

# POSITION STATEMENTS

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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<sup>1</sup> (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.

### ISSUE

Knowledge about biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards is increasing rapidly, yet practical application of this information is lacking. Supporting the prevention of IDD and valuing the lives, diversity, and contributions of persons with IDD are compatible positions.

Despite dramatic advances in our Nation’s view of disability and supports and services for individuals with disabilities, quality of life remains elusive for far too many persons with IDD. When individuals with IDD do not receive adequate, comprehensive health care, including access to mental health, habilitative and dental health services across the lifespan, therapies, education, and access to assistive technology, preventable secondary conditions can occur.

### POSITION

The Nation must investigate the causes, avoid those that are preventable, and limit the negative effects of conditions that cause IDD through prevention programs, policies, and practices which must include:

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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

- Research on the conditions that cause IDD, including, but not limited to, biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards.

## Public Health Programs

- Promotion of folic acid supplementation among women of child-bearing age, with emphasis in communities where the incidence of neural tube defects is higher;
- Efforts to prevent accidental childhood injuries, such as programs to promote the use of car seats, seatbelts, and bicycle and other sports helmets;
- Compliance with state laws on immunizations of children for preventable contagious diseases associated with IDD to achieve public health objectives and optimal health outcomes;
- Encouragement of immunizations for women of child-bearing age for preventable contagious diseases that are associated with IDD;
- Programs to ensure that prospective parents and pregnant women have coverage for and access to comprehensive prenatal care to support the best possible birth outcomes. In the case of mothers with IDD, such care must meet the mother's disability and communication needs;
- Disability sensitive information and supports for post-natal care for mothers with IDD;
- Programs to ensure that pregnant women (including those with IDD), infants, and children receive adequate nutrition and healthcare;
- Information and care before, during, and following birth, including frequent physical/developmental checks, and referral to community resources, if appropriate;
- Programs to ensure that children who live in poverty have access to adequate health and development support;
- Education of professionals and the public on the risks of prenatal and childhood exposure to agents that may harm brain development, such as alcohol, drugs, tobacco, polychlorinated biphenyls (PCBs) and environmental hazards such as lead and mercury. In addition, professionals, families, and self-advocates should be made aware that individuals with IDD who experience compromised health or limited access to healthcare may be uniquely vulnerable to environmental hazards;
- Reduced exposure to and protection against infectious agents and environmental hazards known to cause or contribute to IDD, such as insect-borne diseases like the Zika virus, and lead, mercury, and polychlorinated biphenyls (PCBs), as well as improved workplace safety initiatives;
- Programs and education to reduce the incidence of disabilities resulting from child abuse, particularly Shaken Baby Syndrome;
- Expansion of newborn screening and early childhood developmental screening programs to identify conditions that require specialized medical treatment at birth or soon after, and to provide for timely referral to early intervention services. Such programs should be modeled on the highly successful efforts to prevent IDD resulting from PKU and hypothyroidism; and

- Enforcement of existing public policies designed to prevent IDD.

## **Quality of Life**

Investigating the causes, avoiding those that are preventable, and limiting negative effects of conditions that cause IDD will contribute to individual and family quality of life. It is also imperative that individuals with IDD engage in person-centered and self-directed services and supports that are appropriate and affordable in order to improve quality of life, as well as to address secondary conditions through the following:

- Appropriate funding for interventions, preventive health care, habilitation services, educational services, community-based supports, and assistive technology to maximize independence and lessen the development of preventable secondary conditions in people with IDD who often are at greater risk for health problems that can be prevented;
- Proactive efforts in policy development and program design to identify and prevent health disparities and the development of secondary conditions in persons with IDD;
- Continued research into and application of promising interventions, best practices, and community-based supports that maximize independence and enhance quality of life for individuals with intellectual and/or developmental disabilities; and
- Dissemination of knowledge about research-based best practices.

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