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Abstract

This article discusses the fact that while most people with disabilities spend much of their lives with their natural families, little attention has been given in the past by governments, agencies and researchers to the long term needs of families. It reviews the trends in the provision of support to families, with a specific emphasis on the balance (or imbalance) between services that support and those that supplant the natural family. It concludes with recommendations for research that is needed to inform the policy-making and program design process. **Keyword: Families**

Chapter

13

Patterns and Trends
in Public Services to
Families with a
Mentally Retarded Member

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FAMILIES WITH A mentally retarded member face two enduring challenges: to marshal their own emotional, physical, and economic resources to maintain the family unit and to ensure that the mentally retarded member receives the best care and training possible. To a large extent, public policies and programs have been geared to the latter challenge. Families have received only sporadic public support in coping with the, at times, overwhelming task of adjusting family life and relationships to meet the responsibilities of care for the mentally retarded member.

Family members themselves have enriched our knowledge of the effects on the family of having a handicapped child. There is a substantial body of literature written by parents and siblings of handicapped persons that describes in vivid detail the ways in which family and personal lives are affected (Darling, 1979; Featherstone, 1980; Massie & Massie, 1975; Park, 1967; Turnbull & Turnbull, 1984). These portraits often provide startling accounts of the insensitivity of professionals, the public, and society at large to the daily concerns and needs of families in providing care and love to a handicapped family member.

There is also a considerable amount of empirically based research showing the effects on families of having a mentally retarded child. Although comprehensive reviews of this research are available elsewhere (Blacher, 1984. Crnic, Friedrich, & Greenberg, 1983, Skrtic, Summers, Brotherson, & Turnbull, 1984), it has generally been characterised by the enumeration of negative outcomes for families (e.g., social isolation, physical and financial burdens, increased familial stress). Farber (Chapter 1) argues that these studies were based on the notion that the birth of a handicapped child precipitates a family crisis and that the purpose of the research undertaken was to determine the ways in which family life departed from the norms of a "healthy" family life. Further, research tended to define and justify areas of need for families with a handicapped member and to analyze the efficacy of various remediation strategies. Despite the advances that were made in the development of such strategies as parent

training (Baker, 1984) and specialised social work practices (Dickerson, 1981; Dybwad, 1964), comparatively little was achieved in the development of family support services that focused on the family rather than on the handicapped child as the target of services (Dybwad, 1982).

There has been a renewed interest, however, on the part of social planners, researchers, and service providers in identifying, analysing, and meeting the long-term needs of families with a mentally retarded member (Horejsi, 1979; Perlman & Giele, 1983). This interest has been fuelled by the assumption that family support services will contribute to the prevention or delay of out-of-home placement of the mentally retarded family member. Strategies to achieve a reduction in the use of inappropriate out-of-home placement both to promote optimal individual development and to curb the costs of publicly supported residential programs have become a major public policy issue. Although the available research testing this assumption is limited and inconclusive (Seltzer & Krauss, 1984a; Sherman & Cocozza, 1984; Townsend & Flanagan, 1976; Zimmerman, 1984), the need to include variables measuring social and community support in studies on family adaptation processes and placement decision outcomes is widely acknowledged.

For example, Crnic et al. (1983), drawing on both the family systems and mental retardation literature, point out that internal family dynamics and coping mechanisms, mediated by the ecological system within which families interact and are acted on, may provide more salient explanations of the observed variability in family adaptation patterns. Their analysis includes a theoretical model that integrates the concepts of stress, coping, and ecological systems to guide future studies of family adaptation and functioning. Of particular interest for the present discussion is their inclusion of ecological factors (e.g., the external environments, such as schools, home, agencies, neighbourhoods, workplaces, and social networks) as predictor variables of family adjustment. Further, their conceptualisation of the family as a system of interdependent members and functions

appropriately recasts the focus of support services to the family as a unit, rather than to a single member of the family (e.g., the mother or the handicapped child).

Despite the centrality of the family in providing care for mentally retarded members, very little research has been conducted on the constellation of services needed by families to support or ensure their long-term caregiving capacity. Indeed, there is considerable public ambivalence regarding the appropriate relationship between the family and its caregiving functions, on the one hand, and the state and its power to support, supplement, or substitute for familial roles and responsibilities (Farber, 1979; Gelman, 1979.1 Steiner, 1981). The lack of consensus regarding the legitimacy and forms of family-oriented services has resulted in families, as a type of social services, being largely ignored in policy and program development (Moroney, 1983). Bruininks (1979) summarises the situation as follows:

Given the fact that most developmentally disabled people spend much of their lives with members of their natural families.... it is surprising that so little attention has been given by units of government, agencies, and researchers to the needs of natural or surrogate families with developmentally disabled members... there is little in the published literature regarding the social, economic, or programmatic issues involved in providing care and opportunities for developmentally disabled people in family care settings. (P.3)

The purpose of this chapter is to review current trends in the provision of support services to families with a mentally retarded member. It focuses on the general patterns of services available to families, with a specific emphasis on the balance (or imbalance) between services that support and those that supplant the natural family (Skarnulis, 1979). The chapter reviews the recent development of family support programs in the various states and concludes with recommendations for research that is needed to inform the policy-making and program-design process. The chapter thus concentrates on broader or macro-level service delivery issues rather than on the determinants or outcomes of the relationships between individual families and service providers.

SERVICE NEEDS OF FAMILIES

Although the impact on families of having a mentally retarded child has been a subject of research for decades, it is only recently that comprehensive programs of family support have been conceptualized and/or promulgated. Evidence of the current activity in identifying, analysing, and meeting the long-term needs of families may be seen in, for example, a national conference on family care of developmentally disabled members (Bruininks & Krantz, 1979), the establishment of a national clearinghouse for information on home-based services to children (Maybanks & Bryce, 1979), and the compilation of a nation-wide resource guide on family support service (Michigan Association of Community Mental Health Boards, 1983).

These activities have analyzed and restated problems that are voiced by families with a mentally retarded member; namely, that support services are fragmented, lack co-ordination, have seemingly capricious eligibility criteria, and are not structured or organised in ways that reflect family preference or need (Berger & Foster, 1976). Indeed, much of the research conducted on service needs of families reports that parents are frequently unaware of services that may be available to them or their families and/or they are not receiving adequate support from the services that they are receiving (Gollay, Freedman, Wyngaarden, & Kurtz, 1978; Justice, O'Connor, & Warren, 1971). For example, Bruininks, Morreau, and Williams (1979) surveyed parents, policymakers, and state agency personnel in six states and found that nearly all respondents indicated family-related services to be both low in availability and quality.

An earlier study by the Minnesota Department of Welfare (Minnesota State Planning Agency, 1975) asked parents of developmentally disabled children which types of services were needed to maintain the child at home. The services were rank-ordered as follows: medical, supplemental income, home assistance, special school programs, respite care, social activities for the child, transportation for the child, home tutors, parent guidance, and day activity centres. In a similarly focused investigation, Dunlap (1976) surveyed 404 families of mentally retarded, cerebral palsied, or epileptic individuals in Alabama to determine which services were most useful or needed by the families. The responses indicated that financial assistance and educational services were the most needed services, followed by transportation, training, and medical services.

Although empirical studies on the services most needed by families are rather consistent in their findings, there are only a limited number of studies on the services utilised over time by families. Such investigations are needed for they reveal the variability in service needs across different stages in the mentally retarded child's development and in the family's progression through the life cycle (Turnbull, Summers, & Brotherson, Chapter 3, this volume). Suelzle and Keenan (1981) studied the utilization of personal and professional support networks of 330 parents over the life cycle of their mentally retarded children. Four distinct stages were posited: pre-school (birth to 5 years old), elementary (6 to 12 years old), teenage (13 to 18 years old), and young adult (19 to 21 years old). They found that utilization of personal support networks (e.g., use of family members or friends as babysitters, parent support groups) declined over the life cycle, whereas utilization of health care professionals and school personnel increased over

time. Differences were also found regarding parental perceptions of unmet service needs. Although the majority of parents of younger children perceived inadequate diagnostic services and living alternatives, parents of young adults perceived deficiencies in these services more acutely. Further, a U-shaped function was reported for unmet family support services (e.g., crisis lines, respite care, and counselling services). Unmet needs in these areas were reportedly high among parents of pre-schoolers and young adults, whereas parents of children in the middle two age groups were less likely to report unmet family support service needs.

Wikler (1981), who analyzed the types of periodic and predictable stresses offers additional support for the variability in family needs over time those families of mentally retarded children experience. She noted, as have others (Berger & Foster, 1976), that professionals tend to concentrate on the needs of families primarily during the early years of their child's development, rather than on management issues that arise over time. Her analysis posits specific events and developmental milestones that can be expected to be accompanied by more pronounced stress for families. These events and milestones are thus occasions when more intensive and skilled parental support services may be especially crucial.

In an empirical investigation of the extent to which chronic versus time-bound stress is experienced, Wikler, Wasow, and Hatfield (1981) found that both parents and social workers indicated that increased stress is associated with developmental and crisis periods. There were differences in the accuracy of social workers' assessments of stressful periods, however. For example, professionals tended to overestimate the amount of stress experienced during the child's early years of development and underestimate the amount of stress that accompanied events during the young adulthood period.

Other recent studies have compared the amount of individual, marital, and parenting stress experienced by families with and without a handicapped child (Kazak & Marvin, 1984), the coping mechanisms developed by families with a handicapped or chronically ill child (Longo & Bond, 1984; McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983; Schilling, Gilchrist, & Schinke, 1984), and the characteristics of the social networks of such families (Friedrich & Friedrich, 198 1; Kazak & Marvin, 1984; Schilling & Schinke, 1983). The accumulating evidence suggests that an interactive model is needed for understanding the ways in which families are affected by a handicapped child and for analysing the services needed by these families to maintain the family and to ensure their child's optimal development (Turnbull, Brotherson & Summers, 1985). As Crnic et al. (1983) note, "Family functioning cannot be considered simply as a response to a retarded child; rather, it is more meaningful to consider familial adaptation as a response to the child mediated by the coping resources available and influenced by the family's ecological environments" (p. 136).

SERVICE PROVIDED TO FAMILIES

Although the knowledge base is expanding regarding the needs of families, it is particularly sobering to consider the publicly supported services available to meet these needs. Virtually any analysis of the dominant characteristic of the service system currently in place to assist families with a mentally retarded member confirms the fact that the most concentrated effort is in support of out-of-home care (Gruber, 1978; Lakin, Bruininks, Doth, Hill & Hauber, 1982; MacEachron & Krauss, 1983; Moroney, 1983; Seltzer & Krauss, 1984b; Skarnulis, 1979). As Moroney notes (1979):

Despite the rhetoric of choice and preferences for the disabled and their families, priority (resources) has been given to institutional care. And yet, the evidence is that most families favour home care over institutional care, that they actually are providing a supportive environment for their disabled members whether they are severely retarded children or elderly parents, and that they are doing so with little support from the organised health and welfare system. (pp. 68-69)

A brief review of current expenditures for services to mentally retarded persons and their families supports Moroney's conclusions. Braddock, Howes, and Hemp (1984) analyzed the distribution of federal, regional, and state funds for services to the mentally retarded and other developmentally disabled populations. Their findings for the cumulative federal reimbursements under the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program between FY 1977-1984 show that, of the $12:9 billion expended, 82% was for institutional programs and 18% for community-based residential programs. Comparisons of the total annual expenditures from all sources for institutional versus community services during this same period indicate that the amount spent for community-based services (which would include services to families) is less than 50% of that spent for institutional services for 5 of the 8 years included.

Moroney (1981) examined 31 federal programs sponsored by the (then) Department of Health, Education and Welfare in 1976 that could in principle be supportive to families with handicapped members. Of the $102.7 billion obligated by these programs, various income maintenance programs, 25% by programs supporting medical services and 4% accounted for 71% for the provision of services. He notes (1981) that, "While services and financial support are provided to handicapped persons - the elderly, the sick and the disabled - their families are not the object of the policy or service… These policies

have tended to ignore the family with a handicapped member, just as they ignore families in general" (p. 226).

These conclusions are supported by other investigations that indicate that families of deinstitutionalised mentally retarded members receive far fewer support services and have more pronounced unmet service needs than other providers of care (Gollay et al., 1978), that families of mentally retarded children receiving public social services are more likely to have out-of-home placements recommended and implemented for their children than other families receiving social services (MacEachron & Krauss, 1983), and that the absence of community-based support services to families contributes to the decision to seek an out-of-home placement (Eyman, Dingman, & Sabagh, 1966; Sherman & Cocozza, 1984).

There are some powerful reasons offered for the absence of public services, programs, and policies designed to shore up families' internal and external resources to maintain their mentally retarded member at home. The factors reflect both societal ambivalence about the appropriate role of governmental bodies in family life and general political concerns about the fiscal feasibility of offering more targeted services to families. For example, Moroney (1979) cites five reasons for the emphasis on substitute services for families: 1) lack of sufficient resources to meet the demand for services; 2) lack of professional skill and knowledge about methods to support families; 3) perceptions that families are themselves part of the "problem," rather than social units to be supported; 4) a service tendency to focus on the individual, rather than the family, as the recipient of services; and 5) the technical ease of substituting for the family compared to developing a plan of shared responsibility. Tapper (1979) echoes several of these points in his analysis of the barriers to family subsidy programs. He adds, however, the perceived problem of parental accountability in the use of public funds and the notion that parents are less organised and thus less likely than the professional service-providing establishment to compete successfully for public monies.

Although these barriers or factors represent potent obstacles, the pattern of services to families is undergoing some fundamental changes. The development and implementation of formalised family support programs in various states across the country signals a sharp break with previous service and policy patterns of ignoring or in many ways subverting family-based care. The next section of this chapter considers the scope, characteristics, and benefits of these innovative, though limited, family support programs.

FAMILY SUPPORT PROGRAMS

A family support program has been defined as "a state-wide initiative to provide systematic support to families with developmentally disabled members that is funded and monitored through the administrative auspices of the state" (Human Services Research Institute, 1984, p. 5). The development and implementation of family support programs mark a significant change in the states' approach to serving mentally retarded and other developmentally disabled persons because their focus is on supporting the natural families' efforts to care for their developmentally disabled member. In this sense, families are increasingly being seen as providers of the same type of social services that states have traditionally funded more formalised agencies to provide (Moroney, 1983).

Conceptualisations about the types of services that should be included in a model family support program have been offered by a number of policy analysts (Klerman, 1983; Moroney, 1979; Michigan Association of Community Mental Health Boards, 1983; Zimmerman, 1979). In general, the services that are identified provide instrumental or concrete support to the family, such as case management, respite care, financial assistance or subsidies, parent training, homemakers, and architectural modifications to the home.

Results from three national surveys of state-administered family support programs (Human Services Research Institute, 1984; Michigan Association of Community Mental Health Boards, 1983; New York State Office of Mental Retardation and Developmental Disabilities, 1984) illustrate the extent to which state supported community-based service systems are recognising the critical role of the family in achieving two specific policy objectives. First, family support programs are intended to prevent or delay the premature or unnecessary out-of-home placement of the family's developmentally disabled member. The assumption is that, by assisting families to mediate the known stresses often accompanying in-home care; families will be better able to continue to keep the disabled member in the family unit. For example, providing periodic respite care services is expected to cushion the impact of the physical and emotional demands of round-the-clock care that many retarded persons require. The second and related objective of family support programs is to enhance the caregiving capacity of families. This objective reflects the belief that families provide the most enduring, committed, and dependable source of care to its members and that, with specific and concrete assistance, families will provide the optimal environment in which the retarded member's development will be maximised.

The most comprehensive national survey of family support programs was conducted by the National Association of State Mental Retardation Program Directors and the Human Services Research Institute (HSRI) between November, 1983 and February, 1984 (Human Services Research Institute, 1984). The results show that 41 states currently

operate a family support program. Of the nine states without a program (Illinois, Kansas, Mississippi, Missouri, New York, Oklahoma, South Dakota, West Virginia, and Wyoming), two states (Illinois and New York) have pilot family support programs, and two other states (Kansas and Missouri) offer local family support services as demonstration projects. In contrast, earlier national surveys indicated that only 21 states (Michigan Association of Community Mental Health Boards, 1983) or 17 states (New York Office of Mental Retardation and Developmental Disabilities, 1984) had such programs.

The HSRI survey documents the considerable variability in the states' programs in terms of services included, eligibility criteria, numbers of families served, and costs of the program. This variability may be due to each state developing programs that reflect its unique service needs and capabilities, or it may reflect the relative youth of the programs. Only seven states had family support program during the 1970s, with the remaining states initiating their programs within the last 4 years. Thus, no single or core model has emerged from these efforts as the most effective or efficient system to achieve the twin objectives described earlier. (For detailed descriptions of family support programs, see Herman, 1983; Michigan Association of Community Mental Health Boards, 1983; Rosenau, 1983).

Although over 35 different types of services are offered among the 41 state programs, the most commonly offered services are respite care, case management, and parent training, home adaptations, special equipment, and transportation. HSRI (1984) has categorised the program models as follows: 1) cash subsidy programs that provide money directly to families for the purchase of services and/or habilitation materials (11 states), 2) supportive programs that provide direct services to families from providers contracted by the state (24 states), and 3) combination programs that offer both cash subsidies and direct services (5 states). One obvious distinction that can be drawn among the three types of programs is the degree to which families take a primary role (as in cash subsidy programs) or a secondary role (as in supportive programs) in defining what services are needed and utilised. Research comparing the cost-effectiveness and family satisfaction with various program models is obviously needed to determine the relative advantages to both the state and the service recipients of the administrative options available for defining the services and/or mechanisms by which services are obtained.

The eligibility criteria that the states use for their family support programs indicate that the issue of the extent to which such programs should achieve vertical or horizontal equity is still unresolved. Vertical equity is achieved when programs are targeted toward those most in need of the services. Need may be determined on the basis of income, severity of the disability, or some measure of the vulnerability of the family to unmanageable stress that is likely to result in a request for a residential placement for the disabled family member. The underlying assumption of services that are organised along vertical equity principles is that resources should be placed at the disposal of those whose objective or inferred needs are greater than other persons or families. Horizontal equity refers to the principle that services or programs should be available to all members of a specified target group, regardless of additional criteria based on need or other arbitrary limitations. The underlying assumption of services organised along horizontal equity principles is that it is either impossible or undesirable to judge relative need and/or that all persons (or families) with a common characteristic (e.g., a mentally retarded member living at home) will have periodic or sustained needs for the services offered.

According to the data presented by HSRI (1984), all states have eligibility criteria for services, but there is considerable variability among these criteria. Of the 11 states with a cash subsidy program, 4 have no additional criteria beyond the family having a developmentally disabled or mentally retarded member living at home. In three states, there are age limitations, with the disabled member being either under 21 or 18. One state has an income restriction for the family, and one state targets its program to those families with a profoundly retarded family member living at home. Other criteria include families with a child returning from an institutional setting, families who are "needy" (not defined), or families for whom services are unavailable elsewhere.

Eligibility information was presented for only 7 of the 21 states with supportive family programs. Of these seven states, however, five had no additional criteria for program services beyond having a mentally retarded child at home. In two states there is an age criterion (0-6 years or under 22), and one of these states also imposes restrictions based on the child being either in an out-of-home placement or at risk of being placed outside the home.

Of the five states that offer both cash subsidies and supportive family services, only two had no additional criteria beyond having a mentally retarded person living at home. Other states impose such criteria as age (e.g., child under 18), severity of handicapping condition (e.g., severely disabled), and having a child recently institutionalised for over 90 days.

Although the data are not complete regarding eligibility criteria across the three types of programs, it may be suggested that programs that provide supportive services are more likely to be horizontally equitable (e.g., have the fewest eligibility criteria) and thus be targeted for the broadest range of families, and programs offering

cash subsidies are the most vertically equitable (e.g., targeted to those most in need). Further research is needed to determine the most effective ways for states to manage such-programs and to control the resources available to families. The above analysis suggests, however, that control is either exercised through eligibility criteria (vertical vs. horizontal equity) or through family-driven (cash subsidy programs) or state-determined (supportive services programs) systems. An important area for further investigation is the extent to which these administrative options available to the states meet the specific objectives to which the programs are directed.

The number of families served by family support programs varies widely from over 35,000 families in California (which offers supportive services) to 15 in South Carolina (which offers a cash subsidy program). This spread in state coverage cannot be explained solely on the basis of the state's eligibility criteria. For example, Louisiana has only 25 families receiving cash subsidies, and the program criteria do not include age or income restrictions. Important areas for further study are the factors that explain utilization of the available programs. It appears that factors other than specific program eligibility criteria operate to reduce the number of recipients, and these factors need to be uncovered.

As expected, the costs of family support programs vary, depending on the types of services offered and the number of families served. Pennsylvania spends over $3.4 million a year to serve over 11,500 families (for an average of approximately $295 per family), whereas South Carolina spends $23,000 a year for 15 families (for an average of approximately $1533 per family).

That almost all states either have a family support program or are on the verge of establishing the legislative authority to implement one is clearly a positive sign. Family care is emerging as a legitimate arena for public support and as a focus of social policy. However, support for family care has not achieved parity with the public support given to out-of-home care and is, indeed, lagging far behind. As HSRI (1984) concludes, "Our survey findings substantiate the observation that relative to available institutional and community based services, family support systems do not offer a comprehensive service array, lack continuity from state to state, and are grossly under-funded" (p. 34).

AN ALTERNATIVE MECHANISM FOR PROVIDING FAMILY SUPPORT SERVICES

Virtually all the family support programs developed in the 41 states are funded solely from local or state revenues. Recent changes in the federal policies regarding the use of Title XIX (Medicaid) funds for services to mentally retarded people are expected, however, to encourage states to finance some of the

services typically included in family support programs from federal sources.

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35) authorised the waiver of statutory requirements of Title XIX to permit states to finance non-institutional long-term care services for Medicaid-eligible individuals. The purpose of the waiver program is to remove the financial incentives for placement in Medicaid – reimbursable settings, such as ICFs/MR, of persons whose care can be more efficiently and appropriately provided in the home or other type of community-based service system. States must apply to the Health Care Financing Administration for authorisation to waive existing Title XIX regulations and, as of February 15, 1983, 26 states had been granted such a waiver (Lakin, Greenberg, Schmitz, & Hill, 1984). Of these 26 states, 16 had included community-based services to mentally retarded persons among their specifically targeted populations.

The waiver program specifies seven core services that may be included in the states' community-based service plan: case management, homemaker services, home health aide services, personal care, adult day health services, habilitation services, and respite care. Except for adult day health services, these services are typically included in both conceptualisations about family support programs and in the programs currently provided in the 41 states. For the 16 states receiving waivers that targeted their alternative programs to mentally retarded persons, the most commonly included services were habilitation services (15 states), case management (13 states), respite care (12 states), homemaker services (7 states), personal care services (7 states), adult day health services (6 states), and home health aides (5 states) (Lakin et al., 1984).

It is not yet known how and if states currently operating family support programs will respond to the potential additional source of revenue for financing the specific services covered under the waiver program that are already a part of their family support program. The waiver program does represent, however, a possible mechanism for expanding family support programs (other than cash subsidy type programs), both in terms of the number of families eligible for services and the types of services offered.

CONCLUSIONS

This discussion of emerging patterns of services to families with a mentally retarded member suggests that both the resources and commitment needed to support more concretely the staggering amount of care provided by families are on the policy-making and program-development agenda for the future. The degree to which substantial changes in the service delivery systems will occur will depend in

part on the conduct of more extensive research on the effects of family support programs.

Although some preliminary studies have been reported (Herman, 1983; Rosenau, 1983; Zimmerman, 1984), no longitudinal studies have been conducted that permit a more refined understanding of the utilization and effects of family support programs over time. The ultimate benefit of such programs cannot be judged adequately by cross-sectional studies because the basic premise of family support programs is that the services provided will contribute to increasing the long-term "staying power" of families. As noted earlier, research has documented that families' needs vary with the age of their mentally retarded member (Suelzle & Keenan, 1981) and with specific developmental stages (Wikler, 1981). These findings suggest that there may be cyclical demands on family support services unique to each family. It is, therefore, critical that appropriate resources be devoted to investigating the fit between support services and family needs over the life cycle of family-based care.

Research also needs to be conducted on the factors contributing to the design of states' programs. As noted earlier, the variability in services included, eligibility criteria, and program resources suggests that states are using a wide range of administrative options to limit access to family support programs. This variation in program design features presents an unusually rich opportunity for large-scale research on the consequences of different types of programs on expected outcomes.

Basic issues with respect to effects of family support programs need to be investigated. For example, some types of family support services may be perceived as more critical to the maintenance of family well being than others. Respite care, and especially home-based respite care, is a frequently expressed need by families (Upshur, 1982). Case management services are also noted as important for relieving individual family members of the responsibility for locating and co-ordinating varied services (MacEachron, this volume). Research needs to be conducted on the comparative value from a family's perspective of the range of services commonly subsumed under family support programs.

Another issue for research is to identify distinguishing characteristics among families that are associated with their need for and/or use of family support services. For example, families with well-developed and extensive informal support networks may be less dependent on publicly financed family support services (Kammeyer & Bolton, 1968). Alternatively, other variables, such as family size, marital status, geographic location, and/or level of the mentally retarded member's functioning, may be important predictors of use, in general, and of specific service needs, in particular. There are currently no published studies that address these questions. More tailored program development is seriously compromised until a more detailed analysis of the efficacy and impact of family support programs for specific types of families with a mentally retarded child is available. It is clear from the discussion about the various eligibility criteria utilised by the 41 programs that there is an underlying assumption that some families "need" support programs more than other families. Research from the family systems and mental retardation fields have begun to address the basic question of why some families cope or adapt better to periodic or chronic stress than other families (McCubbin, 1979; McCubbin, Joy, Cauble, Comeau, Patterson & Needle, 1980; Olson & McCubbin, 1983; Wikler et al. 1981). Both the conceptual models and their operationalizations that have been developed present important guidelines for research into the impact of family support programs on the families' capacities to meet the long-term demands of caring for a mentally retarded child. Recent research on the contribution of family functioning and coping mechanisms to specific child and family outcomes demonstrates that family typologies can be developed that may be equally useful in explaining variability in family outcomes for families served by family support programs (Mink, Meyers, & Nihira, 1984; Mink, Nihira, & Meyers, 1983). Thus, the development of family support programs represents a significant advance for both social policy considerations on publicly financed support for potentially vulnerable families and for research investigating the impact of external resources and services on family functioning.

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