

Preparing for New Roles and Responsibilities – Disability-Competent Care Team Readiness

Leading Healthcare Practices and Training: Delivering Disability-Competent Care

Disability-competent readiness prepares individuals with disabilities, or “participants,” and his or her disability-competent care teams to partner to achieve the participant’s goals and support his or her health and health care. As a result, the participant is better able to take charge of his or her health and health care, rather than simply being a passive recipient of care. Likewise, the care team members become care partners with the participant and are part of a broader participant-focused interdisciplinary care and support team, rather than simply discipline-based caregivers.

Disability-competent care staff readiness to engage in a productive partnership can be facilitated through trainings focused on understanding disability literacy, participant-centeredness, dignity of risk, keeping participants informed, and the rights of patients with disabilities (e.g., the Olmstead decision). The disability-competent care team members should also be responsive to the participant’s needs in all aspects, respect the participant’s preferences, and not assume they know all the answers and being willing to ask questions and partner with the participant to achieve the goals. Moreover, they must be aware of their own emotional responses to disabilities, function as an interdisciplinary team focused on the success of the participant, and proactively address any conflicts or disagreements with the participant or within the team.

As part of their initial orientation and ongoing staff training and coaching, for example, **Independence Care System (ICS)** (*see insert for profile*) prepares their staff to understand the following:

- **Lived experience of disability** – Staff are made aware of stereotypes (e.g. that the disability defines the individual) and self-perceptions among participants. They also discuss how participants have a wide range of unique experiences and reflect upon statements like “people with disabilities cannot/should not...”
- **How to understand a participant’s situation and actively listen** – Staff are encouraged to openly communicate with participants regarding how he or she feels about having a disability. Moreover, they discuss questions such as “How do you think this person would describe him or herself?” and “What do these stories have in common and differ?” Staff also reflect upon the differences between having a disability from birth or early childhood and acquiring a disability in adulthood.
- **Impact of isolation** – Staff reflect upon participant stories and questions such as “How does isolation affect this person?” and “How can this person have more contact with other people with disabilities?” ICS also uses guided imagery to better understand the impact of isolation, as well as the fear of institutionalization that an individual with

Profile: Independence Care System

- Nonprofit, Medicaid managed long-term care plan that was organized in 2000 to serve adults with physical disabilities in New York City
- Includes about 8,000 members, most of whom are eligible for Medicare and Medicaid
- Serves persons 21 years and older whose disabilities are due to severe injury or degenerative neurological and muscular diseases, or the fragility related to aging

- disability may feel. In addition, staff discuss how to encourage participants address any feelings of isolation and help them to identify strategies for dealing with isolation.
- ***Follow the participant-centered independent living values*** – ICS ensures that staff partner with participants, value the expertise of both their staff and their participants, and utilize a care management team approach to implement the integrated care model with every participant.
 - ***Understand disability rights and support participant choices*** – Respecting participant’s dignity of risk and not controlling the participant’s decisions, even where the staff feels the participant is taking a risk, is integral to the participant-centered approach.

Additional Resources

The Disability-Competent Care Model is based on the lived experiences of persons with disabilities and over 20 years of experience at three health plans. For more information, please visit the *Resources for Integrated Care* website (<https://www.resourcesforintegratedcare.com>). There you will find the “Defining and Delivering Disability-Competent Care” webinar series, which was the basis for this brief and other resources on the Disability-Competent Care Model.