

MEASURING COMMUNITY INTEGRATION

Introduction

Measuring community integration is a critical component of a State's Olmstead Plan. The Olmstead vision as articulated in the court case and the subsequent DOJ guidance states "the most integrated setting is one that enables individuals with disabilities to interact with non-disabled persons to the fullest extent". Currently, there is not an agreed upon definition of community integration (it means different things to different people and to different agencies) and therefore there is not a standard to measure community integration. Additionally it is difficult to know if community integration actually occurs just because a person moves from larger setting to a smaller setting. To know if people are actually integrated into the community, one must know about their life experiences in the community. This requires a measurement of more than just the types of places in which they live but also the types of lives they have in the community. It requires outcomes measures related to their quality of life.

There is no common strategy used by states to measure system effectiveness in achieving community integration and inclusion for people with disabilities in Home and Community-Based Services (HCBS). A major impediment is finding agreement amongst stakeholders on what to measure. Since there is finite opportunity to assess each service user, the data sources must prioritize measures and survey items. As a result, the data sources have different strategies to measure the topic. A recent U.S. Department of Health and Human Services environmental scan of measures used in HCBS highlights the challenge (2010), where a number of complimentary outcomes directly intersect with the construct of integration and inclusion. Existing evaluative measures have similar constructs that focus on the following themes: friends and family relationships, support needed for relationships, employment and school attendance, and social roles. In addition, at least 15 existing measures, from many data sources, seek information about community inclusion and integration explicitly.

There is also no common strategy on how to measure the many constructs and domains related to community integration and inclusion. To appropriately evaluate integration and inclusion, it is necessary for measures to adequately capture the diversity of the service delivery system. For example, employment is often times used as an associated measure to integration and inclusion. As pointed out in the environmental scan of measures used in HCBS, employment is measured in a number of different ways. It is often times measured dichotomous, where a person either has a job or is unemployed. Using such a measure to indicate more or less integration or inclusion can be misleading since employment in the HCBS system can be achieved in both integrated and segregated settings (U.S. Dept. of Health and Human Services, 2010).

The Minnesota Olmstead Planning Committee (OPC) has identified the need to develop a robust data system that tracks trends and outcomes of services and supports by population and over time. Currently the State of MN has fragmented data systems within the Department of Human Services and across other state agencies. These various systems have been mandated or developed to monitor services for a particular disability population, a specific program or service and therefore they are not integrated. Thus they can be difficult to use to identify trends over time and across populations. Additionally, the

data is often not easily understood by all stakeholders because terminology is not consistent and it is difficult to compare information across populations or groups within specific populations. In some instances, data is not collected. In consent decrees/settlements across the nation The Department of Justice is requiring specific data be collected to measure integration over time and across populations. It is important that the state of Minnesota develop a framework and indicators of community integration and implement a process to gather and trend this data over time.

There are several examples of measurement tools that have been developed and used by state's to measure community integration and the outcomes of community services long term services and supports. To assist state's in assessing community integration for a state's mental health system for adults with serious mental illness and children with serious emotional disturbances the Substance Abuse and Mental Health Services Administration (SAMHSA) recently developed "A Pilot Self-Assessment Tool For State Mental Health Agencies: An Effort to promote Community Integration of Persons with SMI and SED placed in Institutional Treatment Settings" available on our website. This provides an example of the type of measurement documentation that will need to be developed that includes community integration progress indicators across long term services and supports for the disability populations that fall within the scope of the Minnesota Olmstead Plan.

As evidenced in the recent Measurement tools related to the outcomes and quality of life of people with disabilities have been developed as indicators of community integration. The National Core Indicators were developed by the Human Services Research Institute and the National Association of State Directors of Developmental Disability Services and are currently used in 36 states (<http://www.nationalcoreindicators.org/>). The Participant Experience Survey, which was originally developed by Thompson Reuter through a contract with CMS was developed for use with Home and Community Based Services, and adapted by Minnesota for use with older adults and people with disabilities of all ages. Region 10, in Minnesota, developed a VOICE review process to focus on a person's life and inclusion in community activities that is used as an alternative licensing process. The Continuing Care administration has been working on the development of measures of CHOICE outcomes in Minnesota, including work by the Department in developing dashboards and report cards, the HCBS Partner Panel, the State Quality Council, and the MnCHOICES assessment and support planning development. While many options exist to monitor and report outcomes and quality of life indicators related to community integration, currently in Minnesota this type of data is not collected consistently and across populations in a way that progress is trended and reported.

Recommendations

- Develop and implement a measurement rubric that tracks the movement of people with disabilities from specific types of congregate care facilities to community settings over time. In doing so, modify the tool developed by SAMHSA to include measurement domains across financing/resources, movement to the community/recidivism, housing and community capacity/utilization that are appropriate to specific populations (e.g. developmental disability, mental health, brain injury, physical disability) and long term services and supports in Minnesota (e.g. HCBS, nursing home, psychiatric hospitals, sheltered work programs).

- Implement an outcome measurement process that gathers specific outcome indicators related to the populations included in the MN Olmstead Plan about the quality of their lives in the community. This measurement process should gather data across several areas of life domains including health, safety, well-being, employment, social relationships, home, satisfaction with services and supports, choice and control, and inclusion/integration. It should provide comparative analyses opportunities across programs, populations and in comparison with other similar states.
- The data gathered to monitor community integration and the outcomes experienced by people who have been integration should be easily accessible to the general population and should provide comparisons of the progress made in MN over time and in comparison with other similar states. Annual progress should be reported.

U.S. Department of Health and Human Services. (2010). *Environmental Scan of Measures for Medicaid Title XIX Home and Community-Based Services*. AHRQ Publication No. 10-0042-EF, Agency for Healthcare Research and Quality, Rockville, MD. <http://www.ahrq.gov/research>