



POSITION STATEMENT



FAMILY SUPPORT

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

ISSUES

Individuals with intellectual and 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 the core unit of American society in addressing the support needs of their members. Relatively small proportions of federal and state funding for persons with intellectual and developmental disabilities are committed to family support, even though the overwhelming majority of children and adults with intellectual and 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 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 supports needed are unavailable or insufficient to meet their range of support needs.

For the first time in history, millions of people with intellectual and developmental disabilities are aging in the community. This success brings with it new challenges. Approximately 700,000 people with developmental disabilities live with one or more parents 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 developmental disabilities.

POSITION

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

- Provides all supports required by individual families to meet the basic needs of family members with intellectual and developmental disabilities;

- Allows families to make their own decisions, consistent with the right to self-determination of adult family members with intellectual and developmental disabilities;
- Assists families to remain intact to support and rear children and as long as is desired by adults with intellectual and developmental disabilities;
- 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, personal care in the home, 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 care giving unit for persons with intellectual and 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; and
- Based on the best available knowledge and accumulated family wisdom and professional wisdom about the nature and qualities of family options that make family support most effective.

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 participation and quality of life;
- Assists the individual with intellectual and development 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 in the lives of children and adults with intellectual and developmental disabilities.

Adopted: Board of Directors
Date
Congress of Delegates
Date

AAIDD
Date

DRAFT