

# POSITION STATEMENTS

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## RESPONDING TO THE INTERRELATED CAUSES OF INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

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Valuing the lives, diversity, and contributions of people with intellectual and/or developmental disabilities<sup>1</sup> (IDD) AND advancing policies that mitigate the impact of psychoeducational, sociocultural, biomedical, and justice causes of IDD are compatible positions. 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 and in no way diminishes the rights of individuals to participate in or contribute to society.”

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### ISSUE

Knowledge about the psychoeducational, sociocultural, biomedical, and justice causes of IDD is increasing rapidly, yet the will, effort, and resources necessary for meaningful access to and application of the research lag behind. The four broad areas of causation are defined as follows:

- 1) Psychoeducational causes of IDD refer to limited opportunities in learning, adaptive behavior, and intellectual functioning. Examples might include lack of early intervention or lack of opportunities for necessary personal growth.
  - 2) Sociocultural causes refer to limited opportunities to develop in the social context and through social interactions. Examples might include living in an impoverished environment, unstable living conditions, or experiencing social stigma.
  - 3) Biomedical causes refer to problems in physical development or functioning. Examples might include biological conditions or limited brain development.
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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.

4) Justice causes refer to damaging discrimination or denial of legal rights. Examples might include health disparities, social inequality, or denial of human rights.

### ***Examples of Interrelated Causes of IDD***

The four broad areas of possible causation are often interrelated, for example:

- IDD resulting from youth trauma may have biomedical (e.g., the injury), psychoeducational (e.g., the lack of access to appropriate education), sociocultural (e.g., the dangers in the neighborhood), and justice (e.g., the conditions of incarceration) aspects to the causation.
- IDD resulting from homelessness may have biomedical (e.g., malnutrition), psychoeducational (e.g., the lack of access to counseling), sociocultural (e.g., stigma), and justice (e.g., discriminatory denial of financial supports) aspects to the causation.
- IDD resulting from the effects of drugs and alcohol in the development and behavior of young children may have biomedical (e.g., prenatal exposure), psychoeducational (e.g., the lack of access to early education and counseling), sociocultural (e.g., social values), and justice (e.g., criminal charging and sentencing practices) causes of disability.
- IDD resulting from the effects of poverty on children may have biomedical (e.g., lack of prenatal care), psychoeducational (e.g., lack of access to parenting education and supports), sociocultural (e.g., access to stable housing), and justice (e.g., discriminatory loan practices) causes of disability.

## **POSITION**

The nation must value the lives and contributions of individuals with IDD and their families, while also (a) researching the causes of IDD, (2) developing policies to support and enhance individuals' functioning, (c) providing supports, programs, and advanced practices to implement the policies and meet individual needs, and (d) eliminating the roadblocks currently found in values, research, policies, and supports.

## **Values**

The underlying value for all efforts regarding causes of IDD must be respect for the individuals and their families. In addition, the values of autonomy, agency, person-centeredness, self-direction, diversity, and intersectionality must be integrated in a holistic way. Valuing the lives, diversity, and contributions of people with IDD AND advancing policies that mitigate the impact of psychoeducational, sociocultural, biomedical, and justice causes of disability are compatible positions.

### ***Researching the Causes of IDD***

- Research on causes of IDD should include research in the four broad areas of causation: psychoeducational, sociocultural, biomedical, and justice causes of disability. Research should be integrated among the four areas of causation, when appropriate, because causes are often complex and interwoven.
- Research must identify and use standard and rigorous definitions and develop greater quantification of causes of IDD, including data focus and prevalence.

- Research should include people with IDD in the development of research questions, design and implementation of the research, and dissemination of results.
- Research must assure that diversity, equity, and inclusion, including issues of intersectionality, are reflected in design and implementation.
- Research must be equitably funded to attain valued outcomes.
- Research must be broadly disseminated and accessible for maximum impact.

### ***Developing Policies to Enhance Individuals' Functioning***

- Policies addressing causes of IDD should also include the four broad areas of causation.
- Policies must enhance the autonomy and agency of people with IDD.
- Policies must be agile to respond to changing times and reflect new ways of supporting people with IDD toward equality of opportunity, full participation, independent living, and economic self-sufficiency.
- Policies must be informed by people with IDD and their families.

### ***Providing Supports, Programs, and Advanced Practices***

- Supports, programs, and advanced practices addressing causes of IDD should include the four broad areas of causation.
- Supports, programs, and advanced practices should address access to early intervention and inclusive special education; self-advocacy, self-determination, and leadership skills; physical and mental health services; dental and vision care; poverty reduction, adequate nutrition and stable housing; elimination of discrimination; employment; and a safe and healthy environment for all children, as well as other supports that improve health; increase access to education; promote diversity, equity, and inclusion; and promote a society that is fair and just for all.
- Supports, programs, and practices should include family supports that recognize the impact of life-long disability on family members and caregivers.
- Systemic advocacy is needed to assure development of and access to appropriate supports, programs, and advanced practices and should be supported with adequate resources.
- Supports, programs, and advanced practices require sufficient staff who are appropriately compensated, prepared, supported, and valued.

## **CONCLUSION**

Respect for the individuals and their families must be the underlying value for all efforts regarding causes of IDD. People with IDD, their families, and the advocacy community supporting them must be a valued part of all discussions to address causes of IDD. Knowledge about the causes of IDD is continuing to develop. Currently, however, necessary actions are lagging behind the research. Meaningful actions, including promotion of research, strong policies, and advanced practices and supports, must keep pace with the developing knowledge.

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