

Systems Summary

Systems are necessary to support people with intellectual and/or developmental disabilities¹ and their families to enable them to live their lives like other people. These support systems must be of high quality and focused on the people and their families, not the staff.

Addressing the Causes and Effects of Intellectual and Developmental Disabilities

According to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and other federal legislation, “disability is a natural part of the human experience...”. Prevention activities do not diminish the value of individuals with intellectual and/or other developmental disabilities (I/DD), but rather strive to maximize the independence and enhance quality of life for people with I/DD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause I/DD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports.

Long Term Supports and Services

Individuals with intellectual and/or developmental disabilities (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.

Research

Basic and applied research on the causes, challenges and treatment of intellectual and developmental disabilities, as well as research on interventions and services which could improve the lives of people with intellectual and/or developmental disabilities, must be adequately financed, well designed, focused on relevant topics, conducted with the highest ethical standards, presented in formats accessible to multiple audiences, and have a positive impact on people’s lives.

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Support Coordination

Support coordination is critical for finding and coordinating the necessary services, supports and resources within the community that are required by children and adults with intellectual and/or developmental disabilities and their families.

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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