

PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES:

A Unique Population With Unique Needs for Managed Care



IDD MLTSS workgroup

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Although people with disabilities make up a small proportion of Medicaid enrollees, they account for a significant portion of costs.¹ ² In particular, people with intellectual and developmental disabilities (IDD) incur higher annual health care costs despite being a smaller proportion of the population.^{3,4} The aim of this brief is to explain why people with IDD are a large driver of costs, including by pointing to their unique support needs and the uniqueness of service models for people with IDD.



8 million people with IDD in the U.S.⁵



\$53 billion spent on Medicaid IDD services annually⁶



590,000 people with IDD are on waitlists for HCBS⁷



A Brief History of The IDD Service System

Institutions were originally created in the 1800s in the United States as a way to educate people with IDD.⁸ However, as a result of increased censuses, institutions quickly shifted from educational schools to mere custodial institutions.⁸ In the 1950s and 1960s, institutions began to fall out of favor due to severe overcrowding and increased reports of poor care, neglect, and abuse.⁸ Factors such as advocacy by people with IDD and their families, a shift in public opinion, and legal rules and legislation all led to new standards of care for people with IDD, and led to deinstitutionalization – a shift to community-based settings.⁸

The introduction of Long-Term Services and Supports (LTSS), including Medicaid Home and Community Based Services (HCBS) waivers, in particular also helped spur deinstitutionalization. These changes led to the United States census of state institutions for people with IDD peaking in 1967, with the majority of people with IDD moving to community-based settings, such as group homes.⁹ Over the last five decades, the state institutional census has decreased 85% – an average of 4% per year.^{6,9} As of 2015, 70% of Medicaid funding for people with IDD was allocated specifically for Medicaid HCBS waivers.⁶ Not only is community living preferred by people with IDD and their families, it also produces better outcomes, including for people with higher support needs, and it is more cost effective.^{6, 10-14}



Service Needs of People with Intellectual and Developmental Disabilities

People with IDD face a number of health disparities compared to both nondisabled people and people with other disabilities.¹⁵ However, people with IDD's health disparities are only in part due to their disabilities; instead, social determinants, such as social circumstances, environmental conditions, access to healthcare services, poverty, and social exclusion, all play a large role in people with IDD's health.¹⁶ In fact, people with IDD's health and quality of life is largely impacted by, and dependent on, the government services they receive.¹⁷⁻¹⁹ As a result of the unique needs of people with IDD, services and supports are often unique, even compared to people with other types of disabilities.^{3, 6, 18, 20}



How Long-Term Services and Supports Differ from Acute Care or Other Systems

Unlike acute health care, which tends to be more episodic, LTSS are lifelong community- or facility-based services and supports for people who need support to care for themselves because of disability, age, or functional limitations. LTSS go beyond health and wellness, and cover quality of life more broadly, including by addressing social determinants of health. LTSS for people with IDD often include not only traditional acute health care services, but wrap-around services, such as residential habilitation, supports for people to live in their own homes or family homes, employment supports, and many more services.²¹ In fact, less than 5% of the HCBS IDD waiver spending in fiscal year (FY) 2015 was allocated for traditional acute care services.^{6, 21} Instead, the majority of spending in FY 2015 was projected for wrap-around type services, such as residential habilitation (42%), supports for people to live in their own or family home (20%), and day habilitation (16%).²¹ As such, traditional acute care metrics cannot simply be applied to alternative payment systems for the LTSS of people with IDD.



Quality Outcomes for People with IDD

IDD LTSS are more expensive because, unlike episodic acute care, the IDD LTSS system attends to social determinants of health. Attention to social determinants not only helps promote health outcomes and health equity, it can increase quality of life. In addition, by reducing health disparities there is also an opportunity for cost savings. For example, our research suggests respect, meaningful days, staff training, and many more social determinants have an impact on people with IDD's emergency room visits, injuries, medication errors, and behavioral events – by focusing on quality, it may be possible to lower more traditional health care and programmatic costs.²²⁻²⁷

As a result of the uniqueness of IDD LTSS, as well as a lack of quality standards for managed LTSS for people with IDD²⁸, our workgroup recently released a report on person-centered quality outcomes for managed LTSS for people with IDD: *Alternative Funding Models for People with Intellectual and Developmental Disabilities: Quality Outcomes and Measurement Metrics*.²⁹ This report, which is based on best-practices and evidence based research, includes a set of recommendations regarding outcomes related to managed LTSS and people with IDD. The report also includes a crosswalk matrix between recommended outcomes and existing metrics at the individual, provider/payer, and state level. States and MCOs can utilize our recommended outcomes for establishing value-based payments, monitoring, and/or quality improvement.