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NATIONAL SURVEY OF FAMILY SUPPORT SERVICES IN DEVELOPMENTAL DISABILITIES

by

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The University of Illinois at Chicago

University Affiliated Program in Developmental Disabilities
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Overview and Summary

The needs of families caring for relatives with disabilities can be characterized as numerous, diverse, and generally ill-served by the formal systems of care. That the care of one's child at home has represented a path of relative isolation, with little, if any, assistance from public agencies, is well known; there has been extensive documentation of the concerns and needs of such families (e.g., Agosta & Bradley, 1985; Bates, 1983; Bruininks & Krantz, 1979; Cohen, Agosta, Cohen, & Warren, 1989; Farber, 1968; Gallagher & Vietze, 1986). These issues will not be further elaborated on here. Suffice it to say that families have had limited options and minimal support and that this state of affairs is the result of public policies emphasizing the *substitution* of the family rather than its *enhancement* (Moroney, 1979). However, there are compelling reasons for shifting priority to family empowerments, reasons that range from American cultural values which have emphasized the inviolability of the family unit, to more tangible rationales, such as the potential of supports to attenuate or delay out-of-home placements. This latter reason has stimulated interest among policy planners in the states (e.g., Knoll & Bersani, 1989; Parrott & Herman, 1987) and among researchers studying factors associated with caregiving ability (e.g., Engelhardt, Brubaker, & Lutzer, 1988; Kotsopoulous & Matathia, 1980). New models of service delivery, focused on the family and designed specifically for the enhancement of their caregiving capacities, have been developed across the nation in recent years. Some of the most exciting developments have occurred in the area of fiscal supports.

There are three components to the report: (1) An analysis of Fiscal Year 1988 expenditures committed to family support services by state mental retardation and developmental disability agencies. A summary of the study and results appears in **Part I**; (2) An in-depth discussion of the rationale for the importance of family support policies. The discussion summarizes the recent evolution of out-of-home services in the United States and describes current and future challenges to these service systems. The discussion appears in **Part II**; and (3) A narrative summary of the existing statutory and administrative framework of 45 states identified as having exisiting or in-development family support programs. In contrast to the expenditure analysis, these state-by-state program summaries are not restricted to a single state agency. Summaries appear in **Part III**.

Part I: Analysis of Expenditures

Basis of the Report

The Family Support Survey was based on data collected as part of the larger 18-month investigation of the fiscal and programmatic structure of states' mental retardation service delivery systems (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). The activities of the *principal mental retardation services state agency* were the primary focus of the study, though representatives of the state Medicaid and other social services agencies were frequently consulted. Published state executive budgets were collected directly from the states and evaluated for direct references to family support programs. The level of detail within these published documents was typically inadequate or required substantial amplification and extensive interviews and written communication with financial management and program staff in the relevant agencies were necessary. The Wisconsin Developmental Disabilities Council family support survey (Bates, 1985) served as an additional resource for information and state contacts.

Methods and Definitions

The term *Family Support* encompasses many different forms of services across the states. State systems vary in both the types and methods of service delivery as well as guidelines for eligibility. In the absence of a common constellation of services, any method of definition and classification short of the inclusion of *all* services will necessarily fail to fully represent the true scope of a state's service system. Broadly speaking, any non-residential service can be construed to be a form of support and from this perspective, virtually all states provide some form of family support. In the survey however, a moderately restrictive set of definitions was employed. It was our intent to assess the level of state *policy effort* emanating from the principle mental retardation services agency. Thus the survey of programs and related expenditures was constrained to discretely funded initiatives that had achieved *formal status*, either in the form of a line item in the state budget or in the agency's internal accounting and planning system. The program's *visibility* within the state bureaucracy was taken to be representative of its *priority*.

Family support consisted of any community-based service administered by the state mental retardation services agency providing for vouchers, direct cash payments to families, reimbursement, or direct payments to service providers which the state agency itself identified as family support. Examples of family support programs other than cash subsidy, included respite care (a distinct category of data collection employed in the study), family counseling, equipment purchase, architectural adaptation of the home, in-home training, education and behavior management services. In many states without a formal family support program initiative there were a variety of relevant discretionary activities being carried out by local providers with state assistance.

Synopsis of Findings

In their survey of family support services, Agosta, Jennings, & Bryant (1985) found some 62,000 families receiving state-government sponsored family support programs in 22 states. Wieck (1985) estimated expenditures at $50 million. In this most recent analysis, a discrete, MR/DD agency-based family support initiative--either cash subsidy, respite, or other family support was identified in 42 of the 51 states. In these 42 states, an estimated 168,314 families were served, representing $171 million in total expenditures for 1988. The $171 million in discretely funded family support funds represented a mere 3% of all MR/DD services spending. Table 1 summarizes the state-by-state survey data.

TABLE 1. Family Support Programs Administered by State MR/DD Agencies in FY 1988 [1]

	Cash Subsidy		Respite Care		Other Family Support		Total Family Support	
State	*Expenditures*	*Clients*	*Expenditures*	*Clients*	*Expenditures*	*Clients*	*Expenditures*	*Clients*
AK	$0	0	$718,900	436	$0	0	$718,900	436
AL	$0	0	$250,000	341	$75,000	*	$325,000	*
AR	$0	0	$206,000	40	$0	0	$206,000	40
AZ	$0	0	$227,600	754	$3,748,300	1,027	$3,975,900	1781
CA	$0	0	$10,791,546	10,754	$19,720,293	22,159	$30,511,839	32,913
CO	$0	0	$94,894	*	$195,000	65	$289,894	*
CT	$0	0	$836,228	*	$1,067,181	*	$1,903,409	1,492
DC	$0	0	$342,896	400	$150,186	30	$493,082	430
DE	$0	0	$71,818	266	$8,534	*	$80,352	266
FL	$5,100	12	$318,566	*	$10,961,568	*	$11,285,234	*
GA	$0	0	$311,562	856	$300,000	200	$611,562	1,056
HI	$0	0	*	*	*	*	$115,000	400
IA	$0	0	$0	0	$0	0	$0	0
ID	*	*	$71,500	250	$42,000	122	$113,500	372
IL	$0	0	$4,409,600	3,147	$7,905,900	8,903	$12,315,500	12,050
IN	*	*	$333,488	*	$37,054	*	$370,542	1,000
KS	$0	0	$0	0	$0	0	$0	0
KY	$0	0	$991,312	*	$1,741,645	*	$2,732,957	*
LA	$45,743	169	*	*	*	*	$45,743	169
MA	$0	0	$15,000,000	*	$3,900,000	*	$18,900,000	*
MD	$0	0	*	*	$4,050,136	2,008	$4,050,136	2,008
ME	$0	0	$197,306	500	$0	0	$197,306	500
MI	$9,429,251	3,288	*	*	$5,250,000	*	$14,679,251	*
MN	$1,062,700	410	*	*	$1,618,000	*	$2,680,700	*
MO	$0	0	$362,500	340	$174,155	160	$536,655	500
MS	$0	0	$0	0	$0	0	$0	0
MT	$0	0	$269,400	557	$2,575,000	1,198	$2,844,400	1,755
NC	$0	0	$1,070,200	1,369	$2,700	26	$1,072,900	1,395
ND	$460,100	255	$317,100	*	*	*	$777,200	*
NE	$0	0	$0	0	$0	0	$0	0
NH	$0	0	*	*	*	*	$936,174	1,285
NM	$0	0	$187,770	224	$0	0	$187,770	224
NJ	$0	0	$5,357,000	*	$3,436,000	*	$8,793,000	*
NV	$162,200	70	*	*	$0	0	$162,200	70
NY	$0	0	$1,000,000	*	$15,536,000	*	$16,536,000	20,000
OH	$0	0	$0	0	$3,562,462	*	$3,562,462	*
OK	$0	0	$0	0	$0	0	$0	0
OR	$0	0	$0	0	$0	0	$0	0
PA	$0	0	*	*	$10,086,219	15,639	$10,086,219	15,639
RI	$320,000	75	$300,000	100	$1,080,000	*	$1,700,000	175
SC	$180,000	175	$1,242,100	66	$0	0	$1,422,100	241
SD	$0	0	$0	0	$0	0	$0	0
TN	$0	0	$104,860	187	$0	0	$104,860	187
TX	$1,000,000	267	$1,272,276	498	$7,370,580	2,884	$9,642,856	3,649
UT	$154,100	21	$183,000	354	$110,000	*	$447,100	*
VA	$0	0	$0	0	$0	0	$0	0
VT	$0	0	$572,500	375	$16,000	45	$588,500	420
WA	$0	0	$1,900,000	*	$566,094	*	$2,466,094	900
WI	$723,100	533	$1,077,960	2,362	$723,100	533	$2,524,160	3,428
WV	$0	0	$114,850	*	$0	0	$114,850	*
WY	$0	0	$0	0	$0	0	$0	0
Reporting States	$13,542,294	5,275	$50,504,732	24,176	$106,009,107	54,999	$171,107,307	104,781
TOTAL (imputed)	-	-	-	50,369	-	102,181	-	168,314

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[1] *An asterisk indicates that data were not available and "0" indicates that a discrete family support activity was not identified. Alabama and North Dakota reported client-hours of service. These are not included in client data totals. Hawaii and New Hampshire reported total Family Support Expenditures only. Client data may include duplicate counts. Several states were able to report expenditures but not client data. In those instances, the imputed U.S. column totals for clients served in Respite Care, Other Family Support, and Total Family Support were imputed from the average expenditures per client for all reporting states.*

Source: U. of Illinois at Chicago UAP

Cash Subsidy Programs

Thirteen state MR/DD agencies were identified as having cash subsidy programs. Detailed information on the number of families served (5,275 nationally) and level of expenditure ($13.5 million) were available from 11 states (no data were available from ID and IN). The subsidy programs fell into three basic categories:

(1) direct cash payments to families with no restrictions on the way the money was used;

(2) direct cash payments tied to a tracking mechanism such as receipts or individual habilitation plans; and,

(3) reimbursements after the family procures services on its own.

It is noteworthy that only Michigan expended in excess of 1% of its total mental retardation services budget in 1988 for cash subsidies to families with a developmentally disabled member. In fact, Michigan's expenditure represented 70% of all cash subsidy expenditures identified in the study. Most states active in cash subsidy programs had only instituted programs within the past one to three years. The average annual cash subsidy expenditure per client in the U.S. in 1988 was $2,567. Virginia's program, the Family Support Project, was based in the state Department of Human Resources and was therefore excluded from the survey as a "non-MR" agency-based program. Families received up to $3.6 thousand per year; approximately 201 families were served in Virginia in FY 1988.

Non-Subsidy Support Programs

Considerably larger and more numerous programs providing *respite care* were identified in the states. Thirty-three states reported funds specifically budgeted for this activity. Total nationwide expenditures were $50.5 million for an estimated 50,369 clients. The largest programs were identified in California, Massachusetts, New Jersey, and Illinois. *Other family support* activities, ranging from family counseling to in-home behavior therapy programs, were reported in 30 states serving an additional estimated 102,181 families. The total national expenditure for the *other family support* category was $106 million.

Part II:
The Fiscal & Demographic Imperatives

The nation's system of services for persons with mental retardation has undergone a fundamental transformation during the past two decades. Since 1967 the institutional census has been in steady decline as states have shifted away from reliance on traditional institutionally-based service systems. In this same period we have witnessed the collateral expansion of community-based service networks. While there has been widespread commitment of state policies to these changes, segregated, large congregate-based care systems still dominate, both in terms of fiscal commitments and numbers of persons served (Braddock, Hemp, Fujiura, Bachelder, & Mitchell, 1990). The transformation is far from complete and substantial challenges lie ahead as we enter the concluding years of the twentieth century.

In this section fiscal and demographic trends from the 1970's through the end of the 1980's are evaluated and the contemporary character of the nation's system of care is critically assessed. Two central themes emerge from the analysis: 1) Despite the impressive advances in community services development, substantial additional growth in the national capacity will be required to meet current needs. Funding for this expansion, seen in the context of the national economy, may well depend on the continued advocacy of the needs and rights of citizens with mental retardation; and 2) A considerable share of future need will emanate from the American family, a sector of the population not yet adequately served by the nation's formal systems of care. Our analysis of contemporary challenges confronting state service systems suggests that the family must be a principal component of policy initiatives for the future. To this end, special emphasis has been given to current developments in family support services and the results of a recent survey of family support program initiatives are summarized in the concluding section.

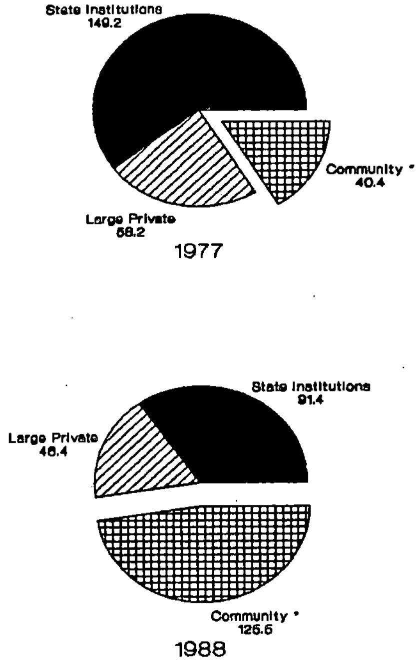
A Recent History of Trends

The following discussion is largely based on a national and state-by-state survey of mental retardation and related developmental disabilities expenditures and programs completed as part of the *Third National Study of Public Expenditures for Mental Retardation and Developmental Disabilities* (Braddock, et al., 1990) and related studies (Braddock & Fujiura, in press; Braddock, Fujiura, Hemp, Bachelder, & Mitchell, in press). The research has longitudinally tracked state and federal mental retardation services funding from 1977 through 1988.

The Residential Services System: 1977-88

In 1977, a decade after institutional populations peaked in the United States, 84 out of every 100 persons with mental retardation in residential programs were still located in large congregate facilities. They included 149 thousand residents of state-operated institutions and an additional 58 thousand persons in 16+ bed, privately-operated facilities (see Figure 1).

FIGURE 1
Residential Services: 1977 vs 1988
(In Thousands of Residents)

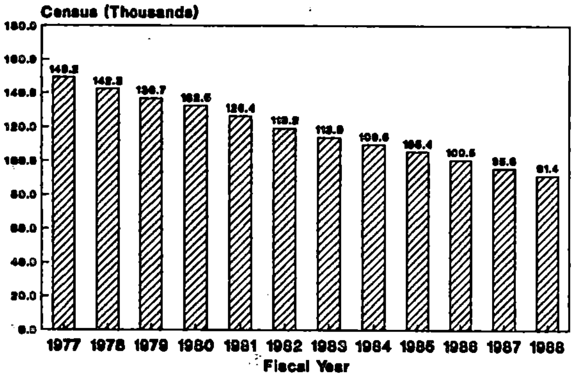


* 16-Bed or less facilities

In that same year, there were approximately 40 thousand persons with mental retardation residing in smaller, 15-bed or less facilities (White, Lakin, Wright, Hill, & Menke, 1989). By 1988 the relative proportions were more nearly equal - 135 thousand residents in large congregate facilities versus approximately 123 thousand persons living in smaller residences (Braddock, et al., 1990). The character of the nation's out-of-home residential system had been significantly recast during the twelve-year period.

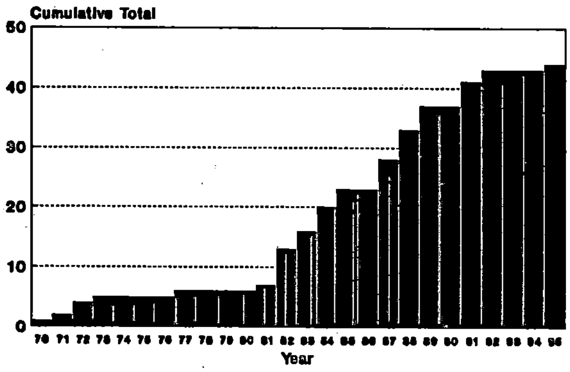
Institutional closures. The central dynamic for this change has been the reduction in size of the state-operated institutional system. The average daily census in these facilities, which stood at 149 thousand in 1977, had dropped to 91 thousand by 1988. This represented a 39% decline and a dramatic decrease of 53% from the 1967 census of 195 thousand (See Figure 2).

FIGURE 2
Average Daily Residents in State-Operated Institutions: FY 1977-88



Two factors undergirded the declining census: a) downsizing of institutional facilities, which have decreased in average size from 471 beds in 1977 to 315 beds by 1988; and b) closures of institutions. In the most recent survey of institutional programs in the United States (Braddock, et al., in press), 44 completed and in-progress closures were identified. Nearly 90% of these closures occurred during the 1977-88 period and the trend appears likely to continue. Figure 3 graphically illustrates the accumulated closures (completed and in-progress) across the 25-year period of 1970-1995.

FIGURE 3
Cumulative Institutional Closures: FY 1970-1995



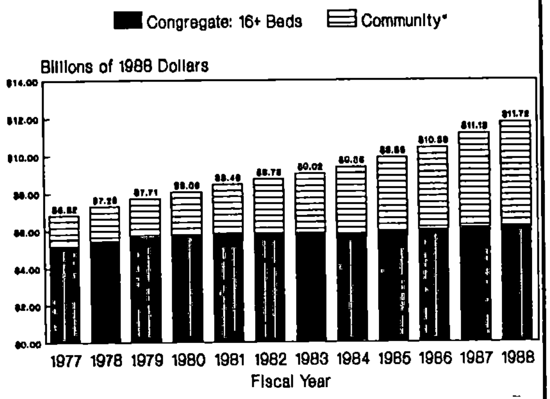
(Includes completed and in-progress closures)

There has been a parallel decline in the census of 16+ bed privately operated residential facilities during the 1977-88 period, though not of a corresponding magnitude (20% vs. 39% for institutional programs). Nearly 32 thousand persons were served in facilities funded through the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program in 1988 and another 14.5 thousand in other large private facilities. Costs have spiraled; though the total numbers of residents have decreased by roughly 10.5 thousand, inflation-adjusted spending has increased by 296%.

Fiscal trends. The decline of the large congregate residential services census and the corresponding expansion in community-based options is partially reflected in the relative balances of fiscal commitments made by states to the two service sectors. Total state and federal commitments to mental retardation services (excluding special education and federal income maintenance payments) have advanced from $3.5 billion in 1977 to $11.7 billion in 1988. The principal focus of this growth is apparent from inspection of Figure 4 on the following page.

The increase in total outlays, which was an impressive 72% in inflation-adjusted dollars, largely represented the rapid increase in monies committed to the development of community services. However, spending on the large congregate care sector did not decrease in accord with the declines in the census. Rather, it increased moderately, from an inflation-adjusted level of $5 billion in 1977 to $6.1 billion in 1988.

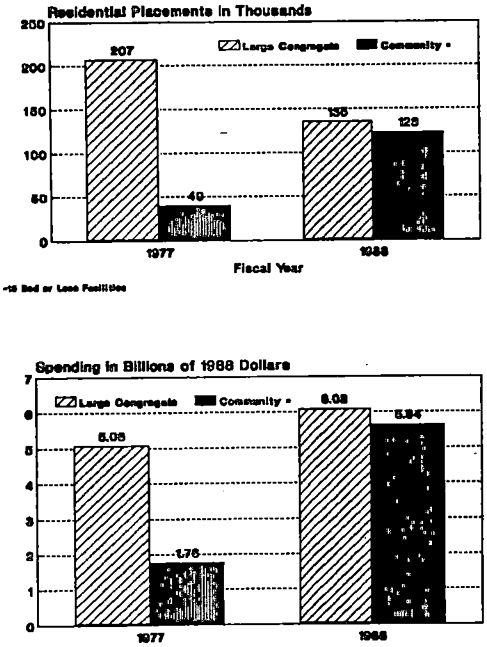
FIGURE 4
Adjusted MR/DD Spending for Congregate Residential & Community Services



* Includes 15 Bed or Less Residential & Other Community Services

The juxtaposition of the 1977 residential counts and fiscal data to the most recently available data from 1988 illustrates two central trends of the 1980's: a) the dramatic expansion of states' community service systems, both in terms of individuals served and monies expended, and b) the rapid escalation of the costs of care within the large congregate residential services sector. In inflation-adjusted dollars, this latter system of services commanded 22% more funds in 1988 than in 1977, while providing services to 72,000 fewer persons. More dollars were supporting substantially fewer persons.

FIGURE 5
Residential Beds and Expenditures: 1977 versus 1988



* Includes 15-Bed or Less Facilities & Other Community Services

Challenges to State Service Systems

The fiscal and programmatic data underscore the impact of federal and state policies that have, in the aggregate, yielded significant gains during the past decade for persons with mental retardation. Yet, despite the real-dollar increases in fiscal commitments, the total number of individuals served in out-of-home residential facilities has grown by only 6%. Excluding nursing home placements, there were approximately 247 thousand out-of-home residential placements in 1977; by 1988, the residential capacity of the nation had increased by only 16 thousand. While a considerable share of the decade's fiscal growth has been devoted to the development of non-residential community services, clearly the additional dollars have not purchased any substantial expansion of the nation's out-of-home residential capacity. Three implications of these trends are discussed below.

The Large Congregate Bias

The aggregated national fiscal profile, which shows community services spending approaching parity with the level of funds committed to the large congregate sector, obscures the remarkable inter-state variability in commitments to community services. There are wide disparities across state systems. Only 21 of the 51 states expended more on community services than on large congregate residential services. Eleven states expend less than one-third of their total mental retardation services resources on community programs. The range of proportions is extreme, from a high of 78% in Michigan to a low of 16% in Mississippi.

With respect to the relative proportions of placements into small versus large residential settings, the 12-year trends and current status parallel the fiscal data. In 1977 the average rate of placements into 15-bed or less facilities was 16.6%, ranging from less than 1% in Oklahoma to 56% in Montana. By 1988, this placement average had increased to 51%, reflecting the dramatic growth in small facility options. However, these changes have manifested themselves unevenly across the nation. Oklahoma, Illinois, Louisiana, South Carolina and Texas, states with the lowest rates of placements into 15-bed or less facilities in 1977, maintained an extensive large congregate service base into 1988. Mississippi and Missouri were virtually unchanged from their levels of 1977. In contrast, states that have been fiscal leaders in community services, such as the District of Columbia, North Dakota and Rhode Island, have radically transformed their systems, having placement rates below 10% in 1977 rising to 70% or more in 1988.

Nationally, less than half the state systems (25) have the majority of residential placements in small facilities; nine states serve fewer than one-third of their residential population in these programs. Table 2 summarizes the proportional

TABLE 2.
Spending and 15-bed or less residential capacity as % of total in 1988[1]

STATE	% COMM FUNDING	1988 RANK	% 15-BED OR LESS	1988 RANK
AK	68.6%	5	83.5%	2
AL	29.0%	46	36.7%	38
AR	28.4%	47	29.5%	45
AZ	59.0%	8	80.0%	5
CA	54.8%	17	54.9%	24
CO	71.1%	3	72.3%	9
CT	60.8%	7	51.3%	26
DC	66.6%	6	72.8%	8
DE	35.3%	40	45.4%	30
FL	44.8%	27	51.5%	25
GA	41.5%	31	44.0%	31
HA	42.2%	30	71.1%	10
IA	45.0%	25	29.7%	44
ID	51.0%	21	38.0%	37
IL	39.3%	34	22.2%	48
IN	46.1%	22	56.0%	23
KS	31.0%	44	46.8%	29
KY	41.1%	32	36.0%	39
LA	32.3%	41	25.5%	47
MA	45.0%	26	59.7%	18
MD	58.5%	10	57.8%	21
ME	55.1%	15	60.4%	16
MI	78.0%	1	81.2%	4
MN	55.3%	14	61.9%	15
MO	38.5%	35	33.4%	42
MS	15.7%	51	12.2%	51
MT	58.8%	9	78.2%	7
NC	29.4%	45	38.2%	36
ND	55.6%	13	78.8%	6
NE	56.1%	11	64.3%	13
NH	72.6%	2	83.0%	3
NJ	40.0%	33	32.4%	43
NM	43.5%	29	58.4%	19
NV	43.7%	28	59.8%	17
NY	54.9%	16	56.9%	22
OH	51.9%	20	40.5%	35
OK	17.2%	50	17.8%	49
OR	36.8%	37	57.9%	20
PA	51.9%	19	49.5%	27
RI	69.2%	4	85.2%	1
SC	32.3%	42	35.6%	40
SD	52.4%	18	67.4%	12
TN	27.9%	49	35.1%	41
TX	28.1%	48	17.6%	50
UT	45.7%	24	42.6%	33
VA	31.4%	43	27.3%	46
VT	56.1%	12	67.5%	11
WA	35.3%	39	48.8%	28
WI	45.8%	23	62.5%	14
WV	37.6%	36	42.8%	32
WY	36.4%	38	41.7%	34

[1] Spending totals include 15-bed or less facilities and other community services

allocation of funds and residents in the community services sectors of each of the 50 states and the District of Columbia. There are many alternative models of community care and the "large" versus "small" facility distinction is an imperfect descriptor of state systems. Nevertheless, it is a useful proxy for evaluating policy emphasis within a state.

For the majority of state systems, the transformation to a community-based service system has just begun. Despite the considerable depopulation of states' institutional facilities, the nation's network of services is still predominantly a large congregate-based system.

The Adequacy of the Residential Supply

A second challenge, and perhaps a more basic concern, is the adequacy of the nation's residential capacity for meeting current and near future demand. While it is impossible to characterize with great precision what the parameters of supply and demand are, a partial answer to the adequacy question may be found in comparing current capacity against secondary indices of service need.

Waiting list data. Virtually every parent or relative of a person with mental retardation has encountered a waiting list. The Association for Retarded Citizens (ARC) conducted a telephone survey to quantify the scope of the problem in 1987 (Davis, 1987). The survey sample was composed of state ARC directors and/or state mental health and mental retardation and developmental disabilities agencies. Thirty-eight states regularly collected waiting list data or had conducted a recent evaluation of waiting lists. Estimates were obtained from those states not systematically assessing this information. Sixty-three thousand persons were estimated to be waiting for residential services. The number very likely underestimated the true extent of residential service need. First, the figure excluded six states for which estimates were unavailable, including California, the nation's most populous state. Second, waiting list data may represent only the subset of persons formally attempting to obtain service rather than the more inclusive population in need. Finally, waiting list data do not reflect those individuals currently in the residential service system but in need of alternative placements.

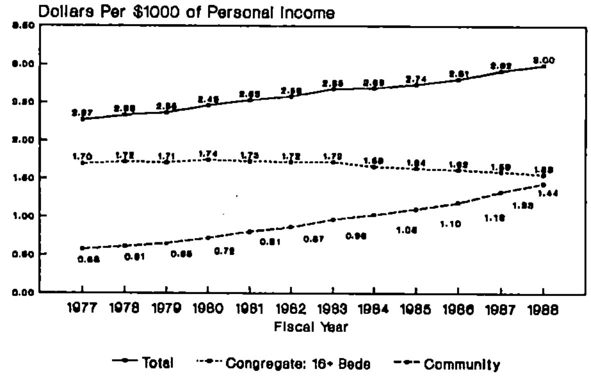
PL 100-203. PL 100-203 (OBRA-1987), passed by Congress in 1987, included sections addressing the issue of quality of care for persons with mental retardation and developmental disabilities placed in nursing homes. The legislation specified that all states must have in place a pre-admission screening program to prevent admission of persons with mental retardation and developmental disabilities into nursing homes unless their primary need was nursing care. Of special significance to the larger issue of the nation's residential capacity, the legislation required states to furnish appropriate services to this population, either through "active treatment" within the facility or *by movement of the resident to alternative care.*

The size of this population and the extent to which states were planning to reduce its size were estimated in a recent study of nursing home placements and associated costs (Mitchell & Braddock, 1990). The study identified 50,606 persons with mental retardation living in nursing homes in 1988, an estimate within the range predicted by the sample-based surveys of the National Center on Health Statistics in 1977 and in 1985.

Thirty-four states provided a projection of the number of nursing home residents who would eventually be moved to alternative facilities. The estimate, 37% of all placements, was questioned by Mitchell and Braddock (1990) as being far too conservative. They cited past studies indicating that the vast majority of nursing home residents with mental retardation and developmental disabilities had been inappropriately placed (e.g., Anderson, Lakin, Bruininks, & Hall, 1987). Even if the 37% figure were accurate, then implementation of the provisions of PL 100-203 would result in another 19 thousand persons attempting to enter the residential service system.

The large congregate issue. Together, the waiting list and nursing home counts amount to over 81 thousand persons with mental retardation in need of service options currently not available. *This total represents the net growth in small residential bed capacity during the period of 1977-88 and nearly one-third of the nation's current MR/DD residential services capacity.* However, included on the supply side of this comparison were the 135 thousand residents of public institutions and large private facilities. These are individuals also in need of family-scale community-based residential alternatives and in the long term, their numbers must be considered part of any future demand. Even if projected demand on community residential services were based only on past rates of movement from the large congregate sector, then thousands more per year could be added to the total count of persons in need of residential options.

FIGURE 6
MR/DD Spending Per
$1000 of Personal Income



The Context of the National Resources

The third challenge is economic, reflecting the uncertain character of public financing in an era of fiscal conservatism and budgetary restraints. Maintenance of dual service systems, based in both the community and the institution, is an expensive proposition for the states. The large congregate residential system, though much constricted in capacity, has absorbed a relatively constant level of fiscal resources over the past 12 years. What gains we have witnessed in community services have been achieved through the infusion of *additional* funds dedicated to the field.

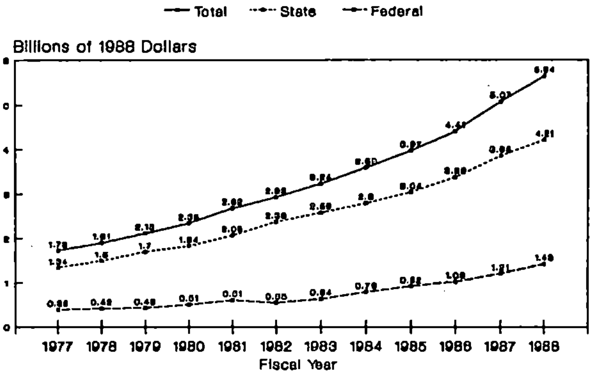
National wealth. Spending for the community sector has grown over three times as fast as *aggregate national wealth,* that is, the total personal income of the United States. The higher rate of growth is graphically displayed in Figure 6, where mental retardation services spending is expressed in terms of dollars spent per $1,000 of aggregate national wealth.

The two trendlines in the lower portion of the chart represent spending per $1,000 of aggregate personal wealth broken out across the two major service sectors - large congregate services and community services. Their divergent slopes reflect the allocation of a majority of these additional resources to expansion of the community services sector. Since 1977, the state and federal governments' commitments to community-based mental retardation services have increased by an average of $.5 billion per year in inflation-adjusted 1988 dollars.

Governmental expenditures. The fiscal trends are even more striking when viewed in relation to total expenditures by all levels of government. Community services funding has increased far more rapidly than total governmental expenditures. In 1977, $1.29 of each $1,000 of total governmental spending was devoted to community mental retardation services. By 1988, this share had more than doubled to $2.94. While absolute levels of spending are modest in terms of total governmental outlays, the rate of growth has been remarkable. In short, the contemporary status of community services has been achieved by the allocation of an increasing share of the nation's wealth and its governmental expenditures over these past twelve years.

The burden of this growth has been shared unequally by the federal, state and local governments. Figure 7 graphically displays community services mental retardation funding from 1977-88 in terms of state and federal funding. Despite the expanding federal presence in human services during the 1970's and 1980's, the states provided the majority of funds for community-based services. State and local source monies accounted for 75% of all community services funding in 1988, a ratio that has been relatively constant since 1977. *The expansion of the nation's community services base has been largely fueled by state revenues.*

FIGURE 7
Adjusted Federal vs. State Funding for Community Services: FY 1977-88



It has primarily been the states that have set the agenda and allocated the resources for community services development over this past decade. Their response to the challenges of the coming decade will depend on their capacity to redress current inadequacies and perhaps more importantly, on the depth of their commitments to the continued growth of community services. Capacity is an economic question and while economic forecasting is an inexact science, it is likely that the growth of the American economy will slow in the near term from the rates seen in the 1980's. Slower economic growth will tighten state budgets. As we enter the 1990's, state budget surpluses are at their lowest levels in over a decade (Gettings & Smith, 1989; State Policy Research, 1990). The consequences of the slowdown are already being felt; austerity measures have been adopted throughout New England, a region of the country that has recently led the nation in fiscal commitments to community service. How services to persons with mental retardation will fare in this economic climate is unknown. Recent research has suggested the critical role advocacy has played in securing fiscal resources for community services (Braddock & Fujiura, in press); it is reasonable to assume that continued advocacy will be necessary to maintain the commitment of state leadership and government to the community services agenda.

Future Challenges: The Family Issue

To this point, we have presented a summary of the major transformations that have occurred in the nation's mental retardation service delivery system and described trends that reflect quite positively on the past decade's progress. Implicit in the presentation has been a concern that such rates of growth, though impressive, have left us with a system still plagued by inadequacies; an institutional or institution-like service system still dominates while much community service need remains unmet. However, the single largest locus of mental retardation "services" in the nation -- the American family -- has yet to be considered.

Demographics

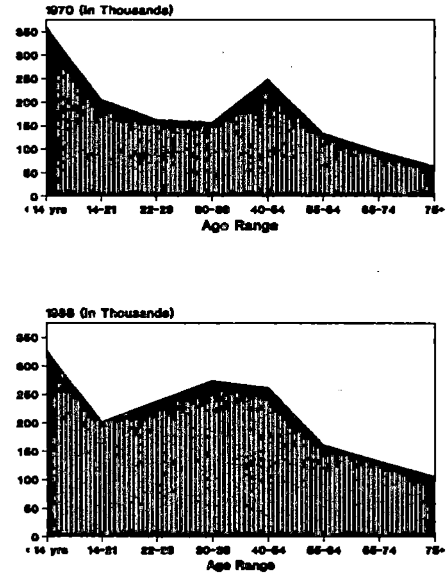
The vast majority of persons with mental retardation are supported at home by their families (Agosta & Bradley, 1985; Bruininks & Krantz, 1979; Wieck, 1985). Out-of-home services have historically been limited and the family has always been the principal care option in the nation. Furthermore, the extent of this role has been reinforced in recent years as a consequence of statutorily mandated access to public education and state policies restricting institutional admissions (e.g., Agosta & Bradley, 1985). Despite the size of the family-based population and the high probability that it has grown in recent years as a consequence of public policy, little is known about the parameters of its size (e.g., Bruininks, 1979; Rowitz, 1984).

To establish an empirical context for the elaboration of these issues it was necessary to derive population estimates, and conservative values were chosen. The intent of this analysis was not the derivation of precise population estimates, but rather to more fully substantiate potential policy concerns for the coming decade. The following discussion of prevalence is restricted to those persons jointly classified as mentally retarded and developmentally disabled. The net effect of this restriction is to consider only that subset of individuals with mental retardation who are functionally limited. The restriction is imposed only to make possible a comparison of the known residential services population against those most likely to access it.

Estimates of the prevalence of developmental disabilities range between 1.20% to 1.65% (e.g., Boggs & Henney, 1979; Administration on Developmental Disabilities, ADD, 1981; Kiernan & Bruininks, 1986). For the purposes of the following exercise, we employed the ADD estimate of 1.2%, its projection of the *noninstitutionalized* population. Approximately 58.4% of the developmentally disabled population were projected to have mental retardation (ADD, 1981), which yields an estimated prevalence rate of .70% for persons jointly classified as mentally retarded and developmentally disabled in the general population. This estimate is consistent with the more conservative population estimates of the numbers of persons with levels of mental retardation in the severe to profound ranges (e.g., McLaren & Bryson, 1987; Baroff, 1982). Applying this rate to the general population of the United States in 1988 yields an estimated 1.7 million children and adults with mental retardation who are considered to have developmental disabilities.

The shape of the age distributions across this population for both 1970 and 1988 are graphically displayed in Figure 8. Age breakouts were based on U.S. Bureau of the Census data for 1970 and the 1988 population projections (U.S. Bureau of the Census, 1987). The age estimates assumed prevalence rates do not exhibit *significant* variations across ages; that is, the distribution of ages across the population with mental retardation parallel the distribution in the general population. While there is some question about derived estimates at the older range of ages (e.g., Seltzer & Seltzer, 1985), the analysis employed rates derived from the general population. Our estimates at these older age ranges appear relatively conservative, falling well below the National Institute for Disability and Rehabilitation Research (LaPlante, 1988) estimates for the cohort aged 45+ years (.23% versus .38%) and slightly higher than the .1% derived by Jacobson, Sutton & Janicki (1985) for those aged 55+ years (.16% in the present analysis).

FIGURE 8
Age Distributions of Persons with MR:
1970 vs. 1988



Implications

Two conclusions can be drawn from inspection of Figure 8. First, that the nation's out-of-home residential system served only a small proportion of all persons with mental retardation in 1988. Total out-of-home placements in 1988, including nursing home placements, were 314 thousand (Braddock, et al., 1990), or less than 19% of all persons with mental retardation who have developmental disabilities. The balance of this population, over 1.38 million persons, were cared for by family members or friends. Though there are significant age-related variations in out-of-home placements -- the distribution is narrow and skewed, with greater numbers of placements in the mid to upper age ranges (Bruininks, et al., 1983) -- the total variance is small relative to the larger population and does not visibly affect the general shape of the family population distribution.

The graphic makes evident a second issue - that there are two very large cohorts, the school-age population and the post-war generation, the "baby-boomers." Should their families seek out-of-home residential options, the already overburdened residential system will be severely tested, a challenge not likely to be met in the near term. The impact of demographic pressure has been cited elsewhere in the literature, particularly in the area of aging and disabilities (e.g., Jacobson, et al., 1985).

The American family is the largest "provider" of care in the nation. It has made relatively limited demands on the formal systems of care provided by the states (Moroney, 1979). However, the foregoing population estimates suggest that there may be impending demands that stem, in part, from governmental policies that have encouraged families to maintain their children at home and from the demographic impact of the post-war "baby-boom," currently in the care of aging parents. These cohorts are unprecedented in size and their demands on the service system have not yet been fully realized.

Conclusion

In the period from 1977 to 1988, the nation increased its community services residential capacity by 83 thousand beds and spending grew by 541%. While this is a tangible manifestation of significant public policy commitments across the nation, it is sobering to consider what additional resources will be required in order to address and ameliorate current systemic inadequacies. The 12-year increase in bed capacity is equal to the current total estimated need from the waiting list and nursing home data. It is a conservative estimate, and one that excludes those currently inappropriately placed in large congregate settings. Further expansion of the community system, while maintaining the institutional sector, dictates the commitment of substantial additional public funds. Rates of growth, exceeding those of the recent past, will be necessary to generate the funds needed to address these inadequacies. In the absence of massive infusions of federal monies, these additional resources must come from state and local revenues, from the governments that to date, have raised the revenue and allocated the funds to drive the community services agenda. Critical challenges lie ahead as we enter an era likely marked by budgetary tensions and constraints on public spending growth.

The nation is not without options. Barring a catastrophic conclusion to the longest lasting economic expansion in our nation's history, fiscal commitments to community services will continue to increase impressively and the base of services will expand. Medicaid reform holds promise of attenuating the institutional bias of federal ICFMR support, making available more resources to community service systems in the states. Nevertheless, it is likely that the discrepancy between service needs and service capacities will continue to be unacceptably large.

We conclude by summarizing the two central themes raised in our analysis. First, that no object of public policy is more central to the larger national portrait of services than the American family: the parents, grandparents, siblings and other relatives of persons with mental retardation who collectively represent the nation's largest alternative "system" of care. Our analysis of family support programs reveals important progress in the development of services, though the total allocations of discretely funded monies remains meager. New policy directions focused on the family must be considered and included among these should be further development and expansion of support programs, and additional economic empowerments through cash support subsidies and other entitlements. Family empowerment must be elevated to the level of a national priority.

Secondly, the impressive growth in services profiled in this chapter should be interpreted as a manifestation of goals accomplished but, more importantly, as a challenge for the new decade. The evolution of the nation's community services network is still underway, and maintenance of the momentum will continue to require additional resources. In this era of fiscal conservatism the commitment of new resources will again depend on the vigorous individual and organizational advocacy that has spearheaded the community movement through the 1970's and 1980's.

Part III:
State Profiles

ALABAMA

Alabama has two family support programs, *Community Respite Services* and *Family Services*. Both programs were funded with General State funds as part of the Department of Mental Health, Division of Developmental Disabilities' budget. The Respite Services program provided respite care to families with children who were developmentally disabled living at home. Family Services included information and referral services, counseling, and case management to families of persons with mental disabilities. Both programs provided services by subcontracting with community agencies for each specific service required.

ALASKA

Alaska provided respite, day care services, homemaker, and family training services to families caring for persons with developmentally disabled family members living at home. Respite services were provided under the Community Developmental Disabilities Grant Program fund through Community Services General funds.

ARIZONA

Family services were provided to families who care for or are capable of caring for a family member with developmental disabilities at home. Services were provided to adults or children living with families as well as adults attempting to live independently or semi-independently. Services covered a variety of areas specifically designed to support and strengthen a family's ability to care for a family member with developmental disabilities as well as to support individuals attempting to live independently. Services included were: Family and client counseling, psychological assessments, recreation and socialization, transportation, adaptive aids and devices, emergency services, respite and sitter, therapy, medical services, in-home services, volunteer coordinator services, program development, social development, parenting skills training, parent aide, rehabilitation instructional services and adult day care, home care program, and home management training.

ARKANSAS

The *Respite Care Program* in Arkansas was designed to provide parents and guardians with an incentive to keep their family member with developmental disabilities at home. The Department of Developmental Services contracted for respite care services through community based providers in five counties. The DDS had recommended that the program be implemented in the remaining 55 counties with community facilities. These facilities were usually vacant in the evenings and on weekends and if funding was available they could be used to provide respite services.

CALIFORNIA

The Department of Developmental Disabilities provided "family support" services through its purchase of service line items. Included in our analysis were "respite" services as well as "home-health" expenditures. Other forms of family support were 65 line items which reflected a comprehensive array of professional services provided to individuals living at home. Also included were funds for equipment and transportation.

COLORADO

Colorado had two family support programs identified in their state budget, the *Family Resource Service Program* (FSRP) and *Respite Services*. The FRSP began in 1983 as a pilot funded by the Developmental Disabilities Council involving three community centered boards (CCB) and six families. In 1986, the Department of Institutions, Division of Developmental Disabilities, received authorization from the general assembly to began administering state funds to continue and expand the program. The FRSP was designed to reduce, delay, or prevent the need for out-of-home placement of children with MR/DD by providing services that assist families in keeping their children at home. The program gave one person, the family specialist, at the CCB level, lead responsibility for setting up the program and working with the family on a day-to-day basis. Criteria for selecting families were probability of out-of-home placement, characteristics of the child which have been demonstrated to influence placement decisions, familial and situational characteristics that may bear on the family's capacity to provide care, and the potential for success of services. Based on the plan developed, services were funded if in accordance with the objectives of the program and identified as allowable by the Division. These services included: respite, training, homemaker services, home health aides, therapies, equipment, behavior management, recreational activities, counseling, general care items, excess medical costs and transportation for medical appointments. Payments for services were paid directly to the provider. In FY 1986, per family costs were capped at $250/month. Respite care, identified as a separate line item in the Division of Developmental Disabilities budget (CRS 27-10. 5-104), was a limited program of relief for families who maintain a person with MR/DD in their home. There were four providers of state-funded respite services: the Archdiocese of Denver, Boulder County ARC, Mesa County ARC, and Pueblo County ARC.

CONNECTICUT

The Connecticut Department of Mental Retardation had initiated an effort to provide in-home support to families who care for a family member with developmental disabilities at home. It was anticipated that the program would develop other services: respite care, family subsidies, homemaker and health aid services, environmental modifications, and educational equipment lending.

In addition, Connecticut had a family support program funded through the Department of Human Services. *Parent Deinstitutionalization Subsidy Aid* was established in 1981 by Public Act 81-839, Laws of 1981, and was implemented in March 1982. The program was designed to assist families with children living at home who were "at risk" of institutionalization, or families planning to return a child in an institution to the home. Program eligibility was determined by family size, gross income of parent, and combined assets of handicapped child and parent. Families received up to $2,000 per year to provide services for a family member with mental or physically handicaps. However, parents had to document need for service and develop a service plan. The plan documented the manner in which the subsidy would be used. Each family plan was reviewed annually to determine if the subsidy would be increased, decreased, or terminated. The subsidy could be terminated if families did not comply with the plan and recommendations made by the Commissioner. Allowable services included medical and dental, educational program, day care, respite, special clothing, special equipment or adaptive devices, transportation, therapeutic and rehabilitative services, counseling, and other <u>unusual</u> expenses related to disability.

DELAWARE

Family support services through the "community services" unit of the DMR were represented by the "family support program," which provided traditional respite services as well as other services to support families in the care of their member with MR/DD. FY 1988 marked the formal beginning of the program though such services had been represented under "purchase of care" appropriations in the past. FY 1988 funding included $71,818 for respite and $8,534 for other support services.

DISTRICT OF COLUMBIA

The District of Columbia provided respite care services and in-home support services. In FY 1988 respite care services were provided for 400 families and 30 families received in-home support services. The number of families who received in-home support services decreased from 65 in FY 1987 to 30 in FY 1988 because of difficulties in obtaining service contracts from community agencies. In FY 1988, total expenditures were $493,082 from the District "local funds" with $342,896 spent for respite care services and $150,186 spent for in-home support services.

FLORIDA

Florida's Developmental Services operated an *Independent Family Living* program which also included a small cash subsidy program, the *Family Placement Program*. The Independent Family Living Program (IFL) was a budgeted entity with Florida's Developmental Services appropriations. Chapter 393, Florida statutes, states in part that the greatest priority shall be given to the development and implementation of community-based treatment programs for persons with retardation; those at home were eligible to receive services through the IFL in order to prevent placement in more costly residential facilities. This program provided a wide range of day-program and education oriented services to clients living at home and support service to the families. Services included: casework services, transportation, respite, education, training, therapy, medical, dental, diagnosis and evaluation, involuntary admission, developmental training, services to public school graduates, services to clients with complex medical problems, OT and PT, and therapeutic equipment.

The Family Placement Program (FPP), a

separate line within the large IFL, was established through a lump sum appropriation provided for the implementation of the Retardation Service Act of 1977. The enacting legislation specifically stated that "when it is determined by the department to be more cost-effective and in the best interest of the client to maintain such a client in the home of a caretaker in order to avoid unnecessary institutionalization, the parent or guardian of the client may enroll the client in the FPP." The Family Placement Program began in FY 1979-80 as a demonstration project and evaluation study to determine the feasibility of establishing a "supplemental income family placement program for persons with developmental disabilities." The program provided subsidies to responsible caretakers for maintaining their handicapped family members in the home setting and avoiding out-of-home placements. The objectives were: a) provision of funds to defray in-home costs; b) allowing families to purchase needed services such as in-home training, therapies, homemaker services, and nursing services; and (c) prevention of placement in more restrictive residential programs. Services covered included any service documented in an Individual Habilitation Plan that could not be funded by another state agency, Title XIX, or other general revenue source deemed more appropriate. Services included but were not limited to: Room and board, medical, respite and sitter, day care, transportation, special equipment and adaptive devices; home adaptation; education and therapeutic services; counseling, parent training, special diets, special clothing, medications, and other extraordinary services related to disability. Specific services, fees, and duration of service were determined by the family caretaker and family placement program committee and were based on individual client needs and availability of funds. Payments range from $30-$680 per month and could be used to pay the caretaker rather than providing funds to purchase specific services.

GEORGIA

The main component of family support in Georgia consisted of Respite Care, provided by institutions, by Community Mental Retardation Residential Services funding of respite care contracts, and within group homes. The Georgia Retardation Center was an example of institutionally-based respite, which during FY 1987 served 179 persons in stays of two weeks. Contract respite care services have been provided since FY 1980, with annual expenditures ranging from $100 thousand in 1980 to $391 thousand in 1988. These expenditures did not include respite services provided in 94 group residences operated by Boards of Health. There were in addition, three "family support demonstration" projects totaling $300,000, that served a total of 200 individuals in the areas of Whitfield, Clayton, and Clarke. It was projected that in FY 1989, family support demonstrations would be provided in an additional 3 demonstration areas, or a total of 6 out of 27 in the state.

HAWAII

An initiative began in FY 1988 which included in-home respite, special adaptive equipment, renovation of building to accommodate the physically handicapped, counseling and training to families, and the provision of special supplies. Hawaii provided respite care services to 400 families in FY 1988. These services were primarily offered through "center-based care" during and after school hours. Other services included "sitter services," short-term "out-of-home" placements, and camps.

IDAHO

Idaho's Department of Health and Welfare Division of Community Rehabilitation funds the *Family In-Home Assistance Program* and *Respite Services*. These programs offer support services to families caring for children who were developmentally disabled. Parents helped develop a plan for services and applied at a Regional Center to obtain approval to purchase services. If services were approved, the family received payment to cover service (a receipt had to be sent to the Division for tracking purposes) or service was contracted with a community agency. There was a $250/month limit on payment for services, but if a more expensive service needed to be provided, the Department could approve it. The total cost was then averaged over the total year. Services covered included specialized equipment, home adaptation, family training, homemaker, and respite.

ILLINOIS

Over the past decade, Illinois has been in the process of developing programs that would lead to the eventual establishment of a state financed family support/cash subsidy program for individuals with chronic disabilities. In 1982, the Department of Mental Health and Developmental Disabilities developed proposals for a Family Support Assistance Program intended to assist individuals with developmental disabilities, mental illness and/or alcoholism to return to or remain in a family setting. However, none of the pilot programs outlined were funded due to budgetary constraints. In 1984 the Governor's Planning Council did fund one pilot program, Individual/Family Assistance Pilot Program, a one year pilot designed to provide services to eight families with members with developmental disabilities. This short lived program provided evidence that this type of family support could be cost effective. The cost to the state for each individual placed in an out-of-home (state operated facility) setting would have been approximately $44,000 annually, and the pilot covered support services costs for all 8 families involved within a $45,000 budget.

More recently the Illinois Legislature has taken an active role in establishing family supports for individuals with disabilities. There were two new statutes, The Family Assistance and Support Program (PA 85-938) and the Home-Based Support Services Law for Disabled Children and Adults (PA 86-921), governing family support. The Family Assistance and Support Program provided up to $2,500 per family per year (exceptions for amounts above this) for an array of respite, counseling and other in-home support services. The Home-Based Support Services Law provided stipends directly to families.

The program was designed to provide two levels of payment: 1) 300% of the monthly federal SSI payment for an individual living alone if the adult was not enrolled in a special education program offered by a local education agency; and 2) 200% of the monthly federal SSI payment for an individual living alone if the adult was enrolled in a special education program offered by a local education agency. Services were offered by community health and developmental service providers.

The third article, Family Assistance Law for Mentally Disabled Children, mandated that DMHDD strengthen and promote families who provide care to children with mental illness or DD who were at risk of out-of-home placement. The expressed objective of this law was to empower families to determine the most appropriate use of resources to address the unique and changing needs of their child with a disability. Eligible families received stipends directly. DMHDD was responsible for informing the family of the available support resources that could be obtained locally (in-home, crisis intervention, respite care, etc). The child's parent or legal guardian had complete discretion over the use of the stipend. Stipends were paid on a monthly basis and were equal to the amount of the monthly federal SSI payment for an individual residing alone. The stipend was designed to complement rather than replace other public assistance or social service benefits based upon economic need and available through other state or federal programs.

Additionally, families wishing to have children who were in out-of-home placements returned home were eligible to receive a one-time advance payment equal to twice the monthly stipend.

The second piece of legislation, Public Act 85-938: The Family Assistance & Support Program, was established to assist families who cared for individuals who were severely or profoundly developmentally disabled, with the expressed intent of preventing or delaying the institutionalization of these family members or returning them to the home setting. This was a reimbursement program. Services included: special adaptive equipment, minor structural modifications to a residence or vehicle, adaptive clothing, medications, and special dietary needs.

INDIANA

In 1981, Indiana implemented a statewide cash subsidy and support services program to assist families in providing care to family members with developmental disabilities living at home. The program was initially designed only to provide services for persons with developmental disabilities, but in FY 1987 it was expanded to include persons with mental illness. The program included respite care services, counseling, case management, prosthetic equipment, special medical treatment, transportation, sitter services, attendant care, and other necessary services as identified on an individual basis. Program eligibility was determined by needs identified by the case manager and family. The family was responsible for a portion of the financial requirements. Ninety percent of the funds allocated for the program were used for respite services. The Department of Mental Health, Division of Residential Services, administered these funds through Regional Offices that contracted with local community agencies for services. Respite was limited to a maximum of 20 days per year. Other necessary services were provided through reimbursements. The family applied for specific services through the Central office. If the family request was approved, they purchased the service and then received a reimbursement. There was a $600 ceiling on subsidy amounts in 1988, but the ceiling could be waived with agency or case management justification.

KENTUCKY

Kentucky utilized waiver funds to provide support services to families with members who were developmentally disabled as well as individuals living in alternative residential placements. Services needed were determined through case management and include respite care, in-home support, and special equipment (i.e., dentures, hearing aids, ramps, etc.) that was not covered by other Medicaid or insurance programs. Respite services were provided on both a 24-hour a day basis and on an hourly basis. In-home support provided any service necessary to maintain an individual with developmental disabilities in a household; services included family training, special equipment, and home modification.

LOUISIANA

The Office of Mental Retardation and Developmental Disabilities had the *Parent Training Programs* and *Family Subsidy Program* listed as activities in the Program Division of their budget document. Parent training programs were designed to: 1) improve the adaptive functioning of individuals living in community settings; 2) to train parents in behavior modification techniques; 3) to prevent or delay institutionalization of persons with MR/DD living in the community; and 4) to reduce family stress associated with caring for an individual with MR/DD in the home. The program provided in-home and group training for parents; parents unable to participate in this training were mailed self-study materials with phone follow-up. The Family Subsidy Program provided families with a subsidy to cover the unusual costs associated with disability. Services covered by the subsidy included special equipment, special clothing, medical expenses, respite care, home health aide, nutritional consultation, family training and therapy, home adaptation, dental care, attendant care, crisis intervention, and other services as needed.

MAINE

Discretely funded family support services funded by the Department of Mental Health and Mental Retardation were limited to respite programs. Approximately 500 individuals were served in 1988 at a total cost of $197 thousand.

MARYLAND

Maryland provided family support services for children, and individual support services for adults; both programs were designed to maintain the individual within the natural home. In addition, the state's Developmental Disabilities Administration paid approximately $250,000 per year to a "family support service consortium" within the state's Health Department.

MASSACHUSETTS

The Department of Mental Retardation operated respite services and a family support program. In 1988, a total of $15 million was spent on respite care, and $3.9 million on "family support," which consisted of funding for area "notebook" information and coordination providing recommendations on available generic services (e.g. health care, recreation, religious services). In addition, private providers were funded to assist families in access to after-school services, YWCAs and YMCAs, Boys' Clubs, and respite services.

MICHIGAN

Michigan had two family support programs, the *Family Support Program* and the *Family Support Subsidy*. Both programs were discretely funded items within the Department of Mental Health budget. The Subsidy Program appeared as a separate line item in the executive budget and the support program was encompassed in a larger program line in the Community Health Programs budget. Both programs were operated through local Community Mental Health Boards whose activities were funded 90% by state funds and the remaining 10% by county funds. Michigan's family support programs grew out of a 3-year short-term respite program that provided respite and in-home care to children and adults with developmental disabilities. The first pilot program, as mandated by P.L. 407 Section 3(2) 1978, was established to maintain children with developmental disabilities in their own communities and when possible in their own homes. In January, 1979, this program, modeled after an experimental family subsidy program created by the Minnesota legislature in 1978, began in Michigan with an $100,000 allocation to a tri-county Mental Health Board for the first year. In the following years several other pilots were implemented and in FY 1981-82, $632,000 was appropriated for a total of 5 programs. Three of these programs were funded by the Michigan Developmental Disabilities Council, one of which was a cash assistance program. The DD Council's cash subsidy program was a two year pilot that provided $480 a month to 13 families of children with mental retardation. The program allowed the families to locate their own services and the majority were provided without agency connection. This program demonstrated that assisting families with developmentally disabled children at home had the potential to produce substantial economic benefits for the state. For example, at $480 a month the pilot program cost Michigan $5,760 a year per family for a total of $74,880 for the year. Institutional placements cost the state approximately $45,000 per year per child. The program saved the state about $39,200 per child annually, for an overall annual savings of $510,100. The current Family Support Subsidy was established in FY 1984 by Public Act 249 (as amended)/Section 155-161, Michigan Complied Laws, December 1983. This program provided direct cash assistance to families who care for children with severe disabilities. The subsidy, designed to assist parents in covering extra expenses incurred due to the child's disability, complemented, rather than supplanted, other public assistance or social services benefits available through governmental programs. The amount of the subsidy was equal to the SSI level for persons living at home (as of September, 1987 this was $255/month or $2,700 annually); its use was determined solely by the family. To be eligible for this program, children had to be 0-18 years old, severely mentally impaired, severely multiply impaired, or autistic; living at home with natural parents, adoptive parents or legal guardian; and family annual income could not exceed $60,000. Participation in this program exceeded original appropriated assumptions and growth was expected to continue at rates equal to prior years.

Michigan's second program in family support was initiated in 1985. The Family Support Program was designed to reduce reliance on more restrictive and more expensive long-term out-of-home placements by providing support services to families with children with developmental disabilities. The program covered a wide range of services: respite care, parent training and family caregivers' support groups. Since its development in 1985, the program has been received enthusiastically and by the end of the first year there were substantial waiting lists, particularly for respite care services. During the FY 1988 and FY 1989 planning process, twenty-six of the fifty-five Community Mental Health Boards who administered the program identified a need for expansion. Several other Boards have recommended altering the existing program to include added capacity for respite care to special subpopulations such as the medically fragile.

MINNESOTA

Through the *Mental Retardation Family Subsidy* (MS. Sec. 252.31), Minnesota's Community Social Services Program provided funding for specific items and costs associated with maintaining a child with developmental disabilities in the natural or adoptive home. Funds were allocated to counties to reimburse families of children with MR/DD up to $250 a month (average $234/month) to cover the costs of specific services. Parents of children with mental retardation and related disabilities who were at risk of placement into, or already in, state or private residential facilities or foster homes, could apply for the subsidy through county social services or human services agencies. An individual program plan, developed by the county agency, included specific reimbursable services needed to return the child to or maintain the child in the home. Services included medical costs, medications, education, sitter services, respite care, special clothing, special diets, special equipment, and transportation. The county agency sent periodic reviews to the Mental Retardation program for eligibility determination. Reimbursements were not made for services available through other public or private funds. All subsidies could be modified at six month intervals. The average per family cost to the state for the Family Subsidy Program was $2.8 thousand versus an ICF/MR cost of $9.7 thousand. Over 100 eligible families who had applied for the subsidy were unable to receive grants due to limited appropriations; the waiting list increased annually at a rate of 60 families per year. The Department requested an additional $852,400 in funding for the FY 1988 and FY 1989 budget to increase the number of families served and reduce the need for out-of-home placements. Unfortunately other state spending priorities precluded additional funding for this program.

MISSOURI

The Division of Mental Retardation and Developmental Disabilities funded a wide range of in-home services including: general respite, respite for behavior training, specialized medical respite, three levels of homemaker services, nursing services, attendant care, parent training and in-home early intervention/infant stimulation. In 1987, an additional appropriation of $500,000 was made to expand in-home services through the "home care program." The data included in the survey did not represent total expenditures for services to families provided in the home. Many services such as infant stimulation, physical therapy, early intervention, consultations, and behavior management were provided either in the home or in a community agency. The Division accounted for many of these services by "type" rather than by the setting in which they were provided.

MONTANA

Montana had several programs that offer family support to families caring for children with

MR/DD. They included family training, specialized family care; respite care; evaluation and diagnosis, and adaptive equipment. Family Training Services provided natural or foster families with the resources and services needed to maintain a family member with developmental disabilities at home. These services included family training in special skills, behavior interventions, and obtaining services; client training by qualified providers; service coordination; and information and referral services. Specialized family care was designed to prevent out-of-family placements and to create movement from more restrictive settings back to family settings. Services were specialized for each family but all included case management, resource services, and purchase of subcontracted services. The program was available to children living in natural homes, foster homes, group homes, nursing homes, and institutional settings. Respite Care Services were provided to natural or foster parents who had a family member with developmental disabilities (or "at risk") living at home. Respite care providers maintained a current list of individuals qualified to provide respite care to families. The respite care providers were also responsible for disbursing funds to families for respite use. The maximum payment to each family was $360 per year. Evaluation and diagnosis services included intake, case coordination, evaluation, case-conferences, treatment planning, interpretation and follow along. An Adaptive Equipment program was designed to provide specialized adaptive equipment and program consultation to individuals who were developmentally disabled. The program goal was to enhance client ability in functioning and self-care and was only used when local resources were not available. The Developmental Disabilities Division made arrangements with private contractors to provide necessary services.

NEBRASKA

The Department of Public Institutions' Community Services Program initiated an *In-home Support Program*. The program offered a variety of services designed to promote the maintenance of individuals with developmental disabilities in natural home settings. Services were provided through contracts with community agencies.

The Disabled Persons and Family Support Act (Chapter 154, Laws of 1981, N. S.), as described in the Bates (1985) report, established a program for families providing support to a family member who is disabled living at home or returning to the home, and persons with disabilities who are living independently. This was a combination support services and cash subsidy program. The program was developed to meet the following objectives: 1) to make services necessary to allow persons with disabilities to remain at home available to families caring for persons with disabilities; 2) to encourage employable persons with disabilities to seek employment and ultimately become self supporting; and 3) to promote cost effective health care alternatives to persons with disabilities. The program served individuals who were medically determined as having severe, chronic disabilities attributable to mental and or physical impairments. Approximately 50% of services were provided to the persons who were developmentally disabled. The program was administered through the Department of Social Services, Aged, and Disabled Unit and covered home modifications, attendant care, family and client counseling and training, transportation, homemaker and home health aide, and respite care services. Families or persons with disabilities received a maximum subsidy payment up to $300 per month, averaged over any one year period. The payments were based on family income and availability of appropriate services through other support programs. The Department of Social Services mades payments directly to the family head, person with disability, or the qualified program or service provider. Expenditure information for this program was not available.

NEVADA

The 1981 Nevada State legislature established the *Home Care Program* (NRS 435. 365). The Home Care Program was designed to prevent institutional placements of persons who are profoundly mentally retarded or severely handicapped. The program was administered by the Department of Human Resources, Mental Hygiene and Mental Retardation Division. Cash subsidies were determined by income, family size, assets and liabilities, degree of disability and was not contingent upon eligibility for other federal or state programs. The assistance payment was designed to give families the flexibility in securing needed services; decisions regarding services were determined exclusively by the caregiver. Families were not required to submit invoices, vouchers, or other expense records to the Division. However, a social service worker maintained quarterly contact to determine that services were being used for the purposes outlined in a financial ability statement.

NEW HAMPSHIRE

New Hampshire's family support program consisted primarily of respite services. In addition, a small program of collateral services such as adaptation of the family's home and special equipment was operated. In 1988, 1,285 individuals with MR/DD received family support services. The total expenditures for this program were $936,174 from state general funds.

NEW JERSEY

New Jersey provides family support services through the *Home Assistance Program.* The program was funded as a subset of the Social Supervision and Consultation line item in the Department of Human Services Executive Budget. The Home Assistance program was initiated in 1976 to provide services to assist families in meeting the special needs and responsibilities of maintaining persons with developmental disabilities at home. Any person with developmental disabilities was eligible to participate in the program if they met the financial criteria and the need for specific services had been documented and was unavailable through other resources. Services provided by the program included respite care, homemaker and home health aide, intervention services, and assistive devices. Respite care and homemaker and home health aide services were limited to a maximum of 270 hours (30 days) to each family for the fiscal year; there was no limit, however, to intervention services or assistive devices. The Home Assistance program was administered by the Department of Mental Retardation at four regional sites. Regional offices and/or the Central office subcontracted the majority of the direct services with individual providers, homemaker and home health aide agencies, and group homes; some were subcontracted to Associations for Retarded

Citizens.

NEW MEXICO

The Health and Environment Department's family support services were represented by respite services. Total FY 1988 respite funds were $187,800. A "parent training project" which provided home training, counseling, transportation, and other related services for parents of children with MR/DD under 5 years of age was also offered by the HED; however, the program was not considered a family support service per se, and was excluded from the survey data.

NEW YORK

In 1985, New York's family support services were provided through the *Family Support Services Demonstration Program* (Chapter 461, Laws of New York, 1984) and a home care program. Family services were revised to develop the current Family Support Services initiative. This initiative provided a comprehensive range of services directed toward assisting families who have family members with developmental disabilities living at home maintain integrity as a family unit. The program provided services through a network of 350 voluntary providers. The range of services included recruitment of providers, case management, family counseling, client counseling, family and caregiver training, outreach and referral services, respite care, home habilitation, homemaker services, crisis intervention, recreation, transportation, and others as needed. The program provided a substantial amount of respite care (FY 1986: 450,747 hours) in ten "free standing" respite facilities. New York was committed to expanding the program on a statewide basis. This commitment was reflected by: 1) a $3 million increase in budget allocations; 2) an average cost per family increase from $870 to $1,000; 3) an RFP for the development of new respite services; 4) discontinuation of the local match (100% state-funded) and 5) the development of a developmental disabilities training program for home care personnel.

NORTH CAROLINA

The Division of Mental Health, Mental Retardation, and Substance Abuse provided "home mobility aids" and "respite care." There were three types of respite care services: "center based," "private home," and "companion." The center-based programs were similar to a group home environment with five to eight individuals served in each center. Private home respite was provided in the homes of certified individuals. Expenditures for companion services paid qualified individuals to go to the home of a client and provide respite service. In 1988, there were 1,369 individuals served by respite services.

NORTH DAKOTA

North Dakota's Family Subsidy Program objective, as outlined in chapter 75-04-04, section 1-10 of the North Dakota Administrative Code, was to enable developmentally disabled children to remain in or return to the homes of their families. The program provided families with the financial resources needed to meet the extraordinary financial obligations that resulted from their child's disability.

There were two types of financial assistance available through the subsidy program, a basic care subsidy and reimbursement for service costs. Families accepted into the program received $15 per week for the basic care of their child. Subsidy payments were made monthly for the basic care subsidy; there were no restrictions on the use of this money.

The service reimbursement allowed families to receive an additional $35 per week for services or treatments that were outlined in the child's individual habilitation plan. Parents signed a habilitation contract and received reimbursement for services only after providing the case manager with a written statement that itemized the expenditures or obligations incurred by carrying out the IHP.

In order to receive assistance through the Subsidy Program, parents (natural, adoptive or legal guardian) had to care for a child with developmental disabilities in their home. Included were parents who wanted children returned to the family from an institution. The child remained eligible for the program until age 22. Level of income earned or resources owned by the family unit was considered in program eligibility. Applications were sent to the Regional Human Service Center where they were assigned to a case manager who in turn certified the applicants' eligibility. A case manager was assigned. Duties included: assessing the child's functional level; gathering all available evaluation data (medical, psychological, educational); and organizing an interagency habilitation team. The habilitation team consisted of the referral source, potential service providers, the child, parent, and others who were necessary for development of an individual habilitation plan (IHP). The habilitation team recommended appropriate services, service settings, and treatment. They were also responsible for recommending changes in level of service, service setting and eligibility status. The habilitation team certified eligibility by signing the IHP.

After the process was completed the parents were offered a contract establishing a funding level consistent with the services outline in the IHP. Families went through a recertification process yearly. The Department of Human Resources developed the following priority for assistance: 1) families currently in the program who are reapplying; 2) individuals on the waiting list; 3) new applicants with children who are currently institutionalized; 4) applicants with children who are determined to have multiple handicaps.

OHIO

The *Ohio Family Resources Program* was enacted in January 1983 (Sections 5123. 171 and 5126. 11, Ohio Revised Code). The program enabled persons with mental retardation or developmental disabilities to remain with their families or return to their homes. The program also provided services to children and adults with disabilities who were currently residing in the community and who are not receiving other services from county boards. The Department of Mental Retardation and Developmental Disabilities allocated funds to the county boards. These county boards provided reimbursements to the individual or family for approved and documented services. Reimbursements were adjusted for income with a maximum annual rate of $2,500 per person or family. The maximum rate was adjusted for more populous urban areas (i.e., Cincinnati, Cleveland). Reimbursable services included respite care, family counseling and training, special diets, special equipment and home adaptation.

OREGON

Oregon was planning to initiate a family support pilot program in FY 1989. The pilot consisted of three projects: a service program in an urban area, a second program in a rural area, and a third program located in a semi-rural setting. The program was designed to have families and family consultants (case manager) develop a plan of needed services as well as strategies for assisting in costs and obtaining the necessary services. The estimated allocation for FY 1989 was $246,000 in state funds and $364,000 from the Federal Developmental Disabilities Services Grant. Funds were disbursed through contracts with community agencies. The pilot was intended to provide services to approximately 150 families.

PENNSYLVANIA

The *Family Resources Services Program* (P.L. 96.50; P.S.; Secs. 4101 et. seq.) existed as a separate programmatic entity within the Department of Public Welfare; budgeted funds however, were subsumed within the larger "Community MR Services" classification of the executive budget. The program was designed to reduce the need for institutionalization and to promote resources that enable individuals with mental retardation to remain at home with their families or to live independently. Program services included: respite, family aid-sitter or companionship services, homemaker services, in-home therapy, family education and training, recreation and socialization services, hearing evaluations, communications training, mobility training, adaptive appliances, home rehabilitation and renovations, and special diet assistance.

RHODE ISLAND

Rhode Island's program was originally established in 1978 for individuals residing in two state institutions. In 1984, the law governing this program was amended to assist individuals residing in other public institutions and other settings. The program was established with the purpose of providing financial assistance or subsidy aid that would make available noninstitutional care, and support and training when it was in the best interest of the health and welfare of the individual.

Individuals who were residents of state mental health and mental retardation facilities for a period of 90 days or more were eligible for participation in the program. Included were individuals who were at risk of placement in a institution. The definition of "handicap" included individuals who were mentally ill, developmentally disabled, or had a long-term chronic impairment that created dependence on others for basic functions of daily living, and individuals with severe behavior problems requiring constant supervision. The program was developed to serve both children and adults. To receive a subsidy the parent or guardian must assume responsibility for care, custody and control of the individual in the parents' place of residence. Care referred to personal care or supervision of activities essential to daily functioning.

When parents were determined eligible to receive the subsidy, an agreement with DMHMR was signed clearly outlining the terms of the subsidy. A general service plan was developed to prioritize each individual's needs. The plan provided the framework through which individual progress could be assessed. Basic areas covered in these professional assessments were: health, physical, mental, social, educational, vocational and leisure needs. Parents were responsible for making written reports every month during the first year and periodically (at least semi-annually), thereafter.

Subsidy payments ranged between $25 and $60 a week for basic care and $5 and $15 a week for training. These amounts were in addition to basic payments made to foster parents. Subsidy payments were authorized for needs that were not met through SSI or other programs. The program required documented evidence that the individual could not be maintained in the home without the subsidy. Eligible families' incomes could not exceed 400 percent of the federal poverty guidelines for a family of their size, including the disabled individual. Contacts were reviewed and redesigned on an annual basis. Services included: respite care, homemaker services, early intervention, assistive services, home modification and others as outlined in the general service plan.

SOUTH CAROLINA

The Department of Mental Retardation funded a statewide *Family Care Program*. This program was developed in order to assist families of children and adults who had MR/DD with the cost of special services related to their family member's disability. The goals of this program were to avoid institutionalization whenever possible and to give individuals residing in institutions the opportunity to return home. Eligibility was based on financial and service need. Families could receive up to $150 per month, as determined by a case manager who assisted them develop a service plan. Families could receive a lump sum of up to $1000 for special service needs. Monthly subsidies were used to purchase sitter services, adaptive devices, medications, special diet, medical costs, transportation, and physical therapy. Respite services were provided through contracts with private agencies.

TENNESSEE

Department of Mental Health and Mental Retardation based family support services were represented by respite programs, offered through the "community residential" program. An estimated 187 individuals were served in FY 1988 at a cost of $105 thousand.

TEXAS

Family support services provided through the Department of Mental Health and Mental Retardation consisted of: (a) respite services (approximately $1.3 million in FY 1988), (b) H.B. 1154, the "In-home and family support program," established in FY 1987 to assist persons with MR/DD live at home (approximately $1 million in FY 1988), and (c) "family support services," that were composed of a variety of service and fiscal supports for families (approximately $7.4 million in FY 1988). The "in-home and family support program," in its developmental phase, was a purchase of service program providing up to $3,600 to each family in purchased services through the local Community Mental Health and Mental Retardation Center boards. There was a co-payment based on family income. A total of $2 million was appropriated for mental health and mental retardation service populations.

UTAH

Over the last two years, Utah's Division of Services to the Handicapped has developed a program of services that will assist families in maintaining a family member with developmental disabilities in the home. The program provided the intensive training, respite care, and support families needed to reduce stress and enhance the quality of life of their disabled family member. The program provided services in small group home and foster home settings, but the Division of Services had recommended that a similar support system be developed for natural families. Anticipated services included family training in handicaps and behaviors, respite care, access to day services, crisis intervention, and access to professional trainers. The small amount of funds that were budgeted for family support and respite were usually exhausted early in the fiscal year and were not sufficient to develop a program to divert individuals from "full time residential services." A pilot project in Attendant Care was funded by the FY 1986 Appropriations Act. The program served 22 persons with handicaps and provided a subsidy of $300 - $500 per month to each individual. Subsidies were determined by the amount of care required. Attendants provided any personal care necessary to enable the person with disabilities to remain in their own home. Each individual was responsible for hiring, supervising, and paying their attendant.

VERMONT

Vermont's *Family Support Services Program* was initiated in 1978 as a pilot program in one county; it had developed into a statewide program by 1988. The program provided limited support for families caring for a family member with mental retardation at home. Services included respite, adaptive equipment and physical therapy. To receive respite services, individuals with mental retardation had to live with parents, relatives, legal guardians or in a specialized foster care setting. There were no family income restrictions. However, when maximum service levels have been exceeded, services were provided on a sliding scale fee. The Department of Mental Health, Community Mental Retardation Programs, provided services through contracts with the state's ten community mental health agencies. These agencies administered the program at the local level. A maximum of 330 hours or 31 days of respite care was available to families; an additional 880 hours or 77 days were available on a sliding fee basis. The state reimbursed community agencies for actual costs of adaptive equipment and physical therapy.

VIRGINIA

In January, 1987, Virginia's Department of Human Resources initiated the *Family Support Project* (FSP), a two-year pilot designed to provide systematic support to families, or family sponsors, who have a family member with disabilities living in the home. FSP provided financial reimbursement for supplies, equipment and services (i.e., respite, recreation, etc.). The objectives of the Family Support Project were: (1) to improve and enhance the quality of life for persons with mental disabilities by strengthening the family's capability to care for their family member; (2) to make it possible for families to choose to have their family member with mental disabilities remain in, or return to the home; (3) to support the most severely disabled and their families; and, (4) to ease the stress of day-to-day demands on families. Families received up to $3,600/year for each family member with disabilities, regardless of age.

WASHINGTON

The Division of Developmental Disabilities had a family support program that consisted of "respite care," "attendant care" (regular ongoing personal care), and "therapeutic services" (behavioral, communication, occupational, physical, and transportation and equipment), to help families cope with a child's difficult behavior. In fiscal year 1988 the program provided services for 900 families. The expenditures for the Family Support program in FY 1988 were $2,466,094.

WEST VIRGINIA

The Office of Behavioral Health's discretely funded family support services were limited to respite programs provided through the local community mental health centers. FY 1988 funding was approximately $115,000.

WISCONSIN

The Wisconsin Family Support Program began as a demonstration project in 1984. In 1985 the State Legislature continued the program through a State Budget Law. The program's objective was to give families caring for individuals with developmental disabilities the necessary supports for home care. Families wishing to keep their child at home or return a child to home from an institutional setting were eligible to receive financial assistance as well as other necessary community services.

The program provided up to $3,000 per year for each child. Additional funding could be approved upon request from the family through the county boards. Eligibility for the program was established through a needs assessment. Although there was no income cap for eligibility, families could be required to share some of the costs for services. Services outlined in the family plan were paid for directly by the agency, or the family was given a subsidy to cover costs. Receipts for services had to be retained.

Administering agencies could request approval through the Division of Community Services to provide assistance to families through the transition to adult living (21 to 24 years of age). A severe disability, as defined by the state, was a diagnosed physical, emotional, or mental impairment, characterized by the need for individually planned and coordinated care, and likely to result in functional limitations.

Eligible families consisted of at least one disabled child and parent. A "parent" was defined as the natural, adoptive, guardian, legal custodian, or other person acting as the parent. The program was administered by county human services, developmental disabilities, or mental health/DD and alcohol & drug abuse boards. County participation was voluntary.

In addition to assisting families, the program helped to coordinate other services: architectural modifications to the home, child care, counseling, dental and medical cost not otherwise covered, specialized diagnosis and evaluation, specialized nutrition and clothing, specialized equipment and supplies, homemaker services, in-home nursing and attendant care, respite care, recreation for child and family, transportation, specialized utility costs, vehicle modifications, OP/PT, and other services as determined necessary by the Dept. of Health and Social Services. State legislation required 90% of the funding allocated to the programs be spent directly for services; the remaining 10% was used to cover administrative and staffing costs.

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