

# POSITION STATEMENTS

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## PARENTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

The presence of an intellectual and/or developmental disability<sup>1</sup> does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.

### ISSUE

The history of discrimination toward individuals with intellectual and/or developmental disabilities includes the denial of rights and opportunities to have and to raise their own children. This history has included segregation and involuntary sterilization of adolescents and adults. After birth, infants have been removed immediately from parental care, and through legal provisions, parents have been denied the opportunity to raise their children in their home.

Examples of social and social service biases and discriminatory practices include:

- Presumption of incompetence, that is, a general belief that people with intellectual and/or developmental disabilities are unfit to be parents;
- Limited supports to parents with intellectual and/or developmental disabilities;
- Professional emphasis on limitations of parents with intellectual and/or developmental disabilities to the point of weakening parents' sense of competence and potential for success;
- Public resources primarily focused on crisis-driven support;
- Lack of trust of service providers or government officials by parents with intellectual and/or

<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.

developmental disabilities based upon fears of losing their children and their vulnerability to arbitrary authority; and

- Disproportionate representation of parents with intellectual and/or developmental disabilities in child custody proceedings, where, their competence as parents is held to higher, less flexible and more frequently applied standards than those applied to other parents.

Despite research which documents the ability of many parents with intellectual and/or developmental disabilities to raise a child successfully with appropriate and effective supports, access to these supports continues to be limited, fragmented and uncertain. Few specialized programs exist. Many family support and early intervention programs are not equipped to provide the intensive and ongoing supports that parents with intellectual and/or developmental disabilities and their children are likely to require.

## POSITION

All adults, when provided access to appropriate and effective supports as needed to fulfill the basic responsibilities of child rearing, are more likely to be effective in their roles as parents.

Parents with intellectual and/or developmental disabilities and their children deserve social and health supports that:

- Recognize the need of parents to be viewed as unique individuals able to learn and improve in their skills and to respond to the needs of their children;
- Distinguish the effects of the family's living conditions and economic status independently from assessing ability to perform a parenting role;
- Build a trusting relationship between the parents, child, and those who provide formal and informal supports to them;
- Recognize, include, and engage the informal supports of family members, neighbors, and their community members to assist parents and the family as a whole;
- Recognize that as the needs of children change, parenting skills must evolve and may require new forms of support for parents and children;
- Respond to the unique learning needs of parents with intellectual and/or developmental disabilities;
- Assist parents in becoming actively engaged in their children's school and community;
- Reflect the full range and multiple components of effective support programs including, as needed:
  - › in-home visits to teach parenting skills;
  - › assistance with daily living skills;
  - › access to nutritional resources such as "ready to feed" formula;
  - › child care, early intervention services, and counseling;
  - › basic academic education for parents;
  - › assistance in accessing public benefits as appropriate;
  - › crisis intervention services, availability of intensive supports as needed, and volunteer mentoring programs; and

- Assure that access to parent supports and to the environments and programs in which parental participation is beneficial to the child and family are provided with proper consideration of Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and related accommodations.

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities support adoption of the United Nation’s Convention on the Rights of Persons with Disabilities. Article 23, “Respect for Home and the Family,” Obligation 4 states that “Parties shall ensure that a child shall not be separated from his or her parent against their will, except when competent authorities subject to judicial review determine, in accordance with applicable laws and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.”

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Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).