

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 disabilities¹ (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.

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 I/DD and valuing the lives, diversity, and contributions of persons with I/DD 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 I/DD. When individuals with I/DD 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 I/DD through prevention programs, policies, and practices which must include:

Research

- Research on the conditions that cause I/DD, 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 I/DD 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 I/DD;
- 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 I/DD, such care must meet the mother's disability and communication needs;
- Disability sensitive information and supports for post-natal care for mothers with I/DD;
- Programs to ensure that pregnant women (including those with I/DD), 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 I/DD 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 I/DD, 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 I/DD resulting from PKU and hypothyroidism; and
- Enforcement of existing public policies designed to prevent I/DD.

Quality of Life

Investigating the causes, avoiding those that are preventable, and limiting negative effects of conditions that cause I/DD will contribute to individual and family quality of life. It is also imperative that individuals with I/DD 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 I/DD 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 I/DD;
- 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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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.