

ISSUE BRIEF

Long-Term Supports and Services for People with IDD

December 2015

People with intellectual and developmental disabilities (IDD) often rely on long-term services and supports (LTSS) to help with activities of daily living, daytime activities, and community participation. Most people with IDD rely on informal supports from family caregivers; however, more than 639,000 people receive formal out-of-home residential supports. Many factors will impact future demand for LTSS, including aging caregivers, increasing waiting lists for services, budget constraints, new federal regulations, and increased expectations for more integrated services. Ongoing research is needed to examine funding inequalities, inconsistencies in quality metrics and measurement, the emergence of managed long-term services and supports (MLTSS) programs for people with IDD, and the availability of behavior supports, particularly positive behavior support (PBS).

► Introduction

While 639,000 people with IDD received publicly financed residential supports in 2013, an estimated 117,000 people were on waiting lists for these supports (Larson et al., 2015). Furthermore, while an additional 366,000 people received supports funded under Medicaid waivers while living with a family member, another 108,000 were waiting for in-home supports (Larson et al., 2015). In 2013, the US spent over \$61 billion on formal LTSS services, with most funding (82%) allocated for residential supports in settings for 6 or less, and for non-residential community supports. Five percent supported individuals in settings for 7-15 people, and 13% supported individuals in institutional settings (Braddock et al., 2015).

Use of state IDD institutions has been declining for nearly five decades. While the census peaked in 1967 at 195,000 people, by 2013 only 25,000 people remained. These facilities are in 37 states—13 states and the District of Columbia have closed all of their state-operated facilities for 16 or more people with developmental disabilities (Braddock et al., 2015). This shift away from institutions has meant that people with IDD have more opportunities to lead lives in the community; however, there is still a lack of meaningful and reliable data and measurement tools for understanding the impact of community-based programs.

Among the recent trends in long-term supports and services for people with IDD has been a movement towards models of managed care, referred to as Managed Long-Term Services and Supports (MLTSS). Prior to 2012, only seven states had MLTSS programs for individuals with IDD. Since then, six additional states have developed or implemented programs and four more plan to do so. While very little is known about the quality and impact of MLTSS on people with IDD and their families, MLTSS does provide opportunities for improved coordination and integration, reduced health disparities, increases in prevention and wellness visits and activities, options and opportunities for self-direction and training of healthcare providers, accelerated rebalancing of systems, reduced waiting lists and unmet needs, and the potential for reinvestment of savings in added benefits. Stakeholder engagement and strong federal and state

oversight are needed to identify barriers and facilitators of effective MLTSS.

National Core Indicators data from 2014 suggests that 43% of adult recipients of IDD services required ongoing

IMPACT

Katie has two part-time jobs in her community. She moved from her parent's home into her own apartment a year ago when she received a housing voucher from HUD. She is enrolled in one of the state's Medicaid HCBS waivers which she uses for job coaching, a life coach, a money manager, and a fiscal broker. When asked about her quality of life, she says "life is good."

Susan grew up in a home with her parents. While she qualified for 10 hours of respite services a month, her parents had problems finding respite workers they felt comfortable leaving her with and didn't use all the respite hours each month. As she got older, Susan's LTSS needs changed and she mostly relied on transportation and speech therapy services. When she turned 22, she moved into an apartment with a friend. While living in the apartment, she learned to cook and enjoyed entertaining friends and family. She had a job she enjoyed in childcare and developed friends among her co-workers. She received intermittent supports from the HCBS waiver. After a few years of living fairly independently, however, her parents (who were also her guardians) placed her in a private institution with 24 hour services because they thought the specialized campus was safer for women with disabilities "like our Susan." Now Susan is sad that she doesn't get to see her friends or works at the daycare center, but instead attends a day program where she does work she describes as "boring."

behavioral supports. While Positive Behavior Supports (PBS) is the preferred approach to support people with complex behavioral needs, it may not be utilized due to lack of knowledge, inconsistent service definitions, and the lack of credentialed providers.

► Need for Research

As the system of publicly funded LTSS evolves, research will be needed to monitor whether adequate funding and quality standards are in place, especially with MLTSS programs and

the application of PBS. What we choose to fund shapes the service system, and in a changing landscape we are challenged to create person-centered, coordinated systems of support. We need quality measures to assess new programs, and to monitor the outcomes of policy changes.

► Funding Research Goals

People with IDD will have funding for and access to the person-centered long term services and supports they need to reach their desired outcomes. This goal encourages research into funding authorities and models that increase access, quality, and efficiency of supports that enable people with IDD to achieve their preferred outcomes. Research should focus on facilitators and barriers of service and funding models to providing appropriate, person-centered supports.

► Quality Research Goals

Research designed to elicit LTSS outcomes data is essential to enable states and service providers to continually improve policies and practices and to facilitate the understanding of successful transitions of service systems that embody the 2014 HCBS settings rule. Metrics to measure service outcomes that are most important to people with IDD, including merging technologies, should be developed; and research should be conducted on decision-making authority and individual's quality-of-life outcomes. In addition, a coordinated system for gathering, analyzing and sharing information on best practices at the individual, provider and state levels regarding best practices should be developed with the goal of improving LTSS outcomes for people with IDD.

► MLTSS Research Goals

While states increasingly delegate control of LTSS delivery to other entities, their obligation for oversight (including gathering, analyzing, and reporting data on performance and outcomes) continues. Research designed to identify effective models of care coordination; barriers to and facilitators of increasing integration between acute, behavioral and LTSS systems; and strategies to ensure access to and continuity of care, is necessary to meet those oversight obligations. The maintenance of robust data systems by states to monitor publicly funded service utilization and outcomes for people with IDD can also be used for ongoing quality enhancement and longitudinal research on LTSS systems.

► Public Policy Research Goals

Research that examines the intended and unintended consequences of shifts in public policy regarding LTSS for

people with IDD on the state and national levels will drive changes in future policy, research and service delivery.

► PBS Research Goals

As individuals with complex behavior needs are increasingly supported in their communities, research on outcomes and costs associated with implementing PBS systems is essential. In particular, this research should focus on how PBS can be effectively and practically implemented, and on the type and nature of technical assistance efforts needed to translate knowledge to practice.

► Conclusion

Addressing these research priorities will achieve multiple meaningful outcomes for people with IDD, including increased implementation of evidence-based (and practice-based) policies, meaningful improvements to services delivered to those in need of behavioral supports, and improved outcomes and quality of life for those receiving home-and community-based LTSS.

► References

- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities*: Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Larson, S.A., Faykin, F., Muchow-Hallis, L., Pettingel, S., Taylor, B., Hewitt, A., Sowers, M., Fay, M.L. (2015). *In-Home and Residential Long-Term Supports and Services for People with Intellectual or Developmental Disabilities: Status and Trends through 2013*. Minneapolis: University of Minnesota, Institute on Community Integration, Residential Information Systems Project.

► Acknowledgements

Brief authors Mary Kay Rizzolo, PhD, and Randall Owen, PhD, both of the University of Illinois at Chicago, gratefully acknowledge the members of the Long Term Supports and Services strand for their contributions to the work of the *National Goals* conference, this policy brief, and other supplemental materials.

This material was created with support, in part, by the American Association on Intellectual and Developmental Disabilities; the Association of University Centers on Disabilities; The Arc of the US, the National Institute on Disability, Independent Living, and Rehabilitation Research; the Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities at the University of Massachusetts Boston (Grant #90RT5028); the Research and Training Center on Community Living and Employment at the University of Minnesota (Grant #90RTT5019); and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago (Grant #90RT5020).

The views and opinions expressed in this document were generated by independent teams at the *National Goals* Conference held August 6–7, 2015 in Washington, DC. They do not necessarily reflect the official policy or position of any of the planning partners or the National Institute on Disability, Independent Living, and Rehabilitation Research—endorsement by the federal government should not be assumed.