

POSITION STATEMENTS

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RESEARCH

Basic and applied research¹ on the causes, challenges and treatment of intellectual and developmental disabilities², 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.

ISSUE

Government and private funding is insufficient to support the broad research agenda that includes issues most important to people with intellectual and/or developmental disabilities and their families. Through basic and applied research, scientists and researchers can learn about causes of intellectual and/or developmental disabilities, address its preventable causes, improve the quality of life of people with intellectual and/or developmental disabilities and their families, and address policy and service-delivery enhancements. Researchers can identify the most promising educational, social and clinical interventions that help people live meaningful lives.

Historically, most people with intellectual and/or developmental disabilities and their families have not had input into the design, methodology, dissemination, use, and evaluation of research. Moreover, most research results have not been presented in ways which are accessible, understandable and useful for multiple audiences, including people with intellectual and/or developmental disabilities and their families.

Few groups are more vulnerable to potential exploitation in research than individuals with intellectual and/or developmental disabilities. Without comprehensive, clear policies, standards

¹ Basic research refers to the study and research of pure science that is meant to increase the scientific knowledge base. Applied research refers to scientific study and research that seeks to solve practical problems and develop innovative approaches.

² 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.

and safeguards in place to protect them, people with intellectual and/or developmental disabilities may be subject to exploitation and harm.

POSITION

To make applied and basic research related to intellectual and/or developmental disabilities a national priority, the following must occur:

- Government and private entities must provide adequate funding to support research;
- Advocacy, service provider and professional organizations, government agencies, the research community, and people with intellectual and/or developmental disabilities and their families must work together in defining, evaluating, and promoting a research agenda;
- Results of research must be available in multiple formats, easily accessible and understandable for a wide audience, including people with intellectual and/or developmental disabilities and their families;
- Stringent scientific and ethical standards must be enforced to ensure efficient and effective use of limited research funds and to prevent exploitation or harm of people with intellectual and/or developmental disabilities and members of their families; and
- For all basic and applied research involving persons with intellectual and/or developmental disabilities:
 - › Specific procedures must be implemented to ensure their full voluntary, informed, initial, and ongoing agreement to participate;
 - › All research must be conducted by qualified researchers, in adequately monitored settings and reviewed for potential risk and benefit by qualified, competent scientific review boards;
 - › No research may be conducted exclusively on persons with intellectual and/or developmental disabilities unless there is reasonable likelihood that the treatment would address unique intellectual and/or developmental disabilities medical issues or apply differentially to them; and
 - › Persons with intellectual and/or developmental disabilities should not be excluded from research that might benefit them as members of the general population.

Entities involved in conducting and financing basic and applied research should ensure that policies and standards with specific guidelines and safeguards are in effect to protect persons with intellectual and/or developmental disabilities and their families.

The Arc and AAIDD are committed to identifying and promoting research-based best practices, setting high standards for direct services and measuring outcomes across all three levels of the organization (local, state and national).

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