



Commemorating 40 Years Of Disability Advocacy 1973-2013

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Dear Dr. Loehrer,

The Consortium for Citizens with Disabilities is a coalition of more than 100 national consumer, advocacy, provider, and professional organizations advocating on behalf of people of all ages with physical and mental disabilities and their families.

On behalf of the Consortium for Citizens with Disabilities Long-Term Services and Supports task force we thank you for publishing the Disability Competent Care Self-Assessment Tool and for accepting our comments and suggestions. We think a self-assessment tool for health plans and systems to evaluate their ability to meet the needs of people with disabilities is an invaluable project and we are impressed with tool you have created. However, there are a few areas which we think could be improved, refined, or clarified. We respectfully submit our feedback and hope that you will find it useful.

We endorse the strong support and clear focus throughout the document on providing care and supports to maximize independent functioning, addressing the barriers to care, supporting dignity of risk, and promoting the participant as the best source of information on his or her care goals and needs. While many health plans and systems have extensive experience providing acute or primary care, we are very concerned that many health plans lack experience in providing long-term services and supports and behavioral health services in a manner that respects self-determination and independence. The increasing proliferation of managed care, including managed LTSS, and other integrated care programs through Medicaid and Medicare necessitate that health plans gain disability competence quickly. With this in mind, we are very supportive of inclusion of the following elements:

- Recognition of medical and institutional bias and the need to address the whole individual in section 1.2.
- The emphasis given to viewing the participant as the best source of information throughout the document, but especially in sections 1.8.1, 3.6.6, and 3.7.1.
- The attention to continuity of care, including maintaining a relationship with an external provider in section 1.3.2.3, the need for that provider to continue communications with the interdisciplinary team (IDT) in section 2.2.5, the need for participants to maintain access to existing personal care attendants (PCAs) in section 3.3.2, continuing self-directed supports already in place in section 3.4.1, and maintaining relationships with existing LTSS providers in section 3.7.2.
- The need for responsiveness of the IDT (section 1.3.2.4).
- The inclusion of non-clinicians, particularly family and friends, in the assessment in section 1.4.4, and as “care partners” in section 1.11, and including direct care workers in IDT interactions in section 3.5.3.
- The importance of the participant feeling empowered and informed of their right to agree or disagree, as well as establishing trust among the IDT (1.5.4).
- The mention of Centers for Independent Living and other peer supports (1.7.4).
- The inclusion of alternative services that are not traditionally covered, but facilitate functional independence and could create costs savings, particularly the idea that the participant may be the best

source of cost-effective alternatives in section 1.8.1 and the creation of a review process for these services in section 3.2.6.

- Recognition of the need for advance directives and sensitivity and counseling related to advance directives generally noted throughout section 1.9.
- The inclusion of employment supports in section 3.1.
- The inclusion of self-direction in section 3.3.1 and throughout section 3.4.
- The inclusion of section 3.6 devoted to transportation, as well as mentioning transportation as a barrier to care in 2.2.2.

There are sections we believe could be further improved, refined, or clarified. For example, the Disability-Competent Model of Care is described as “aspirational.” That descriptor could be omitted since a disability-competent model of care should be the norm toward which all health plans strive, rather than an aspiration they may or may not choose to meet. Keeping in mind the lack knowledge or experience that care plans have in supporting people with disabilities, we offer the following suggestions:

- The term “care” is used throughout the document. People with functional needs clearly have health care needs. However, of equal and sometimes greater importance is their need for long-term services and supports. The term “care” communicates that people with disabilities need to be taken care of, an idea contrary to the goals of the assessment which promote participant control and independent functioning. There are many places in the document where the term care could be omitted, added to, or modified, thus avoiding the negative connotation. Some examples include:
 - Omit the word “care” when the meaning would not be compromised. For example, page 3, paragraph 2, second sentence: “This requires health care professionals to collaborate across disciplines and ~~care~~ settings and engage in meaningful partnership with the participant.” Eliminating the word “care” also expands the concept of settings so that they could include employment or recreation settings.
 - Add the word “health” in front of care. For example, on page 2, paragraph 3, first sentence: “Current models of health care delivery are not always well suited to addressing the needs of those with functional limitations.”
 - Modify language where the word “care” is used. For example, on page 4, paragraph 3, second sentence: “How the model is applied will vary based on the population’s characteristics, ~~care~~ needs for health care and long-term services and supports, and ~~care~~ service utilization patterns.”
- Section 1.1.3 suggests that participants (and families or caregivers) need to be involved in program planning and implementation to ensure a participant-centered focus. Participant involvement is essential and the families’ presence may be warranted when the participant is a child or when the participant has a direct support worker or personal care assistant that facilitates communication. However, participation from families, or caregivers who are already represented on the IDT, may not always be necessary or wanted by a participant. Please consider changing the language to: “participants (and families or ~~caregivers~~ direct support workers where appropriate or requested by a participant)”
- Personal care assistants (PCAs), as mentioned in sections 1.2.2, 3.2.6, and throughout 3.3, is a term somewhat specific to the population of individuals with physical disabilities. People with intellectual and developmental disabilities (I/DD) use different terms, including “direct support worker” (included in the tool in section 3.5.2), and “direct support professional.”
- Section 1.3.1.5 should clarify that in addition to assigning a clinician as team leader, the participant should also be automatically considered a team leader.
- The wording of section 1.3.2.1 seems to indicate that the IDT can meet without the participant. The participant should be invited to all meetings that discuss him or her. This will promote respect for and empowerment of the participant, and facilitate the sharing of key information that only the participant

can provide, supporting your point on page 3 that, “The participant is not merely a passive recipient of medical care, but rather the primary source for defining care goals and needs.”

- Sections 1.3.1.6, 1.5.3, and 1.4.6 mention rehabilitation but not habilitation. While habilitative and rehabilitative services are often provided by the same type of clinician (an occupational therapist for example), habilitation is different from rehabilitation. Habilitation services are provided for a person to attain, maintain, or prevent deterioration of a skill that has never been acquired, while rehabilitation services are provided to help a person regain, maintain or prevent deterioration of a skill that had been acquired but then lost. With the inclusion of both habilitative and rehabilitative services in the essential health benefits of the Affordable Care Act and continued efforts to define habilitation at the state level, it is important to be clear that both are provided by listing both services.
- Section 1.4.5 includes domains to be assessed in creating the IPC. The list of “formal, informal, and social supports” should also include “natural supports,” a term used in the I/DD service system for neighbors, friends, family, and other supporters who are unpaid but nevertheless central to an individual’s life and should be included in discussions of service and care coordination.
- Section 1.6.1 suggests that IDT members be alerted when there is a change in a participant’s health status or care needs that would affect the individualized plan of care (IPC). In Section 1.1.2 you note the importance of discussing a participant’s goals, values, and preferences for his or her care.” Consider suggesting that IDT members be alerted to changes in a participant’s goals, values, and preferences in addition to changes in health status and care needs.
- Section 1.7.4 covers peer support and counseling services. We strongly support this section, especially the mention of Centers for Independent Living. Further examples could also include independent consumer and family monitoring teams as well as peer wellness specialists used in the mental health field.
- Section 1.9 covers advance directives. The term “advance directives” has specific meaning in the mental health community. ADs are developed to communicate preferences should an individual need psychiatric hospitalization and be temporarily unable to clearly communicate preferences. To avoid possible confusion, perhaps another term, such as “living will” would be appropriate. In addition, consider referencing the 1990 Patient Self-Determination Act (PSDA), which encourages everyone to decide about the types and extent of medical care they want to accept or refuse if they become unable to make those decisions due to illness. The PSDA requires all health care agencies to recognize the living will and durable power of attorney for health care. The Substance Abuse and Mental Health Services Administration and the Bazelon Center for Mental Health Law have many excellent resources on the topic of psychiatric advance directives.
- Section 1.9.2 suggests that staff be trained in disability sensitivity, awareness and respect. We support this kind of training and encourage including language making clear that some participants with disabilities will prefer that all possible measures and equipment be offered to support and maintain independence and life.
- In section 1.11 we support the inclusion of individuals chosen by the participant to provide assistance and coaching. However, the term “care partner” denotes being taken care of, and may not accurately represent the relationship between the participant and the chosen individual. People with disabilities frequently choose to have a representative accompany and assist them in planning meetings and visits to health care professionals. They may choose a representative to assist them in directing their own long-term services and supports, including assistance with hiring/firing/supervising direct support workers. In this case, “representative” may be the preferred term. In cases of a friend or family member providing support, the terms “partner” or “supporter” could also be alternatives.
- We support section 2.2 which addresses accessibility and availability of care. However, section 2.2.6 concerns only the physical accessibility of offices and home and community based settings to people who use wheelchairs. People with mobility needs use aides in addition to wheelchairs. This section could be improved by also mentioning other mobility aids, such as walkers, scooters, crutches, braces, and canes (including canes used by blind people), to further educate providers about accessibility.

- We support the inclusion of Section 2.4.1, which addresses access to the proper care and equipment. People with spinal cord injuries or disorders often need medical supplies and customized mobility equipment called complex rehab technology (CRT). However, CMS’ competitive bidding program and “in-the-home” requirements can limit access to these necessary supplies and technology. Please consider adding language to 2.4.1 to reflect the need for appropriate medical supplies and access to CRT to meet participants’ goals, including a suggestion that the care organization maintain connections with a wide provider network and be aware that proper equipment can be difficult to obtain, either because of lack of options due to competitive bidding programs at the national and state levels and Medicare rules limiting types of equipment in the home.
- Section 2.5.1 lists secondary conditions that are common among people with disabilities. Alzheimer’s and other dementias should be added to that list, as people with Down syndrome have a high incidence of early onset Alzheimer’s.
- We support the inclusion of employment supports in section 3.1. Supported employment, a service funded through Medicaid, should also be included.
- We support the inclusion of Section 3.2 on mobility equipment, home modifications, and supplies. Please consider adding language to 3.2.2 to reflect the need for appropriate medical supplies and access to complex rehab technology (CRT) to meet participants’ goals. Additional examples of equipment, modification and evaluation could include: “Proper evaluation for complex rehab technology,” and “specialized medical supplies such as catheters.”
- Section 3.5 covers agency-model supports and shared living. A few changes could make the section more applicable to people with I/DD:
 - The opening paragraph is a good place to reconsider use of the word “care.” “Home-based care” could be replaced with “home and community-based services” and “home care agency” could be replaced with “home and community-based services provider.”
 - The opening paragraph lists settings where participants might be living. The list should also include supported residences, shared living arrangements (which has a specific meaning in the I/DD service system) and group homes.
 - As stated in section 3.5.1, direct support services are often tied to the residential provider in the agency model. However, the I/DD community is trying to move away from a model of bundled housing and direct support services. To acknowledge this trend, the section could be revised to read “Optimally, housing and LTSS are not provided by the same entity; however, since services may be attached to the residential setting, it is important to offer as wide a choice as possible.”

Thank you again for your attention to the important matter of disability-competent services. We hope that you consider our suggestions.

Sincerely,

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