based primary care physician services by having nurse practitioners available for home visits or consultations.

2.2.4 Are mental and behavioral health crisis intervention services available at all times?

Some disability-competent organizations contract with crisis intervention providers who can respond to participants with disabilities at all times, including the provision of home-based services and emergency accessible transportation.

2.2.5 If applicable, do external primary care practitioners routinely communicate with the IDT or primary care manager to ensure adherence to treatment plans and follow up on referrals?

Ongoing communication among members of the IDT is essential for disability-competent care and requires special attention when a participant routinely engages external providers in addition to his or her IDT.

2.2.6 Are offices, including home- and community-based service settings, physically accessible to wheelchair (both manual and motorized) users?

Disability-competence includes awareness of accessibility, especially of clinic entrances, parking facilities, hallways, waiting rooms, restrooms, elevators, and examination rooms.

2.2.7 Do primary care practices and other care settings have adequate equipment (such as scales, exam tables, and lift equipment) to provide comprehensive care for members with physical disabilities?

Disability-competent organizations generally assess and document the availability of adaptive equipment at sites of care most often used by participants with disabilities.

2.3 Medication Management

2.3.1 Are all participant medications reviewed at assessment, reassessment, 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.

2.3.2 Is a consulting clinical pharmacist available to the IDT to assess and address polypharmacy and inappropriate 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). The primary care practitioner on the IDT assumes responsibility for having the medications reviewed and managed.

2.3.3 Is the participant's primary care practitioner, if not a member of the IDT, informed when another practitioner orders a medication change?

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

2.3.4 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 tools needed for self-management should be provided (such as medication cases or bubble-wrapped dosing) should be provided to both the participant and any caregivers or care partners involved in supporting his or her care.

2.4 Communication, Equipment, and Physical Access

2.4.1 Do participants have access to the care and equipment they need to maximize health and independence, both in and outside the home?

If a participant utilizes equipment in his or her home (such as lifts), arrangements will need to be made to have comparable equipment available at all other sites where the participant receives care.

2.4.2 Do all care settings offer communication access?

Communication facilitation may include:

- American Sign Language (ASL) and ASL interpreters
- Teletypewriter (TTY)³ and text support for mobile phone or Internet-based communication
- Amplification devices
- In-office communication devices
- Communications facilitator/care partner

³ TTY is a data terminal that converts incoming phone calls and voice responses into text. This device assists the hearing impaired in using the telephone.

2.5 Preventive Care and Health Education

Disability-competent care requires focusing on maintaining health and preventing avoidable complications.

2.5.1 Do primary care practitioners follow clinical protocols for the identification and treatment of key secondary conditions of disability?

Disability-competent organizations should have clinical protocols for the identification and treatment of skin breakdown, urinary tract infections, upper respiratory infections, bowel impaction, depression, and other secondary complications (see 2.1.8 above).

2.5.2 Do primary care practitioners have guidance on how to tailor care protocols and registries 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 his or her other needs, medications, functional status, and available supports.

2.5.3 Are participants and caregivers/personal care assistants provided with health promotion and self-care education specific to the participant?

The IPC ought to include a health and wellness plan, including:

- Accessing primary care
- Routine health prevention services
- Management of conditions associated with existing disability and chronic illnesses
- Prevention of secondary conditions of disability
- Participant and caregiver self-care for chronic conditions

3 COMPREHENSIVE LONG-TERM SERVICES AND SUPPORTS

Long-term services and supports (LTSS) comprise the range of home- and community-based services and supports that enable a participant to reside in his or her home and participate in the community. Comprehensive LTSS often involves the identification of functional needs and the prioritization and allocation of resources. This commonly requires investing in resources and equipment to support the health and well-being of the participant, which, in turn, may prevent avoidable episodes of illness or progression of illness.

3.1 Employment Supports

Employment, whether volunteer or paid, is often an integral component of an individual's health, wellness, and independence.

3.1.1 Do employed participants (or those desiring to be employed) have access to services and supports needed to maintain employment?

These supports may include ADL supports needed during the day, such as toileting and feeding.

3.2 Mobility Equipment, Home Modifications, and Supplies

Disability-competent care includes the ability to respond immediately to equipment needs. Equipment failure or breakdowns impair a participant's ability to function and puts him or her at risk for secondary health complications such as skin breakdown.

3.2.1 Are participants assessed to identify services 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 the appropriate, safe, and effective use of equipment.

3.2.2 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
- Bathroom grab bars and doorway widening
- Ramps

3.2.3 Is there an adequate network of equipment providers to ensure choice and timely access to needed services?

Due to the importance of equipment and supplies, many participants may have preferred providers who are best able to meet their individual needs.

3.2.4 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 repair requests will vary depending on the equipment (e.g., respirator and cushioning malfunctions versus a cooking or hygiene aide).

3.2.5 Are back-up options in place for all essential equipment and supplies?

Ensure access to loaner equipment (such as wheelchairs) and same-day delivery of necessary supplies. Some disability-competent organizations have found it best to provide a manual back-up wheelchair for all participants who routinely use a power chair.

3.2.6 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 vs. cost. For example, providing a means for a participant to drain his or her own leg-bag can reduce reliance on personal care attendants (PCAs).

3.3 Personal Assistance and Support Living

Participants dependent in ADLs and/or IADLs require access to personal care attendants (PCAs) within their individual or shared living settings. These assistants are provided either by an agency (agency model) or employed directly by the participant (self-directed model).

3.3.1 Are participants given a choice between an agency model and a self-directed model for their personal care attendants?

Most Medicaid programs require that participants be able to choose a self-directed option for PCA services or other LTSS.

3.3.2 Are participants able to maintain access to existing or preferred PCAs?

Many disability-competent organizations maintain an open network model or the option for an existing PCA to move to a contracted provider.

3.3.3 Is there a specified transition plan developed prior to a change in PCA service or model of care?

Since PCA services are utilized daily, any gap in service can be problematic.

3.3.4 Is the participant's IPC available to the PCA (and other caregivers, as appropriate) to direct the delivery of his or her personal care on a daily basis?

If the participant employs his or her own personal care attendant, it is important that the PCA is coached on how to use the participant's IPC to guide the PCA in providing optimal care.

3.3.5 Are all home-based caregivers trained to deliver services and supports based on the participant's IPC?

Many disability-competent organizations provide training materials for both participants and their caregivers/assistants to support communication and clarity of roles and expectations.

3.3.6 Are IDT staff trained to watch for problematic home-based relationships, such as abuse, neglect, and exploitation?

In addition to watching out for problematic interactions and relationships, staff must be trained to respectfully address any concerns with the participant and others as appropriate.

3.3.7 Do all participants have emergency and caregiver back-up plans?

These plans have two components: 1) actions to take if an emergency (fire, electrical failure, severe weather) occurs, and 2) plans for coverage if a caregiver is unexpectedly unavailable (alternative caregivers, respite care).

3.4 Self-directed Option for Home- and Community-based Services

The self-directed model of care allows for the participant to design and direct his or her own community-based support services using a defined annual (or monthly) budget. These commonly include personal care attendants, day activities, homemaker services, and other services.

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

The self-direction option must include recruiting, interviewing, setting or negotiating work schedules and tasks, and evaluating job performance. To promote continuity of care, many disability-competent organizations consider allowing participants to continue with any supports they have had in place prior to their enrollment with the health plan.

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

The skills training should include:

- Caregiver recruitment
- Hiring
- Training
- Direction and supervision

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

Fiscal intermediaries conduct payroll functions such as calculating hours and wages, making benefit and payroll tax deductions, and providing paychecks. The intermediary may also assist in the purchase of goods and services to reach a participant's goals (e.g., assistive technology, home modifications, laundry services, and wellness supports).

3.5 Agency Model and Shared-Living Alternatives

Alternatives involve contracting with an agency for home-based care. Some participants will choose to live in settings with shared services, provided either by a home care agency or housing provider. These settings are commonly referred to as adult foster care, assisted living, or congregate housing (with the terminology varying by state).

3.5.1 Does the participant have a reasonable choice of providers and settings of care?

Since care is usually attached to the residential setting, it is important to offer as wide a choice as possible.

3.5.2 Does the agency assume responsibility for orientation, training, and ongoing supervision of a participant's direct care workers?

While the participant interacts with the direct care worker on a daily basis, he or she must also have access to the direct care worker's supervisor to address issues and concerns as they arise.

3.5.3 Are direct care workers and/or their supervisors included in interactions with the IDT?

Direct care workers commonly are a rich source of information and perspective regarding the participant. With the explicit approval of the participant, disability-competent care plans often involve direct care providers in the assessment and care planning process.

3.6 Transportation

Assess the participant's medical, social, and vocational transportation needs. Accessible public transportation may be a cost-effective option for routine or social travel, while individualized and supported transportation may be required for medical appointment or care.

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

The assessment includes 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.

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

Types of transportation services include:

- Ambulance
- Taxi
- Paratransit services
- Accessible public transportation
- Privately owned vehicles

3.6.3 Is transportation scheduling support available for participants?

Disability-competent plans ensure the participant understands 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.

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

Outside of regular office hours, only ambulance transport is generally available. In addition to the cost of ambulance transport, most wheelchair users are transported on a gurney and therefore do not have their wheelchair for use in the next setting. Individuals can acquire skin breakdowns while waiting in an emergency department on a gurney or in an ill-fitting wheelchair.

3.6.5 Are there clear policies regarding transportation assistance to health care appointments?

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

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

The best source of provider performance is often participants themselves; participants should be asked to periodically provide feedback on transportation providers. Many disability-competent organizations also choose to review any injuries that occur during transit.

3.7 Network Composition and Capacity

LTSS includes, but is not limited to: in-home supports, skilled nursing, personal assistance, durable medical equipment and supplies, home health, home-delivered meals, home chores, adult day health, community-based transportation, housing, and social programs.

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

The participant's goals and priorities, as identified in the assessment and care planning process, must drive the development of his or her community-based support plan.

3.7.2 Are participants able to maintain existing relationships with LTSS providers?

Continuity of care with LTSS providers is a cornerstone of disability-competent care. If a participant's previous provider is not in the network, disability-competent organizations may provide an option to use the out-of-network provider for a determined period of transition.

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

Disability-competent organizations may consider hiring or contracting with LTSS providers or community providers.

3.7.4 Is there capacity to develop specific services not readily available in the community that are specified in the individual's IPC?

If the local community lacks any specific services required by the participant, engage other community-based organizations or social agencies in developing the needed services. Examples may include working with a home care agency to add homemaker services or with local churches to start a food pantry.

This Tool is a work in progress and your feedback allows us to continually improve.
Please send comments to sloehrer@ihi.org.

INTERPRETING YOUR RESULTS

Reviewing Your Results

The following is a suggested approach for reviewing your results from the Disability-Competent Care Self-Assessment Tool.

| | |
|---|--|
| 1 | Convene staff that completed the Tool. |
| 2 | Ask staff to share first impressions and major insights. |
| 3 | Set ground rules for addressing and resolving discrepancies. |
| 4 | Together, assess and prioritize the elements within each of the three domains. |

How do we evaluate our Self-Assessment?

Self-Assessment Evaluation

Each element in the Tool will fall into an Assessment Category (green, yellow, orange, or red) based on your responses. The Assessment Categories are described below.

| ASSESSMENT CATEGORY | PROCESS | RELIABILITY | IMPACT | RESOURCES | Interpretation |
|---|---------|-------------|--------|-----------|--|
|  | Yes | Yes | — | — | Reliable process for the element. No further action required. |
|  | Yes | No | — | — | There is a process for this element, but it is not yet reliable. |
|  | No | — | Higher | Yes | Could create a reliable process with existing resources and will have a higher impact on the population you serve. |
|  | No | — | Higher | No | Require additional resources to create a reliable process and will have a higher impact on the population you serve. |
|  | No | — | Lower | Yes | Could create a reliable process with existing resources, but will have a lower impact on the population you serve. |
|  | No | — | Lower | No | Require additional resources to create a reliable process, but will have a lower impact on the population you serve. |

How can we use the Tool results?

Establishing Priorities Using the Assessment Categories

To guide your organization's priority-setting process, the Tool results are categorized into four Assessment Categories: **green** (existing process is satisfactory and reliable), **yellow** (existing process needs improvement, not reliable), **orange** (no process exists, creating one will have higher impact on population served), and **red** (no process exists, creating one will have a lesser impact on population served).

G

GREEN: Existing Process Is Satisfactory and Reliable

Based on your organization's self-assessment, these elements are satisfied by existing policies, practices, and procedures that are reliable. No further action is required unless your team determines otherwise.

Y

YELLOW: Existing Process Needs Improvement, Not Reliable

These elements are your organization's "lowest hanging fruit" in terms of becoming an organization that is more disability-competent. You might want to review the reliability/unreliability of these processes to determine opportunities for improvement.

As you examine these competency elements, you may want to answer the following questions: Are there adequate resources allocated to existing processes that fulfill these elements? Are policies and procedures being misinterpreted, ignored, or circumvented? What action can you take to better ensure these existing processes fulfill the specific competency elements?

O

ORANGE: No Process Exists, Higher Impact on Population Served

These elements are strategic opportunities for high-impact changes to your organization's disability competence. Although there is no current process in place for these elements, you have suggested that you believe these elements could have a higher impact on disability competence based on your organization's mission, needs, and population served.

As you examine these competency elements, you want to first distinguish between items your organization has resources to support and those for which it might not. To establish priorities for which elements you focus on first, discuss with your team which items could be more easily implemented based on resource availability, allocation, corporate culture, enrollee/member/beneficiary population, etc.

R

RED: No Process Exists, Lesser Impact on Population Served

These elements are strategic opportunities for lower-impact changes to your organization's disability competence. Of all the elements in the Tool, these might be the most challenging to fulfill for your organization since there are no processes in place to fulfill them, and the lower impact of these competency elements establish them as lower priority than higher-impact opportunities in the "orange" category.

As you examine these competency elements, you want to first distinguish between items your organization has resources to support and those for which it might not. To establish priorities, discuss with your team which elements could be more easily implemented based on resource availability, allocation, corporate culture, enrollee/member/beneficiary population, etc.

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APPENDIX A: UNDERSTANDING YOUR POPULATION

How might we better understand the population that benefits from disability-competent care?

Understanding Your Population

Obtaining a comprehensive understanding of the characteristics and needs of the population for whom you are trying to improve care may help as you begin to prioritize the quality, health care utilization, and cost improvements that may be achieved through the provision of disability-competent care.

Data can be helpful in understanding descriptive characteristics, utilization patterns, and cost factors of the population you serve, whether you rely on your own data, data supplied by the payer(s), data from comparable cohorts, or a combination of these. The following key considerations can be particularly helpful in better understanding the care needs of people with disabilities that you serve.

Key Considerations for Care of People with Disabilities

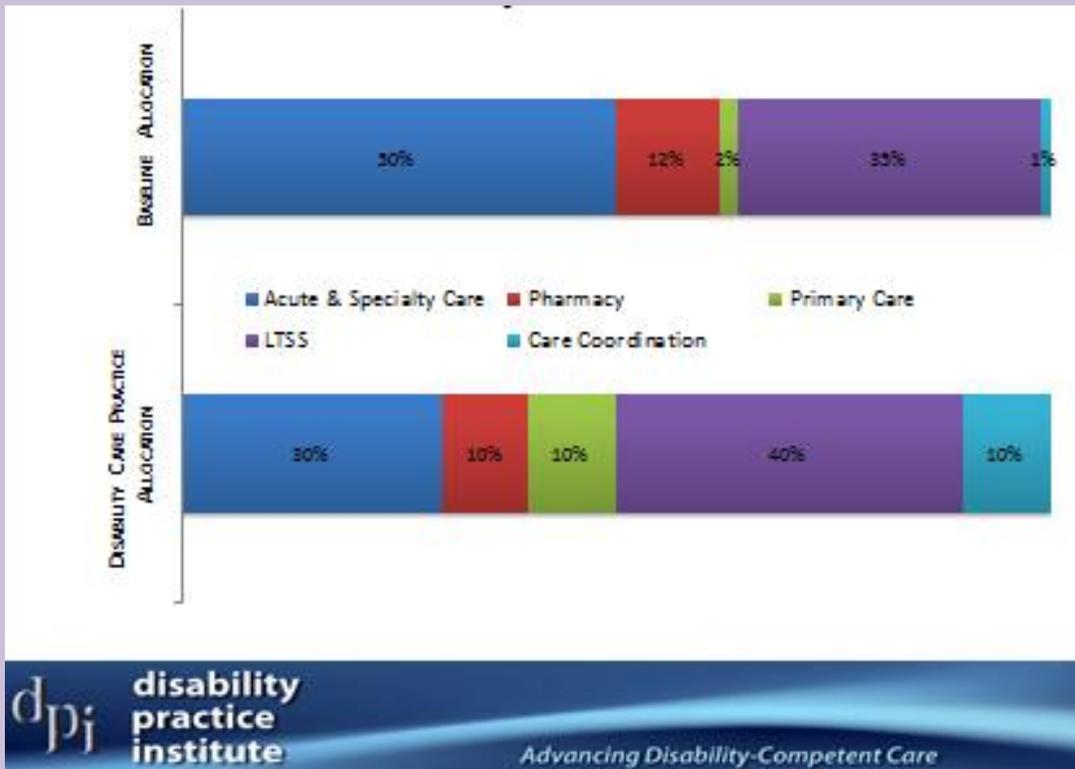
- **Residences:** Independently at home, in a supported living environment, or in an institutional setting
- **Chronic Conditions:** List and frequency of the most common chronic conditions and/or presence of co-morbidities
- **Disability-related Limitations:** Physical, mental, and/or intellectual, as well as ADL dependencies
- **Inpatient Utilization:** Number and cost of hospitalizations per person per year and primary admitting diagnosis
- **Outpatient Encounters:** Encounters occurring in primary and specialty care settings and incidence and cost of the encounters
- **Medications:** Average number of prescriptions per person and categorization based on number of prescriptions (e.g., percent of the population with 1 prescription versus 5 versus 10+)
- **Institutional Care:** Presence of, types, and cost of institutional care
- **Community-based Services and Supports:** Presence of home- and community-based services, types of home- and community-based services, and cost of each type of home- and/or community-based service

Allocating Resources

Identifying where resources are presently allocated may serve as a helpful baseline from which to assess opportunities to reallocate funding to more effectively meet the needs of participants who would be best served by a disability-competent care model.

Diagram 1 represents a typical allocation of resources that is best suited for the population that benefits from disability-competent care.

Diagram 1: Resource Allocation



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