

## Parents with Intellectual Disabilities



### What Is The Arc's Position?

The presence of an intellectual and/or developmental disability 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. Read the entire Position Statement at <http://www.thearc.org/page.aspx?pid=2375>.

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### Who Are Parents with Intellectual Disabilities?

Parents with intellectual disability or developmental disabilities (I/DD) have various levels of cognitive impairment. An intellectual disability occurs before age 18 and is characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills (AAIDD, 2011). Mild cognitive limitation describes individuals who may have been diagnosed with an intellectual disability at some time in their lives. They have lower than average learning, communication, judgment and understanding abilities (Tymchuk, Lakin & Luckasson, 2001). Their eligibility for service varies from state to state, because they do not qualify for services based on having an intellectual disability.

### Why Is The Arc Concerned about Parents with Intellectual Disabilities?

The right to marry and raise children have long been recognized as fundamental under the Constitution of the United States. While these rights apply to parents with intellectual disabilities, their parental rights are sometimes terminated solely upon the determination that a parent has an intellectual disability. Often, there is no assessment of the parents' actual abilities or the likelihood that they could successfully parent with appropriate supports. The Arc's position statement on sexuality states that people with I/DD have the right to make decisions about having and raising children and to have access to the proper supports on an individual basis to assist them in raising their children within their own home (The Arc, 2008). While parents without disabilities often receive support and ideas from other parents, those with I/DD typically are unable to obtain and develop such relationships that provide natural support. Other supports provided through government programs or non-profit agencies are also scarce in most communities.

Parents who have intellectual disabilities may be closely scrutinized for any sign or symptom of abuse or neglect to their children. Parents live in fear of having their children taken away. Many whose children have been removed

don't understand why or how to prevent it next time. Many others are not identified as having an intellectual disability and try to hide their disability, depriving themselves of any opportunity for accommodations. For those parents whose children have been taken from them, the reunification plan usually requires parents to attend counseling sessions and parenting classes that are not cognitively adapted, which dooms most to failure.

### **Are Parents of Children with Intellectual Disabilities Capable of Raising Their Children?**

Contrary to what many people think, people with intellectual disabilities can be good parents. Field and Sanchez (1999) suggest that the ability of a parent to provide adequate child care cannot be predicted on the basis of intelligence alone. As with parents without disabilities, the ability to parent successfully depends on a wide range of factors. Grayson (2000) reviewed studies attempting to identify factors contributing to successful parenting. These factors include: higher IQ (greater than 50 or 60), being married or living with the child's grandparents or daily support from a high functioning adult, having fewer children or only one, adequate motivation and willingness to accept support from service providers or informal

sources, training in the home to enhance generalization, appropriate parent models during childhood, good physical and mental health, adequate finances and low stress and adequate education and reading skills.

### **What Are Strategies for Successful Supports to Parents with Intellectual Disabilities?**

McConnell, Llewellyn & Bye (1997) surveyed service providers and identified four principles associated with effective services to parents with I/DD. These are:

- Services need to be responsive to the parents' individual needs and focus on the whole family to ensure that interests of both parents and children are served.
- Services must include long-term, ongoing supports because the needs of children change and parenting skills must change as children mature.
- Services must consider the special learning needs of the parent. Learning must occur in the home, be repetitive, use demonstration and use resources that require little or no reading.
- Services must assist parents in becoming part of their community.

### **What Kinds of Supports Are Needed?**

Examples of supports that help parents provide appropriate care and stimulation to their children include:

- In-home visits to teach parenting skills and to assess parenting compe-

tency

- Parent training adapted for parents with intellectual disabilities
- Help with shopping and money management
- Service coordination
- Health care, learning to deal with doctors
- Child care, early intervention services
- Mental health counseling
- Counseling for substance abuse and other addictions
- Basic academic education for parents
- Transportation for families
- Play groups for children and parents
- Crisis intervention services

Parents may need varying kinds and levels of support at different times in their child's life. Grandparents, aunts and uncles, friends and other family members often provide a lot of the help and support. Early intervention and/or Head Start can link families of young children to community and natural supports. However, the family may not even qualify for case management services, which means someone needs to be creative in helping the family find positive environments and help for the child. There is a great need for community service agencies to create and provide individualized services based on each family's needs.

### **How Are These Supports Provided?**

Several service approaches have been shown to be effective

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individually and in combination in supporting parents and teaching parenting skills. These include home visiting programs, parenting groups, center-based programs and shared parenting models described below (Anderson & Lakin, 1998).

In-home programs provide an opportunity to model and teach parenting skills in the setting where parents will use them. This makes the skill easier for the parents to learn. The service providers can provide appropriate supports focusing on nutrition, cleanliness, safety issues and other issues related to the home.

Parenting groups can instruct families meeting together on such topics as discipline techniques, child development, health and safety issues and decision-making skills. Studies show that parents consistently gain skills in this type of instruction. They are most successful when the class is followed by home visiting. This allows parents to practice in the home what they have learned in class under the support and observation of their instructor.

Center-based programs provide a variety of services to parents and children at a program site. They can provide services to the parent and the child jointly and separately at the same site. They are most effective when supplemented with in-home training. They typically offer a variety of services and instruction such as parenting skills, cook-

ing, financial management, etc.

Shared parenting provides full-time support when the parent and child live in foster care together. The foster provider acts as a “co-parent” to ensure the needs of children are met.

### **What Are the Effects on the Child’s Development of Having a Parent with an Intellectual Disability?**

Booth & Booth (1997) interviewed 30 adults brought up in a family headed by a parent or parents with intellectual disabilities. Half of these adults had intellectual disabilities themselves. They conclude that the children’s destinies are not fixed by having a mother or father with intellectual disabilities. Their experiences in leaving school to adult life were similar to other people from the same social class and neighborhoods. Most of them maintained a valued relationship with their families. There was little evidence of them assuming responsibility for “parenting their parent.”

Protective factors that fostered resilience in the children are personality characteristics, such as responsiveness to others and an outgoing nature; family characteristics, such as warmth and mutuality and stability; and external supports, such as supportive relationships outside the home and involvement in the wider community.

#### References:

- American Association on Intellectual & Developmental Disabilities. (2011). *Intellectual Disability: Definition, Classification, and Systems of Supports*, 11th Edition. Washington, DC: American Association on Intellectual & Developmental Disabilities.
- Anderson, L. & Lakin, K.C. (1998). Parents with cognitive limitations: What do we know about providing support? *Impact*: 11(1), 6-7.
- Booth, T. & Booth, W. (1997). *Growing up with parents who have learning difficulties*. York, England: Joseph Rowntree Foundation.
- Field, M.A. & Sanchez, V.A. (1999). *Equal Treatment for People with Mental Retardation: Having and Raising Children*. Cambridge: Harvard University Press.
- Grayson, J., ed. (2000). *Parents with mental retardation*. Virginia Child Protection Newsletter. Vol. 57
- McConnell, D., Llewellyn, G., & Bye, R. (1997). Providing services to parents with intellectual disability: Parent needs and service constraints. *Journal of Intellectual and Developmental Disability*, 22(1), 5-17.
- Tymchuk, A.J., Lakin, K.C. & Luckasson, R. (2001). *The Forgotten Generation: The Status and Challenges of Adults with Mild Cognitive Limitations*. Baltimore: Paul H. Brookes Publishing Co.
- The Arc. (2008). *Position Statement on Sexuality*. On-line: <http://www.thearc.org/page.aspx?pid=2375>

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