ISSUES PAPER 1

April, 1988

Prepared for:

The Massachusetts Developmental Disabilities Council 600 Washington (Suite 670)
Boston, MA 02111
(617) 727-4178

Prepared by:

John Agosta, Ph.D.

Research Associate
The Human Services Research Institute
Cambridge, MA 02140
(617) 876-0426

TABLE OF CONTENTS

TOPIC	PAGE
INTRODUCTION	1
THE RANGE OF FAMILY NEEDS	2
A FAVORED RESPONSE TO FAMILY NEEDS	4
Family Centered Approaches	4
Culturally Sensitive Approaches	6
Community-Based Approaches	6
Comprehensive and Well Coordinated Approaches	7
STATE-LEVEL EFFORTS & THE ROLE OF CASH ASSISTANCE	8
Current State Level Efforts	8
The Role Cash Assistance Could Play	9
KEY ADMINISTRATIVE ISSUES AND POTENTIAL LIMITATIONS	11
Administrative Concerns	11
Potential Limitations of Cash Assistance Approach	14
EVALUATION OF EXISTING CASH ASSISTANCE PROGRAMS	15
System Level Findings	16
Family Level Findings	18
SUMMARY AND CONCLUSIONS	21
REFERENCES	22

Families who provide care at home to persons with developmental disabilities can face a variety of extraordinary challenges. In response, a growing number of states are implementing programs to support family efforts, with about 15 offering cash assistance to families to offset the costs they incur (Agosta, Jennings & Bradley, 1985; Wolk, 1987).

Plans to implement cash assistance programs, however, often spur lively discussion that frequently revolves around these three topics:

- 1. Conflicting beliefs regarding cash assistance and families. Should families be given cash to help offset the costs of providing care? This question will often prompt debate among professionals and family members alike. Some argue that families are ill-equipped to spend their cash wisely, that the cash will be used to purchase items that are not care-related, or that by receiving cash families are made needlessly dependent on public support for the long term. Others maintain that the provision of cash assures a flexible response to family needs, and reflects a belief that families are responsible caregivers and capable of making informed decisions about the supports they require.
- 2. Administrative uncertainties. Traditionally, a state agency provides for persons with disabilities by either offering services directly or by contracting with a third party service provider. Providing cash directly to families represents a significant departure from this pattern, and may not be easily incorporated into existing administrative structures. Depending on the state, to implement a cash assistance program certain administrative issues may first need to be resolved.
- 3. Programmatic uncertainties. Ideally, families can receive needed supports from: a) the public sector (e.g., public financed programs), b) the private sector (e.g., employers, health insurers), and c) informal support networks (e.g., extended family, friends, neighbors, church groups). The challenge facing policy makers is to define a useful role for cash assistance, and public support programs in general, within the context of these three sources of support. Stated otherwise, given multiple potential sources of support, how can cash assistance be used most efficiently and with greatest effect?

In this paper, a variety of issues surrounding these topics are explored. The paper, divided into six parts, begins with a description of the range of needs families may have. Second, desired responses to family needs are described within the context of an empowered family role and complementing sources of support. Third, current state level initiatives are described, along with the role cash assistance could

play to help accommodate family needs. Fourth, key administrative issues and several potential limitations associated with a cash assistance approach are examined. Fifth, current information is presented regarding the evaluation of cash assistance programs. Finally, discussion is offered concerning future directions pertaining to cash assistance practices.

€.

THE RANGE OF FAMILY NEEDS

Families who provide care at home must learn how to implement specialized care routines while attending to normal family functions. Because of the added pressure, these families can face a variety of challenges over and above the normal responsibilities associated with bringing up a child (e.g., Agosta & Bradley, 1985; Batshaw & Perret, 1986; Hobbs & Perrin, 1985; Lapham & Sherlin, 1986; Longo & Bond, 1984; Turnbull, Summers & Brotherson, 1986; Wikler, 1986). As can be distilled from numerous sources, and as depicted by Figure 1, these potential challenges pertain to the entire family unit as well as its member with disabilities.

Available research suggests that the difficulties actually experienced by individual families are related to multiple factors including the seriousness of the family member's disability, the presence of challenging behavior, family characteristics, specific parenting patterns, the family's capacity for coping with adversity, and the availability of community support services (Agosta, Bass & Spence, 1986; Crnic, Friedrich & Greenberg, 1983; Tausig, 1985). As a result, Moroney (1983) notes that though not all families who provide care at home have extraordinary problems, all are more "at risk" for having difficulties than families without members with disabilities.

Figure 2 shows a range of supports that may be needed to overcome care-related difficulties, and suggests that besides the direct services persons with disabilities may receive, family members may also need support to ease the day-to-day demands of providing care at home, and to enhance their capacity to function as a family. Of course, not all families require all services. Every family is different and requires a unique cluster of services, some of which may not be displayed by the figure below. Moreover, the needs any family may have are not fixed, but often shift in face of changing family circumstances or as the family moves through its life cycle (Konanc & Warren, 1984; Suelzle & Keenan, 1981; Turnbull et al., 1986).

FIGURE 1: POTENTIAL CHALLENGES FAMILIES MAY FACE

Potential Challenges Concerning the Family Member with Disabilities:

- Health Status: Several types of disabling conditions require frequent monitoring of biological functions, requiring that caretakers be knowledgeable about means for coping with chronic medical needs.
- Adaptive Skills: Persons with mental retardation have problems with learning, while those with disabilities and normal intelligence may acquire skills at a reduced rate due to their physical condition. Regardless of the problem, such persons generally require increased opportunities for learning and can benefit from specialized instructional assistance.
- Socio-behavioral Skills: The inability to grasp concepts quickly, diminished capacity to communicate or the frustrations of having a disability can result in challenging behavior. Eliminating such behavior can require extraordinary effort from parents and may necessitate consultation with a specialist.
- Other Developmental Skills: Persons with disabilities may require specialized treatment such as communication training or physical therapy, or they may require a variety of prosthetics.

Potential Challenges Concerning Caregiving Family Members:

- Natural reactions to the discovery that a family member has a disability, including a sense of shock or numbness, denial, grief, shame, guilt or depression.
- Chronic stress that can affect family interactions and functioning.
- Dramatic changes in lifestyle, often affecting past established social relationships within the family, or with others.
- Financial costs, or lost opportunities for employment or education.
- Extraordinary time demands involved with providing personal care to the family member with disabilities, finding needed specialized professionals, or negotiating bureaucratic systems.
- Difficulty with physical management (e.g., lifting, carrying) and in handling challenging behavior.
- Difficulty in undertaking family routines such as shopping and house cleaning, or in finding ample time for recreation.
- Lack of skills needed to cope with potential medical emergencies and/or to teach necessary adaptive skills.

FIGURE 2: LIST OF SERVICES THAT COULD BE REQUIRED

Home-Based Services Centered Around the Person with Disabilities

diagnosis and assessment
educational/therapeutic services
medical or dental services
home health care
recreational opportunity
special clothing
special diets
transportation
adaptive equipment
housing adaptations
adequate health insurance

Home-Based Services Centered Around Family Members

information and referral temporary relief/respite family counseling parent/sibling education day care housekeepers cash assistance futures planning mutual support groups adequate housing

A FAVORED RESPONSE TO FAMILY NEEDS

Though providing care at home to a child with disabilities can be a challenging task, most families reject out-of-home alternatives in favor of continued care at home, especially during the early stages of the child's life (Ashbaugh, Spence, Lubin, Houlihan & Langer, 1985; Lakin, Hill & Bruininks, 1985; Perlman, 1985). The recognition that many persons with disabilities live at home with their families prompts concern for assuring that these persons receive the services they need, and that the efforts of their families are supported and enhanced. For policy makers, once a commitment is made to family-based care, this concern is often translated into the following two part question: What types and amounts of family-related services should be offered, and how should they be administered?

An effective response to family needs requires that a comprehensive and flexible array of supports be made available. Further, there is growing consensus that those supports offered should be administered so that they are family centered, culturally sensitive, community-based, and well coordinated (e.g., Agosta & Bradley, 1985; Turnbull et al., 1986; US Congress Office, Office of Technological Assessment, 1987), concepts that are each discussed in greater detail below. Within this context, providing cash assistance directly to caregiving families is a programmatic option that must be carefully considered.

Family Centered Approaches

Many of the family oriented models of service that have emerged over the last 15 years have embraced a "family-centered" rhetoric. In reality, however, most state and local systems are only just coming to grips with the implications of this concept. As used here, the notion of "family centered" carries three conceptual underpinnings.

(...

First, that services should enable and empower family members to make informed decisions. Service models must be founded on the presumption that families and are potentially capable and willing to make responsible decisions; families want the best for their children. This stance is based in a social systems perspective (e.g., Rappaport, 1981) and suggests two subsequent conditions. First, that family members who fail to display needed skills do so not because of unreconcilable personal deficits, but primarily due to an absence of sufficient opportunities to acquire needed competencies. Consequently, Dunst (1986) suggests that family members should have "enabling experiences" whereby competence can be displayed or learned. Second, that if family members are to claim control over their lives (i.e., become empowered), they must attribute the changes in their lives to their own actions. Given these conditions, the challenge for service practitioners is to establish partnerships between families and professionals that enable and empower service consumers to the maximum feasible extent (Slater & Mithchell, 1984).

Of course, there are limits to the emotional, physical and financial resources of parents and their expertise. When first confronted with the reality of a disability, many family members have little understanding of what overall needs they or their child will have. Moreover, even as time passes, some families are unable or unwilling to accept an empowered role. Yet the absence of needed skills among some or the reluctance of others does not justify the substitution of professional judgement in all cases.

Second, that services should be responsive to the needs of the entire family unit. Johnson (1979) notes that within a family-systems framework the family is viewed as an interacting, reacting system which is delicately balanced and struggles to maintain that balance. A change or problem in one aspect of the system, affects the entire system. Thus, family support and case management practices cannot be solely directed at the needs of the child. Rather, supports should be available to other family caregivers, with the intent of enhancing the family's overall capacity to provide care.

Third, services should be flexible enough to accommodate unique needs. No two families, with or without children with disabilities, are alike. Considerable variation exists regarding disability types and severity, family characteristics and resources, and family perceptions regarding the caregiving situation (Agosta et al., 1985; Sherman, 1988; Tausig, 1985; Wikler, 1986). Moreover, these factors are not static, but evolve over time (Turnbull et al., 1986). These considerations suggest that responsive programs must permit a wide array of supports (i.e., multiple support options) and must encourage each family to select those that are most appropriate to its needs.

Culturally Sensitive Approaches

No single approach to supporting families is likely to work with all families. Differences in family type, culture, income and geographic location call for diversity in the approaches undertaken (Agosta, O'Neal & Toubbeh, 1987; Dunst, 1986; Turnbull et al., 1985). To be most effective, support services must be consistent with the culturally based preferences of individual families. This holds true regardless of the number of families sharing a particular belief system or the degree of difference between the dominant and minority cultures. Further, the same principle can be applied to areas other than cultural differences such as race, geographic diversity (e.g., urban vs. rural) or socioeconomic status (McGoldrick, Pearce, & Giordano, 1982; Turnbull et al., 1986; Wells, Agosta, Berliner, Cox & Bedford, 1988).

Community-Based Approaches

In the recent past, the primary response to disability has been to provide services through the public sector. Present practice, however, increasingly relies on alternatives available in the private sector or within informal helping networks to complement public sector initiatives. In some part, this shift is based on the belief that supports are most effective and least costly when their source is closest to the family, in terms of both geographic and personal proximity (Dunst, 1986; Hobbs, Dokecki, Hoover-Dempsey, Moroney, Shayne & Weeks, 1984; McKnight, 1987).

Many supports can and should be available through informal or private sector means (e.g., extended family, employer benefits, private health insurers) (Akabas, 1984; Dunst, 1986; Griss, 1984; Piccione, 1982). In fact, by focusing on public sector solutions exclusively, existing helping networks may inadvertently be displaced or other potential sources of support may never be utilized (Hobbs et al., 1984).

That informal social support can have a positive influence on family well-being is easily documented (e.g., Dunst, 1986; Cohen & Syme, 1985; Gleidman & Roth, 1980; Wells et al., 1988). Such support, typically found through friendship or ongoing interaction with extended family, can play a key role in easing the day-to-day challenges experienced by families by alleviating their negative impact on the family, promoting the family's integration into the community mainstream, or promting smooth family functioning (e.g., Dunst & Trivette, 1986; 1987; Moore, Hamerlynck, Barsh, Spieker & Jones, 1982; Wikler, 1986).

Likewise, the potential utility of supports offered through more formal private sector structures should not be ignored. Every community contains businesses or organizations that may prove helpful to families. For instance, local building contractors may find ways to make a home barrier free, day care operators, with some specialized training, may be persuaded to serve children with severe disabilities, and employers can tailor benefits packages to satisfy individual family needs. Though the role that could be played by formal indigenous networks is only now being systematically explored, policy and practice advanced in support of families can begin by encouraging a sense of community and mutual aid

(Akabas & Krauskoff, 1984; Balanzo & Beck, 1982; Griss, 1984; Hobbs et al., 1984; Schwartz, 1987).

It is understood, however, that existing private or informal community support structures are not likely to meet the range of complex needs of children with disabilities and their families, and public funds and resources will continue to serve as a necessary complement. For example, children with severe physical limitations or chronic illnesses may require the services of specialized professionals (e.g., Batshaw & Perret, 1986; Goldfarb, Brotherson, Summers & Turnbull, 1986; Hobbs & Perrin, 1985). Likewise, family members could benefit from formalized supports that are not typically available within natural community helping networks, such as futures planning relevant to their member with disabilities or disability related information and referral (e.g., Agosta & Bradley, 1985; Parrot & Herman, 1987).

Comprehensive and Well Coordinated Approaches

Numerous programs presently exist for providing services to children with disabilities and their families. Examples include those extended through: 1) state disabilities agencies or Developmental Disabilities Councils, 2) the public schools as mandated by the Education for the Handicapped Act (P.L. 94-142) and subsequent amendments (P.L. 99-457), 3) university programs supported by federally financed demonstration projects and/or through a University Affiliated Facility (UAF) or Project(UAP), and 4) private sector initiatives sponsored by employers, private businesses, charitable foundations or specialty care settings, such as hospitals, that offer a range of family supports.

Although these programs vary as to target population and services provided, they are part of the potential network of supports that could be used to benefit children with disabilities and their families. Taken together along with informal helping networks, the challenge facing service practioners is twofold: 1) to match child and family needs with appropriate supports, and 2) to build a comprehensive circle of supports around the family unit that takes efficient and effective advantage of all available community resources.

Match Needs To Resources Dunst (1986) argues that to maximize the positive impact of those supports provided, a satisfactory match must be assured between the nature of the help or support sought and the type of assistance provided, based on the unique needs and preferences of individual families. For instance, when a parent indicates a pressing need for housing adaptations to accommodate a child with severe physical limitations, and the needed modifications are made, the assistance is likely to have beneficial outcomes for the child and other family members as well. In contrast, where there is a mis-match between the type of help desired and the supports available, family circumstances will likely not be favorably influenced. For example, when a parent's needs for periodic respite are unpredictable, respite services predicated on a two week notice will do the parent little good. Played out, this mismatch of resources to family need could have a serious negative impact on the family's capacity to provide care at home.

Build a circle of supports around families Figure 3 shows the family unit surrounded by three potential sources of support. As shown, families and their children can benefit from the efforts of the public sector, private sector (e.g., health insurers, accommodating employers, day care operators, officials at local banks), as well as from the informal efforts of a variety of caring persons. The challenge facing service practioners is to weave together these three sources of support whereby: 1) the child with disabilities receives needed habilitative or health related services, 2) family members receive the supports they need to enhance their capacity to care and to function as a family, and 3) potential community centered helping networks, outside the public domain, are utilized to the extent feasible (See Hobbs et al., 1984).

FIGURE 3: THE FAMILY UNIT AND THREE SOURCES OF POTENTIAL SUPPORT

PUBLIC SECTOR SUPPORTS

- -state agencies
- -social service and health providers
- -Medicaid/SSI (Title XIX)
- -public schools

FAMILY UNIT

-caregivers -care recipient

INFORMAL SUPPORTS

- -extended family
- -church groups
- -neighbors
- -friends

PRIVATE SECTOR SUPPORTS

- -day care centers
 -employer benefits
- -employer benefit:
 -health insurance

STATE-LEVEL EFFORTS AND THE ROLE CASH ASSISTANCE COULD PLAY

Current State Level Efforts

In light of such driving concepts as those posed above, many states have recently implemented programs to support family efforts (Agosta, et al., 1985b; Bates, 1985; Bird, 1984). In general, these programs utilize either a support services approach exclusively or provide cash

assistance in combination with support services. Support programs primarily provide families free inkind habilitative materials or services. In these programs, states fund various agencies which in turn provide specified services. It is the most frequently used means of administering a family support system.

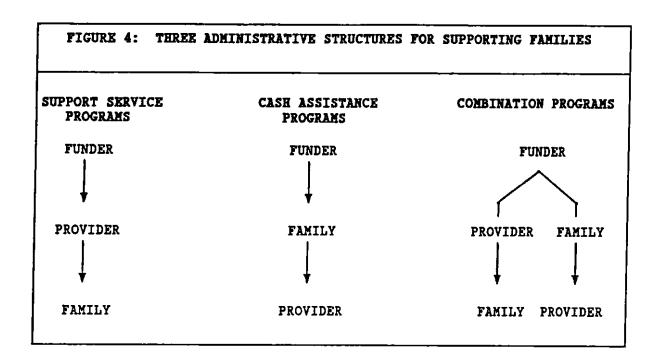
By contrast, cash assistance programs provide money directly to families to offset care related expenses. In such programs, families either receive a periodic subsidy or stipend to pay for future expenses or are reimbursed for the costs that are incurred. Restrictions may be placed on the types of expenses to which the cash may be applied, and family members may need to show receipts to document how the cash was spent. These programs typically provide cash assistance in combination with support services, with the actual mix between the two primary approaches varying by program.

In addition, it should be noted that most existing programs, are rather limited in scope and vulnerable to shifting political priorities. Though there are exceptions (e.g., Wisconsin, Michigan), these programs generally offer few services to relatively few families, place restrictions on the types of supports that may be acquired, do little to utilize existing community helping networks, and are slow to offer family members an empowered role (Agosta, Bradley, Rugg, Spence & Covert, 1985). Further, because these programs are usually funded primarily with state dollars, they are relatively expensive to operate from the state's perspective, especially when compared to initiatives that can utilize federal matching funds, such as the Title XIX Medicaid program (Castellani, 1987; Lakin et al., 1985). Thus the magnitude of the fiscal and programmatic resources allotted to these programs still pales compared to what is spent on out-of-home alternatives (See Agosta & Bradley 1985; Braddock, Howes & Hemp, 1984), and family support programs can be difficult to initiate, expand or maintain, especially where state funds are scarce (Agosta et al., 1985a).

The Role Cash Assistance Could Play

Offering families cash to offset the challenges of providing care at home could play a useful role in enhancing family efforts and in strengthening the composite effects of all available supports. It is instructive to consider the potential value of a cash assistance approach from both a family and system perspective.

Cash Assistance from the Family's Perspective Receiving cash assistance can provide family members with control over the source of those supports acquired and the flexibility to accommodate unique child or family related needs. In this regard, the administrative merits of a support service, strict cash assistance and combination approach can be contrasted. Though the underlying goal of each approach may be to provide families with the supports they need, the processes by which this goal is pursued differ significantly. Figure 4 displays the three administrative strategies in terms of how services are funded and ultimately secured.



As shown, in a "support service" program, the funder (e.g., state department of human services) contracts with a third party agency, which in turn provides services to families. This approach may be least responsive to the needs of families because: 1) service agencies may not offer all those supports a family may need, 2) such systems are not often sufficiently flexible to accommodate unique family needs, and 3) families are not empowered so that they can choose from whom they will receive needed supports.

By contrast, in a strict "cash assistance" approach, the funder provides dollar resources directly to families, who in turn select and pay the support agent(s) of their choice. On its face, this approach empowers families and encourages service providers to be directly accountable to family members. It should be pointed out, however, that:

1) where few services exist, families may not be able to purchase needed supports, 2) family members may not have sufficient information for making informed choices, and 3) some families may not wish to play such an empowered role.

The "combination" approach can be used to offset the disadvantages of a support or cash assistance strategy, while building on the strengths of each. With this approach, funds may be provided either directly to families or to service agencies, depending on the type of support needed, family preferences, or other factors. This approach may represent the most promising means for crafting an effective partnership between families and professionals, because it encourages both to be active and cooperative participants in the service delivery process. Further, while embracing aspects of a support service approach, it assures that family members have some amount of cash on hand to accommodate unique needs or to otherwise enhance family functioning.

For instance, given the availability of cash assistance, families in need of major housing adaptations, often a costly endeavor, can reach agreement with a local building contractor and finance the renovations through a bank, using the cash to make monthly payments on the loan. Others, whose member with disabilities has health costs that are not covered by the terms of an insurance policy can use the cash to offset these expenses. In fact, the cash supplement may make it possible for some to make payments on insurance premiums. Likewise, in securing temporary relief (i.e., respite care) some families may prefer to retain their own respite workers and to pay them a fee of their own choosing.

Cash assistance may also be used to meet other unique needs as well. Regarding the opportunity costs associated with family care, mothers who give up their jobs to provide care at home may rejoin the work force by using the cash to pay for day care, or they can use it to achieve previously abandoned educational goals in order to acquire higher paying employment. Others, after years of lifting and carrying a child with physical disabilities, may develop physical limitations and could use the cash to pay for adaptations or professional advice needed for themselves. Likewise, the family may use the cash to help support a family outing or simply to help ends meet.

Cash Assistance from a System Perspective From a systems perspective, providing families with cash assistance can help to extend the circle of supports around families and to fill existing gaps in services without expanding the role of public sector interests. For instance, where respite care is needed, the state may elect not to fund formalized respite care agencies exclusively, but may opt to place some funds directly into the hands of families and encourage them to use the money to secure their own relief. Likewise, where the family requests professional counseling, providing cash may allow the family to see a counselor of their own choice, without the state or some proxy agency having to make the service available. In essence, a cash approach can simplify and enhance the service delivery process by eliminating the need in all cases for involving a vendor agency holding a contract with some office of the public sector.

KEY ADMINISTRATIVE ISSUES AND POTENTIAL LIMITATIONS

Administrative Concerns

Designers of cash assistance programs, must resolve numerous administrative issues, many of which are interrelated. Six such issues are: 1) deciding on the purpose of the program and the role of the family, 2) setting eligibility criteria, 3) determining how much cash will be provided, 4) deciding what the cash can be used to purchase, 5) determining how the cash will be disbursed, 6) identifying and overcoming potential interagency conflicts or regulatory barriers.

Program Purposes And The Role Of The Family Toward what end should cash be offered to families? There is little disagreement that three primary program goals should be to prevent unnecessary out-of-home

placement, assure that the person with disabilities receives needed services while at home, and enhance family functioning (Agosta & Bradley, 1985). The role cash assistance should play within this context is open to discussion. For instance, the potential flexibility associated with cash assistance approaches may trouble those who believe that the cash should be used exclusively to purchase supports that are easily recognized as related to the care of the person with disabilities, and not spent on other items that are indirectly associated with such care (e.g., foodstuffs for the entire household). This position, however, fails to consider that though meeting the needs of the person with disabilities is essential, enhancing overall family functioning is an important outcome as well, having been associated with continued care at home and improved family coping (e.g., Moore et al, 1982; Parrott & Herman, 1987; Turnbull et al., 1986).

A related issue concerns the role families should play in directing how their cash can be spent. Much policy and practice in the human services field typically discounts the family's role in providing care, presuming familial incompetence while relying on professional judgement (Demos, 1983; Dunst, 1986; Skarnulis, 1979).

The degree of control held by families within existing family support programs is not clear, though the addition of a cash assistance approach may carry greater potential for empowering families than support services alone by providing each family with greater control over the acquisition of needed supports. Yet some may question the intentions of family members or doubt their competence to make informed decisions, concerns that are not easily ignored, given that some number of parents may misuse the cash, either purposefully or not. Where cash programs have been intiated, however, misuse is the exception rather than the rule (Parrott & Herman, 1987; Rosenau, 1983). Moreover, if coupled with systematic feedback, actions interpreted as a "misuse" of cash by professionals may be translated into a concrete enabling experience for family members. In other cases, the roles may reverse themselves as family members broaden the professionals' appreciation of the wide range of activities that can be used to enhance family functioning.

Program Eligibility Who should receive services is a perplexing issue that can severely test a society's capacity for equitably distributing scarce resources to those in need. For admittance to any family support program, prospective consumers must first satisfy the criteria established by the administering agency (e.g., Department of Human Services) concerning the person with disabilities. In addition, other eligibility criteria may also be imposed, such as those pertaining to the family's fiscal resources (e.g., a means income test), the placement status of the family member with disabilities, or an assessment of the family's need for cash.

Amount Of Cash Provided On the one hand, decision makers may elect to "cash out" the entire family support system, providing families with relatively large amounts of money to acquire whatever supports deemed necessary. On the other, families may be provided a small monthly cash allotment to complement the support services they regularly receive.

Permissible Purchases A key to the design of a cash program is a set of guidelines regarding permissible purchases. Determinations will be based on the program's underlying values and overall purposes, and the array of support services already available. Where the program's values are centered exclusively on the person with disabilities or its purposes are narrow, the array of supports for which cash may be used could be restricted. Likewise, given an array of supports already available, decision makers may choose not to undercut existing providers, opting instead to confine cash purchases to supports not already available through the public sector.

Means Of Cash Disbursement Should parents be provided cash prior to purchasing needed services or should they be reimbursed after they have already incurred certain service related expenses? Receiving cash prior to purchasing services could relieve strain on family resources. In contrast, decision makers might prefer a reimbursement strategy because it would be easier to direct and track what is purchased.

A related concern involves the level of accountability that will be expected of family members. After the cash is disbursed and the desired supports are purchased, will receipts need to be shown? Some may argue that because public dollars are involved, family members must document exactly how their cash was spent. Others, noting that those who receive Supplemental Security Income (SSI) through the Social Security Administration need not show exactly how these dollars are spent, may claim that keeping track of how the cash is spent adds a needless demand on the family, and reflects a lack of trust in families that is unwarranted.

Overcoming Potential Interagency Conflict Or Impeding Regulations Each program in a public helping network is typically charged with a specialized mission pertaining to human needs, resulting in divisions of responsibility. As needs are identified, the consumer is passed along to the appropriate agency. Providing cash to families, however, may undermine this tradition, because it could expand the bounds of the "family support program" to encompass needs typically met through other public sector auspices. For instance, where families have little income, should cash acquired through a family support program be used to purchase food or shelter? Or should the family be advised to petition other components of the public system to obtain food and adequate housing, saving their "family support" cash for care related expenses?

Another area of concern involves the impact of existing bureaucratic regulations or precedence. For example, in some states (e.g., Massachusetts) public dollars allotted to certain social endeavors must be spent according to the pre-set rates or costs associated with specific services, leaving little room for families to choose supports not considered previously by the state or to adjust costs. Similarly, though the state may not take issue with families who use public dollars to complete needed housing adaptations, a significant concern may surface if the adaptations enhance the value of the property. In fact, in Massachusetts there is judicial precedent, built around the state's "anti-aid amendment," to suggest that cash assistance will not be easily applied to major housing renovations. Though neither condition presents

an insurmountable barrier to the implementation of a cash assistance program, these examples indicate that in some instances policy makers may need to tailor the program to satisfy prevailing state standards or alter impeding regulations.

Finally, how will the cash received by families be viewed by other public entities? For example, should the cash received by parents be considered taxable income? If viewed as income, the state could be placed in the undesirable position of subsidizing federal tax revenues. Further, such income could jeopardize a family's eligibility for other public assistance benefits (e.g., food stamps, Medicaid). In contrast, if cash assistance is viewed as a "benefit," as it is in Michigan, the cash received by parents would not be taxable and would not affect eligibility for public assistance.

Potential Limitations of Cash Assistance Approach

Even as these administrative issues are resolved, the utility of a cash assistance approach may be tempered by at least these five concerns: 1) assuring that family members are "wise consumers," 2) meeting the needs of families facing multiple challenges, 3) reducing the potential for fostering dependence on the cash assistance, and 4) assuring that needed supports are actually available for purchase.

Assuring That Family Members Are "Wise Consumers" A necessary foundation of cash assistance programs is the presumption that family caregivers have sufficient knowledge regarding the needs of their member with disabilities and the quality of available services. To the extent they do, the chances of their spending their cash efficiently are improved. But some parents may be unprepared to choose and purchase services wisely, or may feel unsure of their decisions (Wells, et al., 1988). Thus, complementing cash assistance programs with case consultant services and family education may be adviseable to provide family members with the knowledge or enabling experiences needed to choose appropriate services (Wikler & Keenan, 1983; Wray & Wieck, 1985).

Meeting The Needs Of Families Facing Multiple Challenges Some families are challenged by circumstances beyond those imposed by their member with disabilities (Wells et al., 1988). Examples include: chronic unemployment of the primary wage earner(s), drug or alchohol dependency among family members, criminal offenses committed by family members, or physical abuse inflicted by a family member on other members (Parrott & Herman, 1987). As a result, a variety of public sector agencies may be involved with the family, or should be. In such cases, the role of cash assistance, and a family support program in general, must be carefully considered in relation to other family circumstances, and the efforts of other human service workers.

Reducing The Potential For Fostering Dependence On Cash Assistance Providing families with a cash supplement effectively extends the family's income, especially if their are few restrictions on how the cash is spent. Some families may choose to spend their allotment to upgrade their standard of living (e.g., move to more costly housing), or to extend their resources further (e.g., take a loan to have needed

housing adaptations completed). By doing so, families may become dependent on the cash assistance for the long term, an undesired outcome given an overall program goal of reducing unnecessary family's dependence on the public sector.

Assuring That Needed Supports Are Available For Purchase When families are provided with cash, it is presumed that the supports that are needed will be available for purchase and will be easily accessible. Where this is untrue, the benefits of providing cash to families may be diminished. In response, states may first need to establish certain frequently demanded services (e.g., respite care), perhaps through the existing disabilities provider network or by creating incentives for private businesses (e.g., day care centers) to develop needed supports.

For less frequently demanded supports (e.g., housing adaptations, special equipment) computerized information networks can be used to form a directory of available sources of support (e.g., suppliers of special equipment, building contractors) to link families with needed services, both locally and regionally. In doing so, family satisfaction with these services can also be tracked to help families choose between competing services and to prompt businesses to provide services of the highest caliber.

EVALUATION OF EXISTING CASH ASSISTANCE PROGRAMS

About 15 states, displayed in Figure 5 along with the dates of program inception, presently offer families cash assistance through family support initiatives (Agosta, et al., 1985b; Bates, 1983; Wolk, 1987). Obtaining exact counts of such programs is a difficult task, given that initiatives undertaken through the state mental retardation or disabilities service system can be complemented by supports made available through other sources (e.g., the public schools, hospitals), and that the circumstances within states are continually evolving.

FIGURE 5: FIFTEEN STATES OFFERING CASH ASSISTANCE *

- 1. Connecticut (1981)
- 2. Florida (1978)
- 3. Idaho (1981)
- 4. Indiana (1982)
- 5. Louisiana (1983)
- 6. Maryland (1984)
- 7. Michigan (1984)
- 8. Minnesota (1975)

- 9. Montana (1975)
- 10. Nebraska (1982)
- 11. Nevada (1981)
- 12. North Dakota (1981)
- 13. Rhode Island (1981)
- 14. South Carolina (1974)
- 15. Wisconsin (1984)

^{*} Source: Wolk, 1987

To date, very few evaluations of any family support programs have been undertaken to identify potential means for improving administrative practices or for assessing their effects, with fewer still of cash assistance initiatives (Agosta & Bradley, 1985). What follows is a presentation of findings generated by evaluations of cash programs that have been completed thus far, from both the perspective of system level decision makers and individual families.

System Level Findings

(

Regarding service processes, the family support program in Florida has been examined to improve administrative practices. Problems were identified regarding the staffing of family support services and the time taken to reimburse parents for the costs of certain services (Bates, 1983), and steps were taken to improve such procedures. In addition, the state decided to do away with its system for assessing parental income and resources to determine the amount of cash assistance a family could receive (i.e., sliding scale eligibility). Examination of this practice revealed that it cost the state more to collect information and allocate services according to a sliding scale than the state was saving through its use (Agosta et al., 1985a).

The Minnesota Developmental Disabilities Council sponsored an evaluation of the state's cash subsidy program (Minnesota Developmental Disabilities Program, 1983). A stratified sample of 38 families participating in the program were asked a series of questions regarding how administrative practices could be improved. Respondents suggested a range of useful activities, including: 1) expanding the program to include adults, 2) requiring that applications be completed once per year rather than twice, 3) providing specialized training about the program to local social and health service staff, 4) using parents to publicize the program, 5) increasing benefits for families with extraordinary needs, and 6) increasing benefits for emergency respite care and long distance medical phone calls.

In Michigan, families of children aged 18 years or below who qualify for the state's cash program receive a monthly subsidy, paid through the mail by check. Based on an evaluation of the program, Parrott & Herman (1987) offered numerous recommendations for program improvement, many of which were incorporated into the program. For instance, the amount of the subsidy was intially set at \$225.54/month (based on the Supplemental Security Income (SSI) payment for an adult person in a household of one), but it was recommended and later approved that the amount be increased to \$243.33/month to match an increase in the SSI allowance for adults. Additionally, action was taken to 1) expand the program to include previously excluded persons with severe multiple impairments, 2) increase the appropriations set aside for complementing support services (e.g., respite), and 3) to assure that families are informed of the full range of supports available.

For program outcomes, there is insufficient information regarding the effects of family support services, including cash assistance, on the overall system of services. One popular claim has been that family support services are cost effective because they diminish the need for funding expensive out-of-home residential arrangements by making it possible for families either to keep their member with a disability at home or have him/her return home from an out-of-home placement. In this regard, Michigan officials, noting institutional costs of \$136.90/day per resident compared to \$7.41/day per family receiving a subsidy, anticipated significant savings in the long term because of an emphasis on family support (Stabenow, 1983).

While such reasoning is appealing, conclusive substantiating evidence is not yet available. As is shown below, several researchers report that receiving cash assistance can have a positive impact on family placement decisions (e.g., Rosenau, 1983; Zimmerman, 1984; Herman, 1983; Parrott & Herman, 1987). These findings, however, must be weighed against at least four other factors. First, the overwhelming majority of families do not place their sons or daughters with disabilities out of the home, especially during the childs first years (Ashbaugh, et al., 1985; Perlman, 1985). Thus unless family services are successfully targeted only to families likely to seek an out-of-home placement, an enormously difficult task, the cost savings realized by states would not be substantial. In fact, in the short term at least, the costs of funding an extensive family support program may even add to the aggregate costs of services for persons with developmental disabilities.

Second, review of existing services reveals that once a person with disabilities is placed out of the family home, few families bring the person back home. For instance, of the 74 children (of 3,300) paticipating in the Michigan cash program from 1984-87 who were placed out of home, only six have a goal of returning home (Parrott & Herman, 1987). Thus the cost savings to states in this regard may also not be immediately recognized.

Third, available information suggests that among parents who seek out-of-home placements there is no one overriding factor that cuts across all families. Rather, there are numerous factors that vary from family to family, and change as the family member with a disability ages and as the family's composition, characteristics, resources, and perception of the problem are altered (Tausig, 1985; Agosta, et al., 1986; Sherman, 1988).

Sherman and Cocozza (1984) present an extensive review of the literature on this matter and show that when families do decide to place their son or daughter with disabilities out-of-home, their decision is related to four factors: 1) characteristics of the child with disabilities such as level of disability, IQ, and functioning level; 2) characteristics of the family such as family size, age of the parents, socioeconomic level, marital and family relations, and the presence of other family problems; 3) perception of the problem as related to the level of stress family members experience and its source (e.g., financial burdens, difficulty with physical management of the child, lack of parenting skills, and strained family relationships); and 4) the availability of community services and social supports that can diminish the severity of the problems experienced by families who provide long-term care to members with disabilities. These considerations suggest

that measuring the impact of family support services, or cash assistance in particular, on placement decisions is complicated by the multiple factors that may influence the decision.

Finally, evaluation of the effects of support programs on placement must be weighed against the recognition that all family-based care eventually ends through death or illness of primary family caregivers, or independence of the person with disabilities. Thus, a more relevant issue is whether the duration of family care is extended to the point where separation from the family is desirable and appropriate.

In sum, the claim that family support services will save states substantial amounts of money has not yet been clearly documented. For some, until such savings are shown, funding extensive family support services, including those with a cash component, may appear politically unattractive. However, decisions regarding funding for these services should not be based simply on demonstrations of their cost savings to the state. Numerous other benefits to such programs have been demonstrated for families and must also be taken into consideration.

Family Level Findings

[

Three primary issues concerning the efficacy of family support programs involve their impact on the family member with disabilities and on the family, and family placement decisions. Present evidence suggests that the family member with a disability can benefit as a function of family support services and cash assistance. For instance, Zimmerman (1984) reports that the majority of families receiving cash subsidies in Minnesota think that their child improved socially, physically, intellectually, and emotionally. Similarly, a comparison between children with disabilities living with families receiving support/cash services and children living with non-participating families reveals that children living with participating families show significant increases in adaptive skills and decreases in challenging behavior, whereas children living with non-participating families do not show similar changes (Rosenau, 1983).

Likewise, present evidence also suggests that the family unit may benefit as well. For instance, in perhaps the most extensive study of a cash program to date, Parrott & Herman (1987) reported that during its first three years of operation the Michigan cash program served 3,300 families with 74 children leaving the program for an out-of-home placement. A survey of about 1,000 of the participating families indicated that the majority of families felt that the subsidy was of sufficient size (65%), improved their ability to care for their member with disabilities (61%), eased financial worries (61%), and helped the family to do more things together (55%). Near majorities reported that the subsidy reduced the stress in family life (48%), improved overall family life (47%), and helped the family to be more like other families (42%).

Moreover, as shown by Figure 6, families applied their subsidies to a great variety of materials or activities, of which some may have been impossible to secure within a program lacking a cash component. The

substantial percent of families who used their subsidies on items that are not clearly tied to care related expenses (e.g., clothing, general household expenses) should not go unnoticed. Taken together, these findings led the authors to conclude that the cash program has had a positive effect on family functioning and placement decisions.

.

Expense Category	Percent of Families Indicating Use of Cash
-	
Clothing	86.0% of families
Educational aides/toys	63.0
Sitters for the child with disabilities	59.9
General household expenses	59.0
Medical expenses/health related needs	55.5
Diapers	55.0
Special foods	40.8
Transportation expenses	40.0
Adaptive equipment	26.5
Respite care	20.2
Home renovation projects	14.0
Care for children without disabilities	9.0
Camp	7.7
Therapy (physical or speech)	5.7
Counseling services	3.8
Home nursing care	2.7

Regarding family placement decisions, the newness of most family support programs makes evaluation of their long term impact on parental placement decisions very difficult. The weight of the evidence that does exist, however, suggests that support/cash services do deter out-of-home placements in favor of continued family-based care.

Rosenau (1983) describes a pilot family support project in Michigan that served 13 families for two years. This project offered families a \$480 cash subsidy per month, a home trainer who entered the home for 20 hours per week to provide parent training, and case management services. Study results showed that continued home placement for 10 of the children was achieved and three children with disabilities were returned successfully to their natural families. In addition, results of a follow-up questionnaire indicated that if project services had not been available, eight families indicated that they "definitely" would have sought an out-of-home placement and two other families "probably" would have.

Herman (1983) described a meta-evaluation of family support services that served 252 families for two years in three counties of Michigan, with 13 of these families having participated in the study completed by Rosenau (1983). Services varied somewhat by county and four models of family support emerged from the meta-analysis: a) intensified services through case management, b) intense in-home intervention, c) out-of-home respite and cash subsidy, and d) case management with respite care and cash assistance. Study results indicated that, for the most part, families retained their member with disabilities at home throughout the course of the projects but that the placement decisions of these families did not differ markedly from those of parents not participating in the projects. Further analysis, however, revealed that significant numbers of participating families indicated that they would have sought out-of-home placements if not for the projects' services, and that families with past histories of repeated use of out-of-home options used these options less. Thus, family support services, including those utilizing a cash component, appeared to have some positive effect on family placement decisions.

Zimmerman (1984) presented findings of a telephone survey of a stratified random sample of 38 families receiving financial subsidies ranging between \$76 and \$250 per month in Minnesota. Half the families had received the subsidy for less than two years with only four families participating in the subsidy program since its inception (4-6 years). Results indicated that, in part due to the program, 36 of the families had no present plan for seeking an out-of-home placement. Moreover, the program had helped make it possible for one family to bring home one of its members with a disability.

In sum, it is apparent that much of the qualitative evidence that has been collected documents the efficacy of cash assistance approaches. Families indicate that they appreciate such services, and are satisfied with their effects (Herman, 1983; Rosenau, 1983; Zimmerman 1984; Parrott & Herman, 1987). Further, families report that they benefit most when they are provided with multiple service options (e.g., respite care, financial assistance and parent education) and least when they are offered fewer services (e.g., respite care only) (Moore et al., 1982). This suggests that no single service component is sufficient for achieving the goals of family support; Several may be necessary.

The quantitative evidence is less conclusive. Much additional work must be done to gain a greater consensus regarding specific program objectives and to acquire sufficiently sophisticated evaluative measures and models. With these developments, the effects of support services and cash assistance on children and on the capacity of families to provide care can be more definitively determined. Moreover, existing programs can be modified so that they more effectively match the needs of individual families.

The present difficulty with this type of evaluation, however, pertains to the need for time to pass before sizeable effects can be expected. Snapshot studies or longitudinal studies of short duration are insufficient. Due to the nature of developmental disabilities, service benefits are not always easily or promptly observed, leading

Halpern (1984) to suggest that current measures may underestimate program effects. Moreover, Weiss (1983) notes that intervention centering on the entire family requires that measures be capable of monitoring changes within family dynamics. Such measures have yet to be perfected (See Dunst & Trivette, 1985).

SUMMARY AND CONCLUSIONS

Since 1980, several states have initiated programs on behalf of families who have a member with disabilities, with about 15 incorporating a cash component. Establishing an effective statewide system, however, is a complicated task requiring consideration of several philosophical and programmatic concerns. Though there is growing consensus that families should be offered a comprehensive circle of supports that is family centered, culturally sensitive, communitybased and well coordinated, the substantial variance that is apparent among existing state initiatives serves notice that little agreement has emerged regarding the most efficient and effective means of operating such programs. Among the several administrative issues that must be resolved are: the role of the family in service planning and delivery, program eligibility criteria, means of service administration, permissible supports, and the contrasting roles of the public, private and informal sectors in providing support. Within this context lies discussion over the utility and feasibility of implementing a cash assistance program.

The biggest problem facing decision makers is the lack of clarity regarding the goals of family support efforts. Should services be justified solely on their ability to save tax dollars for the cost of out-of-home placement, or is the goal of improved quality of life for the family as a whole and the person with disabilities in particular a sufficient public good? Contemporary thought (e.g., Agosta & Bradley, Dunst, 1986; Parrott & Herman, 1987; Turnbull et al., 1986) on the topic suggests that the enhancement of the quality of life of the family -though not directly related to cost savings -- does result in substantial benefits to the larger society including increased family self reliance, maximization of family cohesiveness, and improvements in the productivity of individual family members including the person with disabilities. Though these gains are somewhat more ineffable, they should likewise be part of any systematic exploration of family support practices. In this regard, the role cash assistance could play in helping to achieve these ends should be carefully assessed.

REFERENCES

- Agosta, J.M., Bass, A. & Spence (1986). The needs of families: Results of a statewide survey in Massachusetts. Cambridge, MA: Human Services Research Institute.
- Agosta, J.M. & Bradley, V.J. (Eds.) (1985). Family care for persons with developmental disabilities: A growing commitment. Cambridge, MA: Human Services Research Institute.
- Agosta, J.M., Bradley, V.J., Rugg, A., Spence, R. & Covert, S. (1985a).

 Designing programs to support family care for persons with

 developmental disabilities: Concepts to practice. Cambridge, MA:

 Human Services Research Institute.
- Agosta, J.M., Jennings, D. & Bradley, V.J. (1985b). Statewide family support programs: Results of a national survey. In J.M. Agosta and V.J. Bradley (Eds.), Family care for persons with developmental disabilities: A growing commitment. Cambridge, MA: Human Services Research Institute.
- Agosta, J.M., O'Neal, M.A. & Toubbeh, J. (1987). A path to peace of mind: Providing exemplary services to Navajo children with developmental disabilities. Window Rock, AZ: Save the Children Federation and the Navajo Tribal Council.
- Akabas, S.H. (1984). Workers are parents too. Child Welfare, 63(5), 387-399.
- Akabas, S.H. & Krauskoff, M.S. (1984). Families and work: Creative workplace responses to employees with disabled children. New York, NY: Columbia University School of Social Work, Industrial Social Welfare Center.
- Ashbaugh, J., Spence, R., Lubin, R., Houlihan, J. & Langer, M. (1985).

 <u>Summary of data on handicapped children and youth</u>. Cambridge, MA:

 Human Services Research Institute.
- Balanzo, M.P. & Beck, M.M. (1982). The social programs of organized labor. In J.A. Meter (Ed.), Meeting human needs: Toward a new public philosophy. Washington, D.C.: American Enterprise Institute for Public Policy Research.
- Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. Psychological Review, 84, 191-215.
- Bates, M.V. (1985). State family support/cash subsidy programs. Madison, WI: Wisconsin Council on Developmental Disabilities.

Batshaw, M.L. & Perret, Y.M. (Eds.) (1986). Children with handicaps: A medical primer (Second Edition). Baltimore, MD: Paul H. Brookes Publishing Company.

(

- Bird, W.A. (1984). A survey of family support programs in seventeen states. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities.
- Braddock, D., Howes R. & Hemp, R. (1984). Public expenditures: Mental retardation and developmental disabilities services. Chicago, IL: Institute for the Study of Developmental Disabilities, University of Illinois at Chicago.
- Castellani, P. (1987). The political economy of developmental disabilities. Baltimore, MD: Paul Brookes Publishing.
- Cohen, S. & Syme, S.L. (1985). Social support and health. New York, NY: Academic Press.
- Crnic, K.A., Friedrich, W.N. & Greenberg, M.T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping and family ecology. American Journal of Mental Defiency, 88(2), 125-138.
- Demos, J. (1983). Family home care: Historical notes and reflections. In R. Perlman (Ed.), Family home care: Critical issues for services and policies. New York, NY: The Haworth Press.
- Dunst, C. (1986). Helping relationships and enabling and empowering families. Morganton, NC: Family, Infant and Preschool Program, Western Carolina Center.
- Dunst, C. & Trivette, C.M. (1985). A guide to measures of social support and family behaviors. Chapel Hill, NC: University of North Carolina, Frank Porter Graham Child Development Center, Technical Assistance Development Systems.
- Dunst, C. & Trivette, C.M. (1986). <u>Helping, helplessness and harm</u>. Morganton, NC: Family, Infant and Preschool Program, Western Carolina Center.
- Dunst, C. & Trivette, C.M. (1987). Enabling and empowering families: Conceptual and intervention issues. Morganton, NC: Family, Infant and Preschool Program, Western Carolina Center.
- Gliedman, J. & Roth, W. (1980). The unexpected minority: Handicapped children in America. New York, NY: Harcourt, Brace and Javanovich.
- Goldfarb, L.A., Brotherson, M.J., Summers, J.A. & Turnbull, A.P. (1986). Meeting the challenge of disability or chronic illness: A family guide. Baltimore, MD: Paul H. Brookes Publishing Company.
- Griss, R. (1984). The role of vouchers and informal help networks in long term support. East Lansing, MI: Department of Health and

- Social Services, Division of Community Services, Office of Program Initiatives.
- Halpern, R. (1984). Lack of effects for home based early intervention?: Some possible explanations. American Journal of Orthopsychiatry, 54(1), 33-42.
- Herman, S.E. (1983). Family support services: Reports on metaevaluation studies. Lansing, MI: Michigan Department of Mental Health.
- Hobbs, N. & Perrin, J.M. (1985). Issues in the care of children with chronic illness. San Francisco, CA: Jossey-Bass Publishers.
- Hobbs, N., Dokecki, P.R., Hoover-Dempsey, K.V., Moroney, R.M., Shayne, M.W. & Weeks, K.H. (1984). Strengthening families. San Francisco, CA: Jossey-Bass.
- Johnson, S.H. (1979). <u>High risk parenting: Nursing assessment and strategies for the family at risk</u>. Philadelphia, PA: J.B. Lippioncott Publishing.
- Konanc, J.T. & Warren, N.J. (1984). Graduation: Transitional crisis for mildly developmentally disabled adolescents and their families. Family Relations, 33, 135-142.

(

- Lakin, K.C., Hill, B.K. & Bruininks, R.H. (1985) An analysis of Medicaid's intermediate care facility for the mentally retarded (ICF-MR) program. Minneapolis, MN: University of Minnesota, Department of Educational Psychology.
- Lapham, V.E. & Sherlin, K.M. (1986). The impact of chronic illness on psychosocial stages of human development. Washington, DC: Georgetown University Hospital and Medical Center, Department of Social Work.
- Linder, T.W. (1983). <u>Early childhood special education</u>. Baltimore, MD: Paul Brookes Publishing.
- Longo, D.C. & Bond, L. (1984). Families of the handicapped child: Research and practice. Family Relations, 33, 57-66.
- McGoldrick, M., Pearce, J.K. & Giordano, J. (Eds.) (1982). Ethnicity and family therapy. New York, NY: The Guilford Press.
- McKnight, J.L. (1987, Winter). Regenerating community. Social Policy, pp. 54-58
- Minnesota Developmental Disabilities Program (1983). The Minnesota family subsidy programs: Its effects on families with a developmentally disabled child (Policy Analysis No. 18). St. Paul, MN: Minnesota Deelopmental Disabilities Planning Council.

Moore, J.A., Hamerlynck, L.A., Barsh, E.T., Spieker, S. & Jones, R. (1982). Extending family resources (Second Edition). Seattle, WA: Children Clinic and Preschool, University of Washington.

(::

- Moroney, R.M. (1983). Families, care of the handicapped, and public policy. In R. Perlman (Ed.), <u>Family home care: Critical issues for services and policies</u>. New York, NY: The Haworth Press.
- Parrott, M.E. & Herman, S.E. (1986). Report on the Michigan family support subsidy program. Lansing, MI: Michigan Department of Mental Health.
- Perlman, R.H. (1985). Family home care: Critical issues for services and policies. New York, NY: The Haworth Press.
- Piccione, J. (1982). The human services option: New funding for the charitable sector. Washington, DC: Free Congress Research and Education Foundation.
- Rappaport, J. (1981). In praise of paradox: A social policy of empowerment over prevention. American Journal of Community Psychology, 9, 1-25.
- Rosenau, N. (1983). Final evaluation of a family support program.

 Macomb-Oakland, MI: Macomb County Community Mental Health and Macomb-Oakland Regional Center.
- Schwartz, D. (1987). Re-visioning developmental disabilities councils:
 One council's search for the middle kingdom. Harrisburg, PA:
 Pennsylvania Developmental Disabilities Planning Council.
- Sherman, B. R. (1988). Predictors of the decision to place a developmentally disabled family member in residential care. <u>American</u> <u>Journal</u> on Mental Retardation, 92(4), 344-351.
- Sherman, B.R. & Cocozza, J.J. (1984). Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. <u>Family Relations</u>, 33(1), 95-104.
- Skarnulis, E. (1979). Support, not supplant, the natural home: Serving handicapped children and adults. In S. Maybanks & M. Bryce (Eds.), Home-based services for children and families: Policy, practice and research. Springfield, IL: Charles C. Thomas.
- Slater, M.A. & Mitchell, P. (1984). Family support services: A parent/professional partnership. Stillwater, OK: National Clearinghouse of Rehabilitation Training Materials.
- Stabenow, D. (1983). The family support subsidy act: Questions and answers on P.A. 249 of 1983 (H.B. 4448). Lansing, MI: 412 Roosevelt Building, State Capitol.

Suelzle, M. & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded persons. American Journal on Mental Deficiency, 86, 267-274.

C

- Tausig, M. (1985). Factors in family decsion-making about placement for developmentally disabled individuals. American Journal on Mental Deficiency, 89, 352-361.
- Turnbull, A., Summers, J. & Brotherson, M. (1985). Family life cycle: Theoretical and empirical implications, and future directions for families with mentally retarded members. In J. Gallagher and P. Vietze (Eds.), Research on families with retarded children. Baltimore, MD: University Park Press.
- U.S. Congress, Office of Technology Assessment (May, 1987). Technology dependent children: Hospitals v. home care -A technical memorandum, OTA-TM-H-38. Washington, DC: US Government Printing Office.
- Weiss, H. (1983). Issues in the evaluation of family support and education programs. Family Resource Coalition Report, 2(4), 10-11.
- Wells, A.I., Agosta, J.M., Berliner, S., Cox, H. & Bedford, S. (1988).

 <u>Supporting Pennsylvania families: Strengthening the Pennsylvania family support system</u>. Cambridge, MA: Human Services Research Institute.
- Wikler, L. (1983). Chronic stress of families of mentally retarded children. In D.H. Olson & B.C. Miller (Eds.), Family studies review yearbook (Vol. 1). Beverly Hills, CA: Sage Publications.
- Wikler, L. (1986). Family stress theory and research on families with children with mental retardation. In J. Gallagher and P. Vietze (Eds.), Research on families with retarded children. Baltimore, MD: University Park Press.
- Wikler, L. & Keenan (Eds.) (1983) <u>Developmental disabilities: No longer a private tragedy</u>. Silver Spring, MD: National Association of Social Workers.
- Wolk, L. (1987). A cash assistance program for Massachusetts? Boston, MA: Massachusetts Developmental Disabilities Planning Council.
- Wray, L. & Wieck, C. (1985). Moving persons with developmental disabilities toward less restrictive environments through case management. In K. C. Lakin & R. H. Bruininks (Eds.) Strategies for achieving community integration for developmentally disabled citizens (pp. 219-230). Baltimore: Brookes
- Zimmerman, S. (1984). The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. Family Relations, 33, 105-118.

ISSUES PAPER 1

April, 1988

ISSUES PAPER 1

April, 1988

ISSUES PAPER 1

April, 1988