

# POSITION STATEMENTS

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## SYSTEMS SUMMARY

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Systems are necessary to support people with intellectual and/or developmental disabilities<sup>1</sup> 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.

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## 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 (IDD), but rather strive to maximize the independence and enhance quality of life for people with IDD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause IDD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports.

## LONG TERM SUPPORTS AND SERVICES

All people with intellectual and/or developmental disabilities<sup>1</sup> (IDD) have the right to full lives in communities of their choosing where they can live, learn, work, and enjoy life. To achieve this, people with IDD need access to comprehensive, person-centered and self-directed high quality long term supports and services (LTSS). Robust, reliable, and immediately accessible funding sources that include Medicaid are needed. There must be a flexible public policy framework that emphasizes self-direction, is well-funded, responsive, and nimble, and is developed with—and not for—people with IDD. Waiting lists for home and community-based supports and services must be eliminated.

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<sup>1</sup> Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act”, are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym “IDD” is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

## 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.

## 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.