



For people with intellectual  
and developmental disabilities



# Position Statement Family Support

Family support services should be available to all families who need them because they strengthen the capacity of the family to support family members with intellectual and/or developmental disabilities<sup>1</sup> both in the home and the community in a cost effective way.

## Issue

Individuals with intellectual and/or developmental disabilities, by definition, require greater intensities of support than other individuals to perform basic, daily activities and to achieve the goals of equality of opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelming the primary and often only source of support for their family member with an intellectual and/or developmental disability. Relatively small proportions of federal and state funding for persons with intellectual and/or developmental disabilities are committed to family support, even though the majority of children and adults with intellectual and/or developmental disabilities live at home with their families. Families were once offered few support options beyond out-of-home placement. With the advent of family support, much greater numbers of persons with intellectual and/or developmental disabilities are living with family members for longer periods, with better outcomes and at enormous cost savings when compared with out-of-home options. Still, for many families the needed supports are unavailable or insufficient.

For the first time in history, millions of people with intellectual and/or developmental disabilities are aging in the community. This success brings with it new challenges. Over 700,000 people with developmental disabilities live with one or more parent over the age of 65. This increasingly common living arrangement requires specialized family support. Families who have often functioned outside a provider system need to be identified. Families need to be helped to develop desired in-home support plans or transition plans to community living for adults with intellectual and/or developmental disabilities.

## Position

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities are committed to comprehensive, universally accessible family support that:

- Provides supports required by individual families to meet the basic needs of fam-

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ily members with intellectual and/or developmental disabilities;

- Allows families to make their own decisions, consistent with the right to self-determination of adult family members with intellectual and/or developmental disabilities;
- Assists families to remain intact;
- Supports adults with intellectual and/or developmental disabilities to live with their families as long as mutually desired;
- Supports opportunities for community inclusion and participation for individuals and families; and
- Recognizes, values and reinvests the substantial cost-benefits of family-based care and support.

The services and subsidies that constitute family support are wide-ranging but may include:

- Cash assistance, information, emotional support, specialized therapy and service coordination and logistical assistance (for example, exploring needs, identifying supports and support providers, completing applications, obtaining transportation); and
- Respite care, in-home personal care, home modifications and specialized equipment, recreation and leisure activities, health and dental services, and any other services or supports which increase and sustain a family's ability to remain effective as the primary caregiving unit for persons with intellectual and/or developmental disabilities.

Such services and subsidies are most effective when they are:

- Provided in the natural environment of the family;
- Available from a range of sources including family members, friends, one-to-one peer support, parent groups/organizations, generic community resources, and specialized community resources;
- Based on the best available knowledge and accumulated family wisdom and professional expertise about the nature and qualities of family options that make family support most effective; and
- Provided with respect to cultural, religious, and economic standing.

When well-designed and adequately financed, family support achieves the following outcomes:

- Strengthens and sustains families' in-home care giving capacities and the individual's family, neighborhood and community networks that derive from family membership;
- Addresses the family's emotional well-being, health, material well-being, parenting skills, disability-related considerations, and family interactions;
- Enables families to make choices about the support they and their family member receive;
- Builds on the family's strengths, is responsive to its cultural values, maximizes the family member's self-determination, and is controlled by the family in partnership with those who provide support;
- Enhances families' community par-

ticipation and quality of life;

- Assists the individual with intellectual and/or developmental disabilities in the process of attaining equal opportunity, full participation, independent living, and economic self-sufficiency;
- Sustains family commitment and success as the primary caregiver; and
- Encourages active, life-long engagement of family members, including siblings, in the lives of children and adults with intellectual and/or developmental disabilities.

**<sup>1</sup>“People with intellectual disabilities and/or developmental disabilities” refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.**

**Adopted:**

**Board of Directors, The Arc of the United States**

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**Board of Directors, AAIDD**

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**Congress of Delegates, The Arc of the United States**

**November 8, 2008**

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