**POSITION STATEMENT**

# Family Support

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Family support services[1] and other means of supporting families should be available to all families to strengthen families' capacities to support family members with intellectual and/or developmental disabilities[2] (I/DD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.

## Issue

Individuals with I/DD frequently require support to perform basic daily activities and to achieve the national goals of equal opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelmingly the primary and often the major source of support for their family member with I/DD.  Nearly three quarters of people with I/DD live in the family home and, according to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, most of these family caregivers provide more than 40 hours of care per week (including 40% who provide more than 80 hours of care per week).

Changing demographics are placing even greater demands on this already limited service system. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers. These aging caregivers will have greater need for family support, such as assistance in developing desired in-home support plans or transition plans to community living for their family member with I/DD when they are no longer able to continue in their caregiving role.

Unfortunately, the increasing reliance on families is not being met with commensurate support.  A generation ago, families were discouraged from keeping their family members with I/DD at home and encouraged to use costly publicly financed institutional placements. Today, they face the other extreme where they are expected to be willing and able to provide lifelong support to their family member with I/DD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adult offspring with I/DD or themselves.

Our service system is increasingly being built around the expectation that adults with I/DD will reside in the family home. This is not consistent with other national policies for vulnerable populations.

Relatively small proportions of federal and state funding for persons with I/DD are committed to family support, despite increasing numbers of people with I/DD living with family for longer periods. Consequently, though family support is critical for avoiding placement in costly and inappropriate institutions for the family member with I/DD, the needed supports are frequently insufficient or unavailable.

There is no comprehensive family support system in the U.S. Instead, the vast majority of publicly provided family support services are funded through Medicaid home and community-based services (HCBS) waivers and some states provide limited family support using state general fund dollars. Consequently, beneficiaries of family support experience the same mobility and portability limitations as those receiving other Medicaid HCBS. This problem is most acutely felt by military families who move frequently and have to begin the application and waiting process anew with each move between states.

Although family support has been a policy of the federal and state governments since the 1980s, families and individuals with I/DD increasingly are using their social capital to achieve the four national goals and attain quality of life outcomes, and are also benefitting from and seeking more policies, practices, and procedures of generic governmental and private-sector entities that support families. Families' reliance on social capital and these other means for supporting families have become important as supplements to, not replacements of, governmental-sponsored family support programs.

## Position

Comprehensive, universally accessible family support must be provided in order to:

- Assist families as they guide their member with a disability toward being self-determined individuals and achieving the nation's goals for people with disabilities as set out in federal legislation, namely, equal opportunity, economic productivity, independent living, and full participation;

- Strengthen the caregiving efforts of families (with special emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction), enhance the quality of life of all family members, and increase their access to supports and services for themselves and their members with I/DD;

- Recognize that relying on families to provide care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;

- Enable families to make informed choices regarding the nature of supports for themselves and their members with disabilities, including the use of supported decision making for family members with I/DD; and

- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions.

Policies of family support and public and private systems for supporting families must:

- Be provided in a manner that builds on the family's strengths;

- Be provided in ways that are sensitive to the family's culture, religion, and socio-economic status;

- Assist the individual and family to maximize

the self-determination of its member with I/DD;

- Be controlled, determined, and directed by the family itself, in partnership with those who provide the service;

- Be provided through best practices and state-of-the-art methods;

- Be available to all family caregivers, including, but not limited to, parents (including those with I/DD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships;

- Be available to all families regardless of whether the person with I/DD resides in the family home or is presently receiving publicly funded services;

- Provide options for family members to be compensated for their time providing essential supports, while ensuring that such arrangements are mutually desired by the family caregiver and member with I/DD and do not impose inappropriate barriers under the guise of regulating medical services provided by paid family caregivers (such as requiring a nursing license to provide g-tube feeding or insulin shots as part of respite care); and

- Be defined as a system of policies, practices, and procedures for supporting families rather than as a "family support program" sponsored by a government or private-sector entity.  Increasingly, these individualized supports should be available from generic (non-disability-specific) governmental and nongovernmental entities.

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