



Grandparents as Parents of Children With Special Needs

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Many grandparents serve as primary caregivers for their grandchildren with disabilities. Interagency committees, community collaboratives and service providers need to have an awareness of the unique considerations and obstacles faced by care-giving grandparents when considering their responsibility to provide family centered services. Grandparenting a child with disabilities involves challenges above and beyond those of other grandparents who have taken the role of primary caregiver for their grandchild in five specific areas.

BACKGROUND ABOUT GRANDPARENTS AS PARENTS

Serving as a care-giving grandparent requires special coping skills for handling family crises involving three generations – themselves, their children and the grandchildren. Whether this arrangement is short or long term, these grandparents and other relatives are keeping families together and serving as a safety net to keep children out of the formal foster care system.

According to Census 2000, nearly two and a half million grandparents in the United States, around 6%, are heads of households who serve as the primary caregivers for their grandchildren. This responsibility often occurs because of a sudden unfortunate event or set of circumstances involving the natural parents, such as:

- death of a parent
- incarceration
- military deployment
- mental illness
- chemical dependency

The results can often be beneficial. Grandparents and other relatives have proven to be a valuable stabilizing force in some families throughout our country's history. Additionally, many grandparents value their role as caretakers and transmitters of family history, culture, values and traditions. Research using data from the National Health Interview Survey show that:

- Children raised by their grandparents tend to be more socially adept.
- Children raised by their grandparents are less likely to act out than children being raised in traditional households.
- Grandparents can make excellent primary caregivers with the benefit of hindsight and more patience.
- Grandparents tend to have fewer career aspirations than adults in their 20s, 30s, and 40s.

However, these caregivers face significant obstacles not encountered by biological parents. Because systems of care are not designed with this family arrangement in mind, major systemic barriers are often encountered by care-giving grandparents.

Policymakers and service providers need to actively explore ways to address challenges in five specific major areas of unmet support needs for care-giving grandparents of children with disabilities that have been identified through two separate studies:

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1. Financial. Grandparents report that they would like information about where to find resources for financial assistance. Having responsibility for the grandchildren has far-reaching financial impact, that includes such difficulties as:

- Inability to place the children on their health insurance policies. The result can be increased expenses for healthcare for themselves, as well as the children.
- Inability to obtain affordable housing in which they can live with the children
- Having to spend their savings, which will be needed for their own future aging needs, to pay the added expenses of the grandchildren
- Having to postpone or forego new career options because of the physical and time demands of care-giving.

2. Legal or guardianship arrangements. While legalizing the care arrangement would enable the grandparents to access services and supports for their grandchild, many caregivers are reluctant to do so for several reasons:

- Hopes of eventual reunification
- Fear of antagonizing other family members
- Cost involved in legal proceedings

Opting for more informal arrangements limits their rights in enrolling the children in school as well as dealing with school, health and other social service agencies, as proof of legal authority often is a prerequisite for providing services.

3. Respite care and access to child care.

- Developmental and other disabilities occur more frequently among grandparent headed households.
- Grandchildren in grandparent headed households have higher rates of asthma and other respiratory problems, weakened immune systems, physical disabilities, poor eating and sleeping patterns, and attention deficit disorders. The impact on grandparents' lives can include:
 - being unable to leave their grandchild alone or with someone else
 - less sleep
 - physical challenges
 - lack of privacy and less time for themselves, for their spouse, and for social-recreational activities

4. Emotional support. Grandparents need to know how to find support groups, reparenting classes and mental health services. Numerous studies reveal that care-giving grandparents for children with disabilities experience depression and anxiety, and feel overwhelmed by the challenges and demands of parenting a grandchild with complex behavior or physical conditions concern about the care-giving demands presented by their grandchildren. They report:

- worry that they will be perceived as inadequate in their roles
- lack of support from their friends and peers
- increased sense of isolation
- physical assault

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- 5. Problems interacting with multiple social service systems.** System policies are most often geared toward nuclear families, so care-giving grandparents face additional obstacles when using existing social service systems. They need system assistance:
- Information about where to find community resources
 - Access to health care – without insurance coverage or legal guardianship, it can be very difficult to actually see a physician
 - Ability to enroll the child in school, to obtain transportation to another school district, avoid additional fees for out of district enrollment, to deal with the school, learn about special education and obtain educational supports
 - Access to housing that is affordable and accessible to accommodate the child's disability

The unique concerns of grandparents caring for grandchildren with disabilities have rarely been considered in the discussions regarding welfare reform. As society changes, schools and other agencies will be involved with grandparents as primary caretakers of children and as actively involved family members. While these caregivers are willing to step in, they are seldom equipped to provide all the care and assistance that the children require. Their efforts need to be supported in law, policy and practice at every level.

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