



State Strategies for People with I/DD with Complex Support Needs

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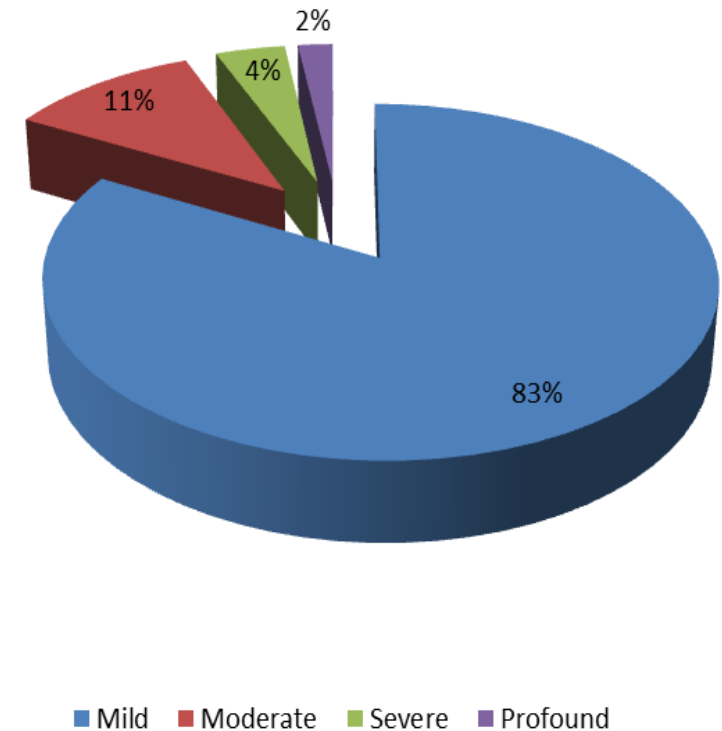
Introduction

- Individuals with cognitive disabilities, including intellectual and developmental disabilities (I/DD) come from different backgrounds and cultures, different socioeconomic backgrounds, have varied language and/or communication preferences, have different interests and passions, have different types of support needs, have different medical conditions, experience love and loss and trauma, may have mental health support needs – just like people who don't have I/DD.
- Federal and state systems of support have not always recognized the nuanced human condition that requires a multifocal approach to supporting people successfully
- To meet the full needs of people, state systems must shed siloed approaches to support and collaborate to achieve true person-centeredness and optimal outcomes

Intellectual/Developmental Disability (I/DD)

- A condition characterized by significant limitations in both intellectual functioning and adaptive behavior that originates before the age of 22.
- Approximately 6.5 million people in the United States have an intellectual disability. Approximately 1 – 3 percent of the global population has an intellectual disability—as many as 200 million people.
- *About one in six children in the U.S. have one or more developmental disabilities or other developmental delays.*
- Developmental disabilities are *a group of conditions due to an impairment in physical, learning, language, or behavior areas*. These conditions begin during the developmental period, may impact day-to-day functioning, and usually last throughout a person's lifetime.

Intellectual Disabilities Categorized by Severity



I/DD and Complex Medical Support Needs

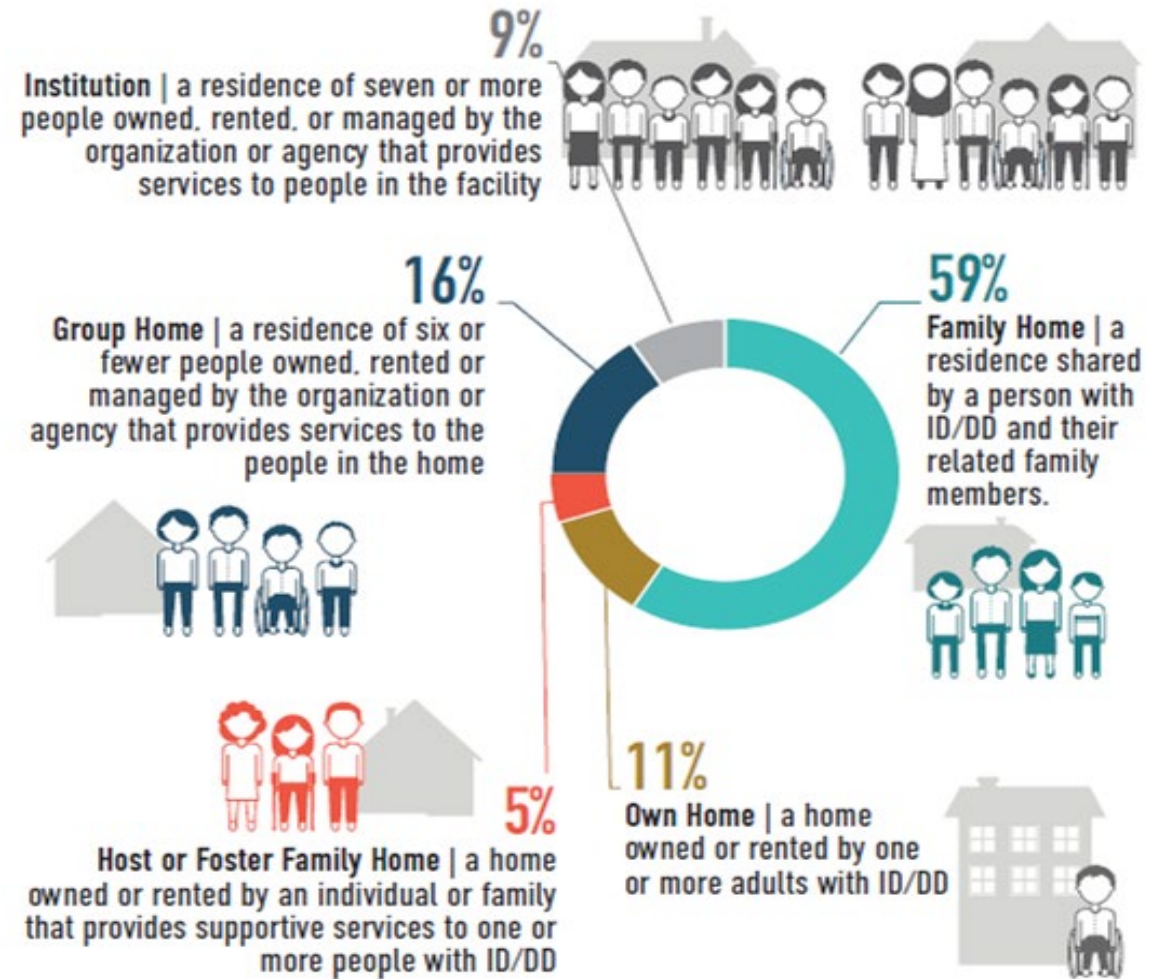
- COVID-19 revealed the intense need for better health care coordination and support for people with I/DD.
 - Individuals with I/DD are at greater risk for infection and adverse health outcomes due to COVID-19 than individuals without I/DD for a variety of reasons, including:
 - a high prevalence of underlying medical conditions;
 - difficulties accessing information, understanding or practicing preventative measures,
 - and communicating symptoms of illness;
 - and residing in a congregate care setting.
- Holistic approaches to wellness and health require cross-system strategies and collaboration for this population

I/DD and Mental Illness (MI) Dual Diagnosis

- **Some people with an intellectual/developmental disability (I/DD) concurrently experience a mental health condition.** While the exact prevalence is unknown, most professionals accept that roughly 35% of people with intellectual disabilities also experience mental health challenges.
- People with I/DD are 2-3 times more likely to also have a MI than general population
 - Comorbidity rate somewhere between 13.9% and 75.2%
 - Most likely due to lack of consistency in diagnostic definitions and assessment instruments; small sample sizes; lack of non-I/DD control sample in studies; and consideration for functioning level and type of disability
- Growing understanding that people with disabilities are not one-dimensional but complex like everyone

Living Arrangements

- Most people with I/DD live with family members
 - 85% of people with I/DD in the United States
 - 59% of long-term supports and services recipients
- Huge state variations
- Residence size has dropped dramatically



Larson, S.A., van der Salm, B., Pettingell, S., Sowers, M., & Anderson, L.L., (2021). Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2018. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

State I/DD Systems are Medicaid Systems

- Medicaid is one of the largest payers for health care in the United States, accounting for about 52 percent of all LTSS spending Medicaid and the Children's Health Insurance Program (CHIP) provide health and long-term care coverage to more than 76.3 million low-income children, pregnant women, adults, seniors, and people with disabilities*
- For individuals with I/DD, Medicaid is the primary source of both health care and LTSS
- Medicaid finances 40% of all long-term care spending
- The vast majority of LTSS for individuals with I/DD are provided through 1915(c) HCBS Waivers
- **Three quarters (74.6 percent) of the total 1915(c) waiver program expenditures were spent on people with autism spectrum disorder or intellectual or developmental disabilities in FY 2019.****



(O'Malley, Watts, et al. 2020)

June 2021 Enrollment Report Medicaid & CHIP Scorecard | Medicaid

**Murray, Caitlin, Alena Tourtellotte, Debra Lipson, and Andrea Wysocki. "Medicaid Long Term Services and Supports Annual Expenditures Report: Federal Fiscal Year 2019." Chicago, IL: Mathematica, December 9, 2021



Top Challenges Facing I/DD Systems

- Workforce (DSP and clinical)
- **Supporting individuals with complex support needs, including individuals with co-occurring I/DD and MH support needs and complex medical needs**
- Waiting list strategies (and reliable data) and equitable access across diverse communities within states
- Data availability and utilization to inform policy direction (including data necessary for forecasting and to inform initiatives related to diversity, equity, and inclusion) – increasingly essential for cross-system collaboration

Landscape of Emerging Medicaid Strategies

- Strong cross-system strategies emerging
- States pivoting to pay for outcomes and performance and striving to ensure the highest calibers of providers
- States building intentional strategies into HCBS to bridge the health and LTSS systems of support (i.e., target group-specific health-related/triage telehealth strategies)
- Exploration of opportunities to leverage Medicaid authorities to maximize person-centered strategies (health homes; contract provisions; case management)
- Investments in improved clinical capacity and DSP/family skills

Essential Elements for Successfully Supporting Individuals with Complex Health and Mental Health Conditions

ELEVATING VOICES OF INDIVIDUALS SUPPORTED AND ALLIES

Ensuring that individuals with lived experiences and their families are at the center of all policies, practices and service modalities is key.

POLICY MODERNIZATION

Many historic federal and state policies, particularly in the Medicaid program, have contributed to the exclusion of individuals with I/DD having equitable access to MH treatment. States making progress in these areas are undertaking policy and practice reviews to identify and eliminate these vestiges.

COMMUNITY SUPPORTS

Focusing on building a continuum of community supports to foster prevention and post-crisis supports is essential to avoid or minimize institutional utilization and to foster successful transitions back to the community when out-of-home options are needed

STATE SYSTEM COLLABORATION

State systems supporting individuals with I/DD and those supporting individuals with Mental Health Support needs must collaborate to identify and remove systemic barriers to effective treatment and ongoing supports for individuals with I/DD and MH support needs.

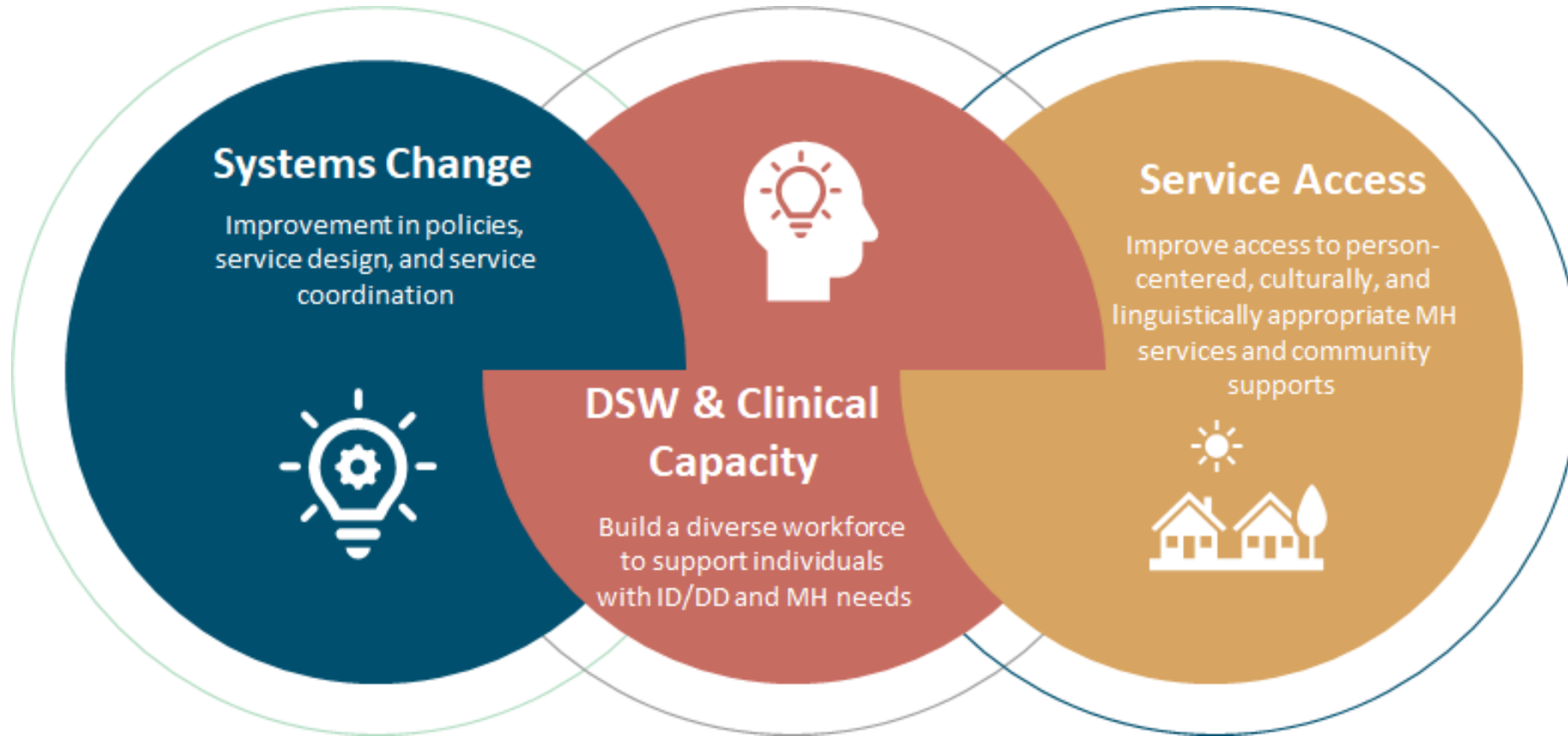
MULTIFOCAL CAPACITY BUILDING

Ensuring both clinical capacity of treating mental health professionals and capacity to support individuals in their homes and communities is essential for the sustainability of a functioning system that successfully supports individuals with I/DD and MH support needs. Devising scalable and replicable practices are key as is the effective use of technology to stretch available capacity.





Key Goals of the TA Center



Questions





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