Family Support Opportunity Policy: A Review of Literature

The University of Washington Center for Disability Policy and Research (CDPR) has conducted two evaluations of the Family Support Opportunity Program of the Washington State Division of Developmental Disabilities. This work examines the needs of people with developmental disabilities and their families in community settings and how well those needs are met by state-financed services. As part of these evaluations, CDPR has performed a review of the academic literature for information on the history of family support policies, the values and beliefs that guide them, and how families’ needs are assessed. This paper summarizes the findings of the review.

History of Family Support Services

As recently as the early 1970s, the parents of a child with developmental disabilities often faced a heartbreaking choice: to provide themselves the support their child needed at home, or to place the child in an institution. The decision to care for and raise a child with disabilities in the family was made without recourse to any social service supports for the child or the family. Since this was also a time when children with more severe disabilities were not educated in public schools, families had to provide 24-hour support for children they raised at home.

As states implemented deinstitutionalization of people with developmental disabilities, families increasingly advocated for services that would aid in the care of people with disabilities in their family home. Today, a family with a child with a disability has a variety of options, due in great part to the family support movement and family support programs.

Bradley (1992) divided the history of the family support movement into three distinct phases. Segregation and institutionalization of people with developmental disabilities characterized the first phase, prominent through the early ‘70s. The second phase, during the 1970s and through the mid-1980s, saw deinstitutionalization and community development as dominant themes in services for people with developmental disabilities. During this period, policy waivers governing the state/federal Medicaid program and
Supplemental Security Income (SSI), the federal disability program, began to free resources to assist low-income families caring for children with disabilities.

This period also saw an increase in services for children through the model of "active treatment" to promote independence and learning. Attitudes about people with disabilities began to change as a result of the civil rights and feminist movements and mounting evidence that people with disabilities could learn formerly unheard-of skills. Passage in 1975 of Public Law 94-142, the Individuals with Disabilities Education Act (reauthorized in 1990), made it possible for families to enroll their children with disabilities in the same schools as their brothers and sisters, thus relieving families of the obligation to provide 24-hour support for children they chose to raise at home.

Research began to reveal the deleterious effects on children of being separated from their families, especially from their mothers, and to acknowledge the family as the most crucial element in the child's development. Policy makers then recognized the value of families caring for and raising their children with disabilities. Finally, and no less significantly, evidence began to accumulate that supporting children with disabilities to be raised at home was far less costly than out-of-home placement (Bradley, 1992).

Knoll, Covert, Osuch, O'Connor, Agosta, and Blaney (1992) reported that the 1980s saw the broad family agenda gain some degree of attention in state and national policy deliberation over such issues as day care and parental work leave. These discussions encouraged policies providing services for families with children with disabilities that were consistent with changes in American family life (Agosta & Bradley, 1985). Growing numbers of working mothers, more single parent families, smaller family size, and the lack of available extended family suggested that modern families might need additional resources to support their family members with disabilities.

The third and current phase of family support identified by Bradley (1992) is community membership. The importance of community integration, an emphasis on quality of life issues, and the individualization of services and supports characterize this phase. The evolution to this stage has also been characterized in social work literature. For example, Mary (1998) writes of the transition from the medical model of the 1960s, with services concentrated in regional centers, through the civil rights era an
deinstitutionalization of the 1970s and ‘80s and the prevalence of the developmental model, to the current model of person- and family-centered supports in community settings.

Functional supports for meeting the day-to-day demands in and out of the home for people with disabilities include formal services such as Medicaid Personal Care, therapeutic services, and counseling, as well as informal support systems such as social networks, available generic community services, and opportunities to interact with other families that have members with disabilities. For families, such functional supports must respect the value of the child living in the family’s home and recognize that special needs and issues may arise in raising children with disabilities under these circumstances.

By the mid-1990s, state governments had clearly demonstrated their willingness to offer services and supports to families without forcing placement of children with disabilities out of the family home (Weisz & Tomkins, 1996). In 1992, Knoll et al. found that 41 states had developed programs supporting families that are raising children with developmental disabilities.

According to Agosta and Melda (1996), family support programs now focus on providing families with supports to live as much like other families as possible. They contend that establishing an effective system for supporting families should begin with the idea that family members play a leading role in decision-making. Racino (1998) indicated that the first step in supporting families is assessing their values, beliefs, and worldviews and only then working with families to determine what role outside support might play in their lives. This empowers families in such a way as to assure that programs are responsive to them (Bradley, Knoll, & Agosta, 1992; Turnbull, Garlow, & Barber, 1991). Comer and Fraser (1998) add that families should be considered consumers who engage in joint decision-making with service providers. Unfortunately, as pointed out by Racino (1998), many family members, including the individual with a disability, still are not involved in decision-making about the use of family support funds.

But the reality of limited family support funding is that not every family of children with disabilities receives services. Agosta and Melda (1996) described the way different
states established criteria for eligibility. States often tried to stretch their limited funding by serving only those families most in need or by limiting the amount of assistance a family could receive based on the extent of its need. This policy has forced some families to show that they are “dysfunctional” in order to access scarce family support funding. This process has understandably been painful to many families.

By the end of the 1990s, research literature increasingly acknowledged pressures on state social service systems for people with developmental disabilities and their families. Bradley (2000) identifies some of these pressures as growing waiting lists, state and federal initiatives to limit Medicaid spending, and restructuring of the provider industry. One response to these pressures with the potential to stretch public resources is the community guide feature of Washington State’s Family Support Opportunity program, which assists families in identifying and securing community-based resources to meet their care needs. The community guide approach is discussed by Nahom, Richardson, Romer, and Porter (2000). Bradley (2000) recognizes a similar approach to increase the effectiveness of family support services through the use of a personal broker who acts as a “knowledgeable guide and advocate.” This is one way, the author explains, that the developmental disabilities movement can continue “moving in a progressive direction.”

Parents and national advocacy organizations during the 1990s began to concentrate their efforts on the creation of family support services that are defined by the needs of each individual family (Bradley, 1992). Within this family-oriented framework, services are: (1) defined by the entire family; (2) change as the family and its needs change; (3) encourage families to use natural community supports; and (4) provide access to coordinated services and resources.

**Needs of Families in Caring for a Child with a Disability**

Several studies have examined the needs of families caring for children and adults with disabilities and how those needs are met through formal and informal services. In one such study, Bailey, Blasco, and Simeonsson (1992) found that only 19% of surveyed
parents received additional help from friends or extended family in caring for their children, and fewer than 10% received assistance from health professionals. Immediate family members provided the remaining daily care. Given those results, it is not surprising that the authors found 71% of the 400 families they surveyed were in need of respite care.

One of the major problems associated with unmet needs is a lack of information for families concerning what assistance is available. This becomes obvious when reviewing the 1992 study by Sloper and Turner that examined 107 families of children with disabilities for their perceived service needs. They found that 78% of the families needed child minding or baby-sitting, but 97% of the families responded that they did not receive information about different services, including respite. Other researchers showed similar results. For example, Stallard's and Lenton's 1992 investigation of 41 parents of pre-school children with disabilities found that parents received neither information about financial benefits nor other forms of help available to them. More specifically, they found that slightly more than half of the parents did not receive information on how to acquire respite care subsidies and that a fourth was uninformed of respite services of any type.

Stallard and Lenton (1992) suggested that 44% of parents were dissatisfied with the amount of information that they received from case managers about different family services. A contributing factor may have been that case workers have other responsibilities that prevent them from informing parents about services. Marcenko and Smith (1992) interviewed 32 mothers who were using Michigan’s family support services along with their case workers. The case workers reported spending 55% of their time finding and arranging funding for family support services such as respite care and nursing care, which were the areas where mothers reported the greatest gains in services use. One of the downfalls of investing so much time in arranging services may be a lack of time to inform individuals about what other services may be available through family support programs.

Several studies have sought to identify the services and training that best improve family functioning. Post-tests from a Minnesota early childhood family education
program showed that after a year of participation, families reported significant gains in parent-child interactions, child management, parental self-care, and parental knowledge of child development (Cooke, 1992). More specifically, Comer and Fraser (1998) studied the effectiveness of six family support programs primarily for low-income families. The findings showed that the programs seemed to produce 12-month gains in parental care, including managing pregnancy complications, parent-child interactions, parental knowledge, and child health and development. Parents reported that they had higher levels of self-esteem and self-sufficiency and their children had significantly higher scores in language development than children who were not in a family support program.

Freedman and Boyer (2000) used focus groups of parents of children with developmental disabilities to examine family needs for services and ways to facilitate family choice and control of supports. Parents cited flexible funding as a means to help them secure services that are the best for their families as well as ensuring continuity and consistency of services and supports. They identified several significant barriers to accessing supports, including lack of information and outreach, service systems that react to crises instead of focusing on prevention, and need for more consistent therapies such as behavioral, physical, occupational, and speech.

Hollingsworth (1992) examined another aspect of family support, financial reimbursements for special equipment, therapies, personal care, and other materials and services for children with disabilities. His findings indicate that 32% of parents receiving subsidies for these services and supports were still dissatisfied due to lack of availability or its inability to meet individual needs. Racino (1998) discussed the various forms of cash assistance, including cash subsidies to give families direct control over funds and vouchers (reimbursements), which must be approved by agencies. Agosta and Melda (1996) pointed out that cash subsidies are restricted to the purchases of certain items and services. One result of this policy is that families learn to request items that are likely to be approved, while other needs may go unrequested. When Fujiura, Roccoforte, and Braddock (1994) examined out-of-pocket expenses of families caring for children with disabilities, they found that day care and respite care were the largest household expenditure ($115/year). In 1996, Agosta and Melda also reported
that although families appreciated cash subsidies, the demands of child care often ended up being greater than families could afford even with the subsidies.

**Family Support Services in Different States**

Family support services vary from state to state. Some of these services provide support for families caring for adults, but most are directed at children with disabilities. Knoll et al. (1992) interviewed the director of each division of state government that assisted people with disabilities. They found that 41 states had developed programs specifically designed for helping families with children with disabilities. The remaining states provided in-home care through community services and Medicaid waivers, but they did not meet the authors' criteria of extensive services—respite care, cash subsidies for family support, and case management—to be considered a dedicated family support program.

There is great diversity in the extent that family supports are firmly established in each state. Some services are mandated by state legislatures, and others are not fully realized or implemented. In the study by Knoll et al. (1992), the states were found to provide child-directed services including physical therapy, behavioral management, attendant care, home health care, day care, and skills training. Services specifically for families included personal counseling, sitter service, transportation, parent training, and rent assistance. The oldest and most generally offered service was respite. Financial assistance was another family service provided by many states. This service provided greater flexibility with purchasing services and items for children with disabilities.

Many states provided a combination of respite services, financial assistance, and case management. Case management was established in 23 states for their family support projects. Knoll et al. (1992) found that case management was crucial to the family support system. They found two main forms of case management: an overall service management that did a general assessment and referral for an array of social services; and direct management of family support services in which a social worker ensured that services were found for the family through the agency or community resources.

Nationwide, the authors found that in 1992,
• 46 states offered respite care and child care programs.

• 32 states offered environmental adaptations;

• 30 states offered Medicaid waivers.

• 32 states offered supportive services such as counseling and support groups.

• 26 states offered in-home services, including house cleaning and personal care.

• 24 states offered training for parents in caring for people with disabilities.

• 14 states offered recreation services, such as summer camps, and recreational day programs.

• 11 states offered community assistive services, which provide and coordinate information and services in the community.

Satisfaction with Family Support Services

Numerous researchers have interviewed family members about the effectiveness of the different types of family support services in particular states. These studies have examined cash subsidy systems, case management effectiveness, and parental satisfaction with respite services, among other issues.

In general terms, researchers from Iowa, Illinois, Louisiana, and Utah have found high satisfaction with family support. Their findings indicated that families feel a higher degree of perceived control over the family support services and an improved capacity to keep up with the household routines, pursue hobbies, seek enjoyment outside of the home, and cope with habilitative needs. Families also indicated an overall improved quality of life.

In more specific terms, families indicated they believed that cash subsidies reduced stress and improved their quality of life (Herman, 1991; Meyers & Marcenko, 1989; Zimmerman, 1984). This money was used for an array of services and items, ranging from respite care to toys for the child. In 1994, Herman reported that families were happy with the amount of the cash subsidy ($256) each month, and the families who
used the subsidy to purchase respite services requested more of the services for the future than those who did not purchase respite care. The findings also indicated that families thought the program was easy to access, and they were satisfied with the experience of using the program.

Agosta’s 1992 study of 140 Iowa families using the subsidy yielded similar results. Monthly payments were equal to monthly SSI programs. Satisfaction levels with the were high; 64% of the sample was either moderately or positively affected on quality of family life scales after using the program. The highest satisfaction ratings from more than half the respondents included easing financial worries, improving family’s life overall, and helping the family do more things together. Eighty-three percent of the participants reported great satisfaction with how the program was administered and how agency staff gave support. The lowest satisfaction level was found with the timeliness of the subsidy payments.

Direct care services, such as respite care, were also examined for their perceived effectiveness in improving family functioning, as well as personal satisfaction with the services. For example, Warren and Cohen (1985) compared 107 families who used respite care to 35 non-users. The families using respite care reported increased satisfaction with life, more hope for the future, improved attitudes toward their child with a disability, and an increased ability to cope. Most users (94%) recommended respite services to other families. Studies examining the effects of respite care suggest that it may relieve parent’s depression and stress. Families also reported an increase in their sense of well-being, improved attitudes and relations with their children, and more free time for work, social, or leisure functions (Botuck & Winsberg, 1991; Halpern, 1985; Marc & MacDonald, 1988; Rimmerman, 1989). Another study found better family functioning and reduced stress levels with the use of respite care (Marc & MacDonald, 1988). Joyce and Singer (1983) found that parents thought that respite services prevented them from feeling overburdened with the care of their child and prevented institutionalization of the child.

Marcenko and Smith (1992) interviewed mothers of children with disabilities about case management and then re-interviewed them a year later. They identified greater access
to services, assistance with financing of services, opportunities to network and support
other families with children with disabilities, and the development of advocacy skills as
ways for case managers to assist them in their lives. In the 1992 study by Knoll et al.,
the authors examined two models of case management; they found the general
caseworker, who gave out information between conducting intakes and coordinating
services, to be less effective than the case manager who assessed families' service
needs and assisted them to gain access to programs. The authors also found that a
leading complaint with family support services was inadequate resource allocation.
Many of the states surveyed revealed that their funding allowed them to serve only a
few families from a large eligibility pool. Another problem was that an upper age limit
defined eligibility for family support services in many states. Consequently, parents of
young adults experienced extreme emotional and financial adjustments due to the
termination of services, typically when the young adult reached age 18 or 21.

Key Elements of Family Support Services

Dunst, Trivette, and Deal (1994) describe the goal of family support programs as
identifying families' needs and locating appropriate informal and formal resources to
meet them. These programs respect the integrity of families and their ability to be self-
reliant in meeting their needs. This approach does not require a family to be dependent
upon a social service system to make decisions or carry out treatment plans designed
by professionals. Rappaport’s 1981 study also notes the benefit of assuming that
families are competent and any functioning that is inadequate is the result of improper
or absent social structures.

Agosta and Melda (1996) listed the four elements that seem to be at the heart of the
family support movement. The first element consists of supporting families' efforts to
raise their children with disabilities at home. The second is family support programs to
promote the family's role as the primary caregiver. The third is acknowledgment that
these programs can prevent inappropriate and unwanted out-of-home placement.
Finally, families may reunite with children who were placed out of the home.

In their 1994 article, Dunst, Trivette, and Deal identified six principles they consider
essential to family support programs. They are 1) enhancing a sense of community,
including teaching families how to access community-based resources, 2) mobilizing resources and supports that are flexible and individualized, 3) sharing responsibility and collaboration to build relationships, 4) protecting family integrity by respecting families’ beliefs and cultural values, 5) strengthening family functioning by capitalizing on family strengths, and 6) emphasizing human services “best practices” such as prevention and health promotion.

Most or all of the six principles touch on incorporating community resources into family support services. Comer and Fraser (1998) also stressed the importance of the relationship between individuals and their environment (community), because this relationship results in opportunities to enhance competencies. A relationship with the community also facilitates social relationships that are based on common interest (McNair & Smith, 1998). Increasing competency and forming social ties are two basic objectives for family support programs. Community resources reflect what average individuals use in their communities, including family, friends, neighbors, day care centers, voluntary associations, and religious groups (McNair & Smith, 1998). Churches, the authors point out, are a natural support, providing a feeling of acceptance and comfort.

The research literature identifies two broad reasons for using community resources or natural supports. First, family support services are too limited to meet the full range of families’ needs (Agosta & Melda, 1996; and Bradley et al., 1992). Second, using natural supports is in accordance with the belief that supports are more effective when their sources are closest to families geographically as well as personally (Hobbs, Perrin & Ireys, 1984). Although combining natural supports with family support services is a positive move, Agosta and Medla (1996) note that this may leave families to negotiate with multiple agencies, adding a new level of frustration in their efforts to secure the services their families need.
References


Stallard, P. & Lenton, S. (1992). How satisfied are parents of pre-school children who have special needs with the services they have received? A consumer survey. *Child Care, Health, and Development, 18*, 197-205.

