

Long Term Supports and Services

Individuals with intellectual and/or developmental disabilities¹ (I/DD) deserve the opportunity for a full life in their community where they can live, learn, work, and socialize. To achieve this goal, they need a comprehensive, person-centered and directed, national system of appropriate high quality long-term supports and services (LTSS), with a reliable and immediately accessible funding source, including Medicaid, and a well-trained, fairly compensated workforce of providers and direct support professionals. Waiting must be eliminated.

Issue

Many barriers remain to ensuring that people with I/DD receive the long term supports and services they require to live a full life in the community.

National Crisis of Unmet Needs

The lack of a comprehensive community long term supports and services system is a national crisis requiring immediate national solutions. The patchwork of limited private LTSS options and the current public program are not designed to address or capable of meeting the demand for community-based LTSS for people of all ages. Individuals and families are forced to navigate a complex, frequently uncoordinated system of care including state-specific publicly funded services, limited supports funded by private pay and charitable giving, and often no clear path to assistance. Many individuals and families experience extraordinary stress due to lack of supports and services. Family caregivers play a critical role in providing services and supports. Almost a million Americans with I/DD are living at home with a caregiver of retirement age. Relying on families to provide care cannot be a substitute for creating a national solution to ensure that everyone who needs LTSS receives them.

Quality Supports and Services

Many individuals with I/DD have not had the opportunity or the support to make choices and decisions about important aspects of their lives. Ensuring that our system of LTSS is based on principles of self-determination, person-centered planning, and individualized supports is critical to having a system that supports people with I/DD. Too often decisions about supports and services are based on availability and cost, not on a person-centered approach made independently of the self-interests of the funder and/or the provider of services. Many people either accept services and supports that are available, but inappropriate and/or inadequate, or receive no supports at all.

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Medicaid

While Medicaid is the lifeline for individuals with I/DD, it falls short of meeting their needs. Medicaid has been the major funding source for all LTSS for people with I/DD. Today most LTSS for people with I/DD are community supports and services; however, the institutional bias remains in the Medicaid program. To become or remain eligible for vital Medicaid LTSS, most people seeking services are forced to impoverish themselves and remain poor for a lifetime. To make matters worse, both federal and state policy makers have attempted to scale down the growth of Medicaid through regulatory and eligibility changes, budget cuts, and program changes designed to reduce costs rather than improve or expand services and supports. Increasingly states are shifting the management of LTSS to managed care organizations — a process that may result in more barriers to needed services.

Waiting Lists and Unmet Needs

The prevalence of people waiting for services and supports is an unacceptable national crisis. Often a state will not even have a process for developing and monitoring a waiting list for Medicaid supports and services. Individuals with disabilities often have to experience the death of a parent, a medical emergency, or other tragic event to obtain the services from Medicaid that they need. They are thus thrust into a new situation without planning at a time of family crisis. Individuals with I/DD remain on waiting lists for years — in some states it can take a decade or more — after requesting necessary supports and services. If ongoing supports and services are not available to young adults with I/DD transitioning out of the education system, educational gains will be lost.

Direct Support Professionals

The quality and effectiveness of LTSS for persons with I/DD depend upon qualified providers of supports and services with necessary skills and training. Inadequate compensation hampers both recruitment and retention. Inadequate funding for training of direct support professionals (DSPs) and their supervisors, as well as lack of sufficient supervision, threatens health and safety.

Position

A comprehensive system of LTSS must include the following:

National Solution

- An LTSS system must enable anyone of any age and disability to obtain LTSS when needed;
- The system must include private and public financing mechanisms because the obligation to provide LTSS is not just a personal responsibility but a shared, societal responsibility;
- The system must be sustainable so that people can count on getting what they need when they need it; and
- Individuals or their families should not be required to impoverish themselves to receive the supports and services they need to live.

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Quality Supports and Services

- It is not only a choice but also a basic civil right that individuals have adequate and appropriate supports and services needed for them to live in the community;
- Individuals must have opportunities to design and direct their own services to the extent that they wish and with the assistance they need;
- Plans must be person-centered and based on the unique needs of the individual and accompanied by measured progress toward person-centered outcomes and flexible funding to meet changing circumstances;
- Services must be delivered promptly in the most integrated setting and with sufficient quality and quantity to meet individual needs; and
- Effective quality monitoring programs to measure the individual and systems outcomes of LTSS need to be in place in every state.

Medicaid

- Medicaid must remain a viable option for individuals who need LTSS and have no access to private insurance options;
- Medicaid programs must enable people to participate fully in their communities, experience a high quality of life and, as adults, achieve economic security and personal independence;
- Medicaid programs should fund person-centered community supports and services with continuing efforts to redirect Medicaid funding from institutional care to home and community-based supports;
- Medicaid funding must be portable across states and other political jurisdictions;
- Medicaid funding must provide for living wages and decent fringe benefits to direct support workers;
- Medicaid reform must preserve the individual entitlement and not simply shift costs to individual beneficiaries or states and must preserve consumer protections such as minimal cost-sharing, appeals and grievance procedures, and independent assessments;
- Medicaid reform must address waiting lists and unmet needs and the quality of service providers and staff; and
- Medicaid service delivery system redesign must be transparent and involve meaningful input of all stakeholders.

Waiting Lists and Unmet Needs

Individuals who need LTSS should not have to wait to receive them. Because there is an absence of a national system of LTSS, where waiting exists at the state level:

- Public systems must actively reach out to individuals and to families with unmet needs to make them aware of the process for obtaining LTSS and must maintain transparency until waiting is eliminated;
- People must receive crucial supports that assist them while they wait for the availability of or enrollment in comprehensive community supports and services; and

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- Until waiting is eliminated, states must develop systems to prioritize delivery of services to individuals who are waiting for services on the waiting list to ensure that those experiencing emergencies (loss of caregiver, imminent threat of institutionalization) receive supports and services immediately.

Direct Support Professionals (DSPs)

- Wages, benefits, and professional development opportunities must increase for DSPs so as to attract and retain the workforce needed to fully support people living in the community;
- Competency-based training must be available to DSPs that covers the essential knowledge, ethical principles and practices, and skills necessary to provide direct support to individuals. DSPs must receive training in the philosophy of self-determination and the value of full inclusion and community participation of individuals;
- National, state, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality direct support workforce;
- Individuals who wish to employ DSPs must have access to high quality information, technical assistance, and training;
- Federal and state quality assurance programs must assess and monitor DSP vacancy rates, recruitment and retention, and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance;
- States must utilize a system for criminal background checks for all public and private DSPs working in the state; and
- States must also develop and make available a list of individuals for whom abuse and neglect charges have been substantiated.

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¹ “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

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