

**COMMUNITY
AND
FAMILY SUPPORT
SYSTEM PLAN**

Louisiana State Planning Council on



DEVELOPMENTAL DISABILITIES

Nan Kemp

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**COMMUNITY AND FAMILY
SUPPORT SYSTEM PLAN**

**Prepared by the
Advisory Committee on the Community and Family Support System
and
Louisiana State Planning Council on Developmental Disabilities**

**In Collaboration with
Human Services Research Institute**

Report prepared pursuant to Act 378 (1989 legislative session)

October 15, 1990



DEVELOPMENTAL DISABILITIES

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October 15, 1990

The Honorable Alphonse Jackson, Jr.
The Honorable Gerry Hinton
The Honorable B. B. Rayburn
Louisiana State Legislature
Capitol Station
Baton Rouge, LA 70804

Dear Gentlemen:

I am pleased to present the Community and Family Support System Plan to the House Committee on Health and Welfare, the Senate Committee on Health and Welfare and the Joint Legislative Committee on the Budget, as authorized by Act 378 of 1989. This Plan has been written as a result of the hard work and vision of many Louisiana citizens. The Advisory Committee of the Community and Family Support System Plan, charged with the task of developing this Plan, was comprised primarily of parents of children and adults with developmental disabilities and individuals with disabilities. This group devoted countless hours over a 12 month period to participating in meetings, researching areas of concern, organizing community forums across the state to listen to what other families and individuals needed in the way of services, and making recommendations. All of the work was done with an attitude of serious dedication and determination.

Now the most challenging task, translating this plan into actual supports and services for persons with developmental disabilities, lies before us. On behalf of individuals with developmental disabilities and their families across the state, I urge you to study this report carefully and begin the steps necessary to begin implementation of this Plan.

Sincerely,

Kay Marcel
Chairperson

KM/pd

TABLE OF CONTENTS

	Contributors	i
I.	Background	1
II.	Information on Programs in Other States	3
	Introduction	3
	Family Support	3
	Community Supports for Adults	7
III.	Recent Funding Opportunities and Initiatives	9
	Early Periodic Screening Diagnosis and Treatment	9
	Tax Equity and Fiscal Responsibility Act (TEFRA)	9
	Supplemental Security Income (SSI)	10
	Early Intervention Program for Infants and Toddlers	10
	Vocational Rehabilitation	10
IV.	Louisiana Programs	11
	Family Support Services	11
	Supports for Adults	13
V.	Proposed Provisions	15
	Family Support Services	15
	Adult Support Services	21
	Evaluation and Performance Indicators	25
	Overall Cost Effectiveness	27
	Funding Strategies	30
	Estimated Costs and Funding Phases	32
	Phases of Implementation	39

VI.	References	44
VII.	Appendices	46
	Appendix A. Act 378 of 1989	47
	Appendix B. Sliding Fee Scale Methodology	57

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I. BACKGROUND

1988 The impetus for the development of a family and individual support agenda in Louisiana came in 1988 when the Louisiana Planning Council on Developmental Disabilities sponsored their first Community Integration Conference. Speakers presented information on state-of-the-art programs from across the country. With this information as a foundation, parents, adults with disabilities and advocates developed a vision of a service system that provides families with the supports they need to keep their children at home and that gives adults supports in their homes so they do not have to move to a specialized program to receive services. At the end of this conference, participants were excited and enthusiastic and resolved to work together to bring about changes in the Louisiana human services system. They organized a group called LaCAN, Louisiana Citizens for Action Now!, which is comprised of parents of people with developmental disabilities and representatives of various advocacy groups such as the Developmental Disabilities Council, Association for Retarded Citizens of Louisiana, Legislative Action for Disabled Persons, the Advocacy Center for the Elderly and Disabled and Project PROMPT.

Created to enhance services in Louisiana to better meet the needs of individuals with disabilities and their families, the members of LaCAN drafted vision statements outlining the principles of the supports and services they needed. Regional forums were held across the state to present the vision statements and obtain comments from families and people with disabilities. The vision statements were used as the basis for drafting legislation which was submitted and passed during the 1989 Legislative Session.

Act 378 of 1989, the Community and Family Support System, calls for the development of a plan for a system of community and family supports for persons with developmental disabilities and their families, and provides for implementation of the plan by the Department of Health and Hospitals in cooperation with the Department of Social Services. (See Appendix A.) Implementation of this plan is to begin July 1, 1991 with full implementation by July 1, 1993.

Act 378 specifies that services for persons with developmental disabilities should be responsive to the needs of the individual and his family, rather than fitting the person into existing programs. The Act further states that it is more cost effective to provide services to adults and children with developmental disabilities living in their own home or with their families rather than in out-of-home placements.

Two basic principles are outlined in the act:

Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. As with all children, children with developmental disabilities need families and family relationships to develop to their fullest potential.

Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens.

Act 378 specifies ideals and guiding principles for the development of the Community and Family Support System Plan and lists an array of community and family supports that will be made available to families and adults. The Act also has very specific time frames for the development and implementation of this plan.

The plan is to be written and submitted to the Secretaries of the Department of Health and Hospitals and the Department of Social Services by August 1, 1990. The Secretaries will review and approve the plan and submit it to the Senate Committee on Health and Welfare, the House Committee on Health and Welfare, and the Joint Legislative Committee on the Budget by September 1, 1990. The Secretary of the Department of Health and Hospital, with any necessary cooperation from the Secretary of the Department of Social Services will begin implementation of the Community and Family Support System Plan by July 1, 1991, with full implementation by July 1, 1993.

The Louisiana State Planning Council on Developmental Disabilities had responsibility for the development of the plan to implement a Community and Family Support System. As authorized under the Act, the Council appointed an advisory committee to assist in the planning process. The advisory committee included parents of children and adults with developmental disabilities, adults with disabilities, and representatives of the various agencies responsible for the implementation of the plan. The advisory committee formed four work groups to address the specific components of the Act dealing with eligibility, funding, services and service coordination, and outreach and point of entry. The full advisory committee met bi-monthly to provide recommendations for the plan.

The document that follows is the legislatively mandated plan. It includes information on other state family and individual support services, federal funding opportunities to finance such programs, an overview of the current service system in Louisiana, specific recommendations for system change, and a discussion of the cost effectiveness of the proposed recommendations. Recommendations address such issues as eligibility criteria, methods of service provision, sliding fee scale, application procedures, the service coordination system, and performance indicators that will measure the effectiveness of the Community and Family Support System.

II. INFORMATION ON PROGRAMS IN OTHER STATES

Introduction

Prior to describing the specific aspects of the Community and Family Support System Plan for Louisiana, it is important to discuss the larger national context and the changes in the state-of-the-art that are indicative of the directions reflected in the Plan.

Family Support

Frustrated by the lack of opportunities and services, parents have historically initiated programs for their sons and daughters with mental retardation and other disabilities. Parents continue in this role by working to increase the opportunities for their children's community participation. Persons with developmental disabilities and their families have for too long been separated from and closed out of their communities.

Best Practices in Family Support. Family support is a concept that is idiosyncratic and defined by individual family needs. When conceptualized in this family-centered fashion, it offers flexibility in service options and delivery, focuses on the entire family, changes as family needs change, encourages families to use natural community supports, and provides a convenient and central access to services and resources.

The first and primary natural environment for all people is the family. To say that children belong in families and that those family connections are of lifelong and primary importance states the obvious. However, only in recent years has public policy begun to recognize that persons with developmental disabilities are entitled to the same basic human rights as other citizens and that first among these is the right to be part of a family. This represents a clear break from earlier times when families were strongly encouraged by medical and social service professionals to seek institutional placements for children born with severe disabilities (McKaig, 1986).

During the childhood years, over 90% of persons with mental retardation and other developmental disabilities live with their families. However, changes in the American family -- increased numbers of working mothers, more single parent families, smaller family size, and lack of available extended family -- would indicate families may have diminished resources at their disposal to provide the care required by their family member with a disability (Agosta & Bradley, 1985). These demographic changes, coupled with the fact that children with severe, multiple disabilities, and complicated medical conditions are surviving past infancy and living at home, all point to the need for more and better support of families.

It is to the credit of grassroots lobbying efforts by families that the concept of family support is beginning to be accepted at both state and national levels (Smith, Card, & McKaig, 1987). Parents who have advocated before Congress, their state legislature, and the boards of regional and local service agencies have been successful in initiating or expanding the support and services available to families caring for children with mental retardation or other disabilities. As service systems begin to change, families will increasingly demand to be included in the design, implementation, and monitoring of family support programs.

State-by-State Analysis. More and more states, with guidance and/or pressure from parents, have begun to recognize their responsibilities to families and are increasing the support and services they provide. In 1972, Pennsylvania became the first state to initiate a family support project. Currently, all but a handful of states provide some form of support to families who have children with mental retardation or other disabilities. These services reflect the guiding values of family and community focus, parent control, and flexibility which are intrinsic in the emerging approach to supporting families. They fall into the following eight distinct categories (Knoll, Covert, Osuch, O'Connor, Agosta, and Blaney 1990).

- 1) **Respite and child care** is the most available support service with 46 states making some provision in this area. As with most supports there is wide variability in what is actually available to families. In some states this service may be restricted to one form of respite no more than 10 days a year. Yet other states provide for a variety of respite options, child care support, and assistance in finding sitter services for both the child with the disability and children without a disability.
- 2) **Environmental adaptation** is provided as a family support in 32 states. This category of support ranges from states where the public sector completely covers the costs associated with making a home fully accessible and obtaining adaptive equipment to states where partial reimbursement is provided for a portion of the costs associated with these needs.
- 3) **Supportive services** are provided in 27 states. These supports can take multiple forms ranging from traditional individual counseling for parents to self-help groups including family support groups, sibling groups, and family counseling services.
- 4) **In-home assistance** is allowed, in some form, as a family support in 26 states. This mode of support provides either for: a) outside assistance to help in the care of the person with a disability, so the primary care-giver can look to the other needs of the family, or b) assistance with the typical household activities, so the family members can see to the needs of the family member with a disability.
- 5) **Extraordinary/ordinary needs** are covered under family support policy in 26 states. There is extreme variability here, particularly since states with cash subsidy programs or very flexible voucher programs see these needs as being covered by those funding mechanisms. Even states with less flexible approaches, however, recognize the fact that the specialized needs of a child with a disability may substantially increase the cost of rent, health insurance, utilities, food, clothing, and so forth.
- 6) **Training** for parents and other family members is covered as a family support in 24 states. This training can vary widely in focus from information related to disability to information related to individual advocacy and systems change.
- 7) **Recreation** is an allowable family support activity in 14 states. In some states this takes the form of special camps and special recreation programs but in an increasing number of states this activity assists families to gain access to the recreational resources that are typically available in their communities.

8) **Systemic assistance** is identified in 11 states as a family support service. This category includes the provision of information to families about the resources that are available to them and, in at least 5 states, direct assistance to assure that families receive all of the services to which they have a right. In several of these latter states, this advocacy activity is consciously aimed at moving other components of the service system into line with family-centered principles.

In the last several years, increasing attention has been paid to financial assistance as a mode for providing flexible family supports. Twenty-five states offer some form of financial assistance to families. Currently, in eight states the only state funded family support is provided by some form of financial assistance. Finally, 17 states use some combination of financial assistance and services to provide support for families.

Key Components. While support to families may take a variety of forms, the major goals of family support programs are to: 1) deter unnecessary out-of-home placements, 2) return persons living in institutions back to a family setting, and 3) enhance the care giving capacity of families (Agosta & Bradley, 1985). The Wisconsin Department of Health and Social Services (1985) gives the following explanation of their Family Support Program:

The program is intended to ensure that ordinary families faced with the extra-ordinary circumstances that come with having a child with severe disabilities will get the help they need without having to give up parental responsibility and control.

In order to ensure that family support programs remain responsive to family needs and circumstances, there are several elements in the design of family support efforts that are important. These eight major structural components have been documented in a 50 state survey conducted by the Human Services Research Institute (Knoll, Covert, Osuch, & O'Connor 1989). None of these individual components guarantees that the ideals of a parent-controlled family-centered approach will be realized. It does seem, however, that the more energy a state or region devotes to these complex issues, the higher the likelihood that it will have a well articulated system of family supports.

1) **Regional control.** At least 32 states indicated that their approach to family supports placed a great deal of control at the regional or county level. In some cases this control was on the level of managing distribution of benefits or providing services; in others the regions or counties, because of their degree of fiscal and programmatic autonomy, actually defined what family support meant in their area. The positive side of this practice places control of resources closer to families. The down side of this approach is it leads to a great deal of regional variation in the benefits available to families.

2) **Central role of case management.** In at least 23 states a person called a case manager plays a central role in the system of family supports. An awareness of a need for professional expertise to assist families in obtaining benefits and services underlies this role. However, there is incredible state to state variability in how the role associated with this job title is defined. In some cases the role is only nominal, as case managers do little more than occasionally refer families (usually those in crisis) to potential services. In other states the case manager is in a very strong position and actually determines what benefits a family needs and gets. Finally, in a small but increasing number of states, the person works in close collaboration with families as their guide through the complexities of the service system.

3) Parent advisory boards. Eighteen states attempt to respond to parents and family members by assuring that they have a high degree of visibility and have a voice on the advisory board that oversees state and/or local family support efforts. In some instances, these boards are really only advisory in nature, although most of the informants indicated that the policy makers do listen to them. In several states these boards are more than merely advisory and are empowered to make policy for the family support program.

4) Individualized family support planning process. There is obviously some sort of planning process associated with every family support effort. Seventeen states pointed out that they had articulated an individualized family support planning process that every eligible family goes through before receiving benefits. Some of these processes were an extension of the Individualized Program Plan which was required for the family member with a disability. Others were, in fact, a field test of the planning process to be used in the state's implementation of PL 99-457. A number of states have developed a process which was specific to their family support effort and focuses on attempting to actualize the ideal of family control.

5) True decision making in the hands of parents. This policy or practice may on its face seem somehow redundant given the description of some of the emerging family-centered approaches to case management, planning, and the role of family advisory boards, but fifteen states have felt compelled to mandate this in the laws, regulations, or guidelines for their family support effort.

6) Use of local agencies. This approach to services is different from the regionalized approach mentioned above. This practice points more to a privatization of family support efforts, since twelve states use local private for-profit and not-for-profit agencies as their principal vehicle for managing and/or providing family supports. In a very few cases this effort has led states to expand beyond the traditional specialized services to some of the generic resources of the community as principal family support resources.

7) An appeal process. Five states have established a process for families to appeal any dispute they may have regarding determination of eligibility or other aspects of family support practice to a higher authority.

8) A mechanism for quality assurance. Only five states indicated that they have established or were planning to establish a formal mechanism to assure that services provided as family support met certain minimum standards of quality. Most states left the entire issue of quality exclusively in the hands of families with little or no recourse other than to either find a new provider or discontinue receiving a service if they felt it was of poor quality.

Medicaid Policy. A major determinant of a state's overall commitment to supporting families can be seen in whether Medicaid policy has been used to finance family support. But the presence of a single waiver does not demonstrate a family focus. The focus is on the degree to which a state has taken a family support perspective on the use of Medicaid. In other words, has the state made it easier for families of people with disabilities to obtain benefits under Medicaid either through use of the wide range of options available under regular Medicaid or through the various waiver options. Reviewing descriptions of family support programs across the country, the five following policy directions emerge:

- o Twenty states indicate that Medicaid is not used to provide family support nor is this policy under review;

- o In five states, currently not using Medicaid to underwrite family supports, that policy is actively under review;
- o Four states indicate that they are in the initial stages of implementing new options which allow Medicaid to cover some family supports;
- o Eleven states indicate that they regard Medicaid as one mechanism for supporting families and they make relatively limited use of it to support activities such as respite or case management; and
- o Ten states see Medicaid as a major source of supports to families and are currently making or planning to make extensive use of it to achieve that goal.

Community Supports for Adults

With supports, adaptations, and acceptance, all natural environments can be open to people with disabilities, even persons with severe disabilities. Community integration means more than just being physically present in the community. It means opportunities and, when necessary, the provision of support to citizens with disabilities in order to make them active participants in the life of the community. Documented best practices in the field have shown that individuals with disabilities can be fellow classmates, good neighbors, contributing co-workers, and involved citizens.

The following principles should govern the conduct of any program of individualized supports for adults with developmental disabilities. First, community living can be accessible to all persons with disabilities, without exception. Everyone has the right to a home. A facility is not a home. Housing options need to be flexible, individualized, and offer adequate support to enable persons with disabilities to truly participate in the life of the community. Second, in addition to being integrated into real neighborhoods, individuals with disabilities should be given the opportunity to be integrated into work and community settings.

Third, people with disabilities and their families need to be provided support (financial, social, and professional) to live in the community. Fourth, individuals with disabilities should be given opportunities to learn. This includes opportunities to learn an array of social, educational, communication, and vocational skills that enable the person to function more independently. Finally, individuals with disabilities should be actively involved in the design, implementation, monitoring, and evaluation of services. This helps to ensure that individual needs are met and personal desires are attained and maintained.

The evolution of a right to community living was set by two landmark cases: Wyatt v. Stickney (1972) that embraced the concepts of normalization and least restrictive environment; and Halderman v. Pennhurst State School and Hospital (1977) that required deinstitutionalization. Community living options for individuals have increased dramatically in the past two decades. In 1967 the overwhelming majority of individuals with disabilities who were not living with their families resided in large state institutions; by 1986 the majority of individuals in this category were living in community facilities and residences (Lakin, Hill, White, & Wright, 1988). However, it is important to note while increasing numbers of individuals with disabilities may be living in communities, they are not necessarily integrated into or active participants in community life (Kregel, Wehman, Seyfarth, & Marshall, 1986). Programs and residences can easily be located in the community without being integrated (Bachrach, 1981).

Large congregate facilities, rather than homes, continue to be the primary residences for individuals with mental retardation and other disabilities who do not live with their families (Bruininks, Kudla, Hauber, Hill, & Wieck, 1981; Lakin et al., 1988). The distinction between home and facility is an important one to make. No one would ever choose to live in a facility. With few exceptions, persons living in housing provided by social service agencies did not choose where they live or with whom they live with. Because services are determined by the type of facility, a change in service needs necessitates a move by the individual. Individuals are denied the opportunity to establish permanency or roots in their communities. Furthermore, with housing owned and controlled by service providers, residents develop neither a sense of ownership nor a feeling of "home" about where they live.

In contrast, supported living programs provide flexible, individualized housing options that encourage persons with mental retardation and other disabilities to exercise control and choice in their living arrangements. Supported living is defined as persons with disabilities living where they want and with whom they want, for as long as they want, with the ongoing support needed to sustain that choice (Ferguson & Olsen, 1989). Some exemplary supported living programs include Options in Community Living, in Wisconsin; Centennial Developmental Services in Colorado; and the Supported Placements in Community Environments (SPICE) program in Illinois. Features shared by these programs include: 1) paid support provided by live-in or on call staff, roommates or companions, attendants, or neighbors; 2) individualization and flexibility; 3) a focus on the individual; 4) a belief that people live in homes not facilities; and 5) consumer and family involvement in planning and quality assurance (Nisbet, Clark, & Covert, 1990).

Options, a private non-profit agency in Madison, Wisconsin provides residential support services to 95 men and women who have developmental disabilities. In operation since 1981, Options provides support and coordinates services to enable adults to live on their own in small, dispersed settings in the community. The agency works with people to help them make their own choices and reach their own goals, with support available to them as often and as long as it is needed. Options is the oldest of such programs in the country and is considered to be the leader of this growing movement.

The State of Colorado has several supported living programs in operation successfully assisting adults with disabilities to live in residential settings of their choice. In Illinois, the SPICE Project (Supported Placements in Integrated Community Environments) is a program that is actively moving people with disabilities out of nursing facilities into their own one or two person homes. SPICE was designed to demonstrate that people with multiple and severe disabilities can live outside of congregate settings if they are provided with appropriate services and supports and to demonstrate a more individualized approach to residential services. Funded through a Medicaid waiver, SPICE serves 40 people throughout the state and has targeted people with multiple and severe disabilities who have not traditionally been considered for community placements.

Additional supported living programs for persons with disabilities include Supervised Apartments in Region V, Nebraska; Seven Counties Services in Louisville, Kentucky; Residential, Inc., New Lexington, Ohio; and Beta Hostels in Attleboro, Massachusetts.

III. RECENT FUNDING OPPORTUNITIES AND INITIATIVES

In considering the ways in which the proposals in this plan can be funded, it is important to review several recent federal initiatives directly relevant to the provision of services to persons with disabilities and their families. They are described below.

Early and Periodic Screening, Diagnostic and Treatment Services (EPSDT)

One recent federal initiative will have a substantial impact on the availability of health care to children with disabilities. EPSDT, a long-standing provision of the Medicaid program, requires that all children under age 21 who are Title XIX eligible must be provided with health screening and treatment necessary to remediate any detected conditions. Specifically, EPSDT requires that states provide a comprehensive physical exam, health and developmental history, vision and hearing testing, appropriate lab tests and a dental exam for participating children. Recent legislation now requires that medical services necessary to treat or ameliorate any defect, physical or mental illness, or a condition identified by a medical screening must be provided to EPSDT participants regardless of whether the treatment is otherwise included as a reimbursable service in the state Medicaid plan, so long as the treatment is one of the Medicaid coverable services. This requirement significantly improves the opportunity for Medicaid eligible children to obtain a full range of health services such as physical and occupational therapy, speech services, and home health care.

Children eligible for EPSDT include all children who are categorically identified (AFDC recipients or SSI recipients). In addition states can include all children who are covered by Medicaid at the option of the state including children who are "medically indigent" and children who qualify as a result of recent mandates provided by Congress (raising the poverty level determination). States cannot select only one of these eligible groups but must cover all optional groups or none at all in EPSDT. Louisiana covers all Medicaid eligible children under the age of 18.

Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA)

Provisions under this federal act permit states to amend their Medicaid plan so that low income requirements are waived for children who have disabling conditions and who are living at home. To be eligible, children must have a disabling condition that meets Supplemental Security Income requirements, they must require the level of care provided in a hospital, skilled nursing facility or intermediate care facility, and the cost of home care cannot exceed the cost were the child placed out of the home. If the state adopts the TEFRA amendment, they must extend Medicaid coverage to all children who become eligible. The state is required to provide all Medicaid services that are ordinarily available under the state Medicaid plan, not an expanded array of service. However, once the child is eligible for Medicaid they may also be eligible for EPSDT. As noted above, if the state includes the optional Medicaid groups (such as "TEFRA children") into EPSDT participation, as Louisiana has chosen to do, then those children become eligible for a complete array of Medicaid reimbursable services.

Supplemental Security Income (SSI)

Supplemental Security Income monthly payments are available to adults whose disabilities prevent them from engaging in "substantial gainful activity." Children who live in families with very low income, or children who reside in a hospital or other institutional care facility, are also eligible to receive SSI payments. Once a child is SSI eligible they become eligible for Medicaid services. Until recently much controversy surrounded the process of the determination of disability for children applying for SSI. A recent Supreme Court ruling, however, clarified that a child's disabling condition can be determined by use of a functional assessment rather than by reference to a list of disabling conditions as was the previous practice. This new process will widen the eligibility criteria for new applicants and for those children who had been unjustly denied their benefits in the past.

Early Intervention Program for Infants and Toddlers

In 1986, amendments to the Education of the Handicapped Act were passed that established a Federal discretionary program to assist states to develop and implement a comprehensive, coordinated, interdisciplinary program of early intervention services for infants and toddlers with handicaps and their families. After several years of planning, states are required to implement a state-wide entitlement to services for eligible infants by October, 1991. The amendments emphasize the central importance of the family for early intervention and require that services are delivered according to an individualized family service plan (IFSP). Recent regulations stress family centered services (rather than child or agency centered) and integration of the child with non-disabled peers.

Vocational Rehabilitation

The Vocational Rehabilitation Act of 1973, amended in 1986, provides federal support for the employment of individuals with mental or physical handicaps. The legislation also emphasizes services to persons who are most severely disabled as determined by an individualized rehabilitation plan. Services include evaluation of job potential, counseling, referral, vocational training, transportation, interpreter services for persons who are deaf, reader services, job placement, and postemployment services. The 1986 amendments created a new funding stream devoted solely to supported employment programs (Wright, 1990, p.12).

IV. LOUISIANA PROGRAMS

Louisiana has the largest per capita institutional population in the nation. Louisiana's rate per 100,000 of the state population is 100.75 as compared to the national average of 55.98 (Lakin, et al., 1990). Over 700 Louisiana children under the age of 21 reside in public institutions. Services for individuals with developmental disabilities, addressed primarily by the Division of Mental Retardation/Developmental Disabilities, have historically been biased toward institutions. Louisiana has nine public institutions (16 or more beds) with approximately 2800 residents statewide. Additionally, over 1550 residents live in large private Intermediate Care Facilities-Mental Retardation (ICFs-MR). During 1988 total funds expended on both public and private institutional care was \$117 million. Louisiana's share of that cost was \$34 million (Braddock, et al., 1990).

Services such as community homes, adult day programs, infant intervention programs and respite care are the traditional community services that have been offered. The total budget for community services during 1988 was \$56 million; Louisiana's share was \$33 million (Braddock, et al., 1990).

A number of community homes were developed during the 1980's and approximately 1800 individuals live in these homes. Public, private non-profit and for profit agencies administer community homes and all are funded through Medicaid. Residential options other than institutions and community homes are scarce.

Community residential services for people with disabilities were developed primarily as a result of the Gary W. class action law suit. The Gary W. law suit involved the care and treatment of Louisiana children placed in Texas institutions. In 1976 the courts mandated the return of these individuals and ordered appropriate services in the least restrictive environment and a special master was appointed in 1980 to oversee compliance with the Judge's order. There were originally 684 class members and by 1989, 324 continued to receive services. Approximately \$37 million in state dollars have been expended in Gary W. services since 1976.

The Division of Mental Retardation/Developmental Disabilities has developed a plan to reduce the census in public and private residential facilities as a means to develop additional community supports. This reduction will be accomplished through normal attrition, transfers to the community and through the Home and Community Based Waiver. Large private ICF-MR residential facilities will be allowed to deploy existing residents to residences with six beds or less.

Family Support Services

In the past, very few services have been available to families who choose to care for their child with a disability at home. However, this is gradually beginning to change. The Division of Mental Retardation/Developmental Disabilities has an in-home and family support program administered through case management in the ten DMR/DD regional offices. Approximately 100 families receive services through this program which enables families to decide the types of services and resources that they will receive. Funding for this program is \$350,000.

The Division of Mental Retardation/Developmental Disabilities also has a substitute family care program which provides family care to children or adults with disabilities. This program currently has placed 164 children and adults in substitute families. Approximately 25 of those placements are children and the annual budget is \$540,000.

Respite care services have been administered through the Department of Social Services with an annual budget of \$1.27 million. During the 1990 Regular Legislative Session, respite funds were cut from the Department of Social Services's budget and the Division of Mental Retardation/Developmental Disabilities has included funds for respite in their appropriations. Local private providers, primarily local Associations for Retarded Citizens, operate both in and out of home respite. Funding for respite is through state funds and funding has not been increased for several years. There are 10 respite care providers in the state and approximately 950 families receive services annually. Requests for respite care services are regularly denied (approximately 90 per month) due to limited staff or beds. During fiscal year 1988-89, there were 15,981 hours of unmet need.

The Department of Social Services has a specialized foster care program which finds qualified foster homes for children with severe disabilities. Children involuntarily placed in state institutions due to neglect or abuse are referred to the program by the regional offices. Families are recruited specifically for each individual child. Families must go through a specially designed training program. Each family can accept a maximum of two children in their home. They receive a flat rate of \$1200 per month and can receive a special board cost at a maximum of \$300 per month. The amount of the special board varies according to the needs of the child and covers services such as relief for a child who requires 24 hour nursing care, transportation to frequent medical appointments, diapers, formula, and so forth. Foster children in specialized placements are eligible for Medicaid services, and the state will pay for services not provided through Medicaid such as ramps and lifts. This program began as a pilot project in Shreveport and became statewide this year. The state has 165 certified homes and has 220 children currently placed. This includes placements through private providers in Baton Rouge and New Orleans. Private placements are funded at \$2 million annually (providers receive \$35/day per child), with state placements funded at \$1.9 million for the \$1200 monthly subsidy and \$885,000 for special board.

In addition to specialized foster care, some children with developmental disabilities are placed in regular foster homes. The board and care received varies depending on the age of the child but averages \$264/month. Families are also able to receive a specialized board at a maximum of \$300 per month depending on the needs of the child.

A subsidized adoption program is also funded through the Department of Social Services and promotes the adoption of children with special needs. Most children adopted through this program are Medicaid eligible. Two kinds of subsidies are offered. A maintenance subsidy is available at 80% of the foster care board (which averages \$264 per month). Potential adoptive families who apply for the maintenance subsidy and are not otherwise eligible for a maintenance subsidy are given a means test based on income guidelines to determine eligibility. A special service subsidy is available to children with special needs if the disability was a documented pre-existing condition prior to adoption. In essence the state becomes the payor of last resort and will cover medical expenses not covered through private insurance or Medicaid.

There is currently no limit on the expenses paid per child and this adoption subsidy is totally state funded. The Department of Social Services places approximately 120 children per year through this program. The total budget including federal funds is \$2,334,805.

Foster care for children with developmental disabilities is primarily provided by the Office of Community Services in the Department of Social Services and does not allow for voluntary placement of children. The larger issue of voluntary placement of children in out-of-home family based settings and permanency planning should be addressed by the State of Louisiana.

The Louisiana State Planning Council on Developmental Disabilities has funded three projects to demonstrate the effectiveness of family supports. Private case management organizations in Lake Charles and Shreveport administer two of the family support projects. Each serves 15 families of children with developmental disabilities. The basic concept behind these two projects is to ensure that a family receives whatever it takes to maintain and enhance the family's capability to provide care at home. Each family receives case management services and a \$250 monthly cash subsidy to help defray the additional costs of raising a child with a disability. The case manager provides assistance in helping the family identify the long and short term support services they need and assists them to gain access to these services. Services available through the grant include but are not limited to respite care, personal care attendants, specialized equipment, home modifications and specialized therapies. These projects are in their second year of funding and should be continued by the Division of Mental Retardation/Developmental Disabilities on a permanent basis as part of the family support system.

The third demonstration project is managed by the Division of Mental Retardation/Developmental Disabilities as part of the In-Home and Family Support Program. Called "Family Ties," this program will reunite children living in out-of-home settings with their families. This pilot will move five children with developmental disabilities who have been living in state institutions or nursing homes into their family homes and will coordinate the supports necessary to do so. Supports available to the families include service coordination, grants to make needed accommodations, a monthly cash subsidy, and an array of specialized services including medical/dental, respite care and necessary equipment and supplies. Most of the children involved in this project have complex health needs and will need intensive supports.

Supports for Adults

To date, the major options available to adults with developmental disabilities have been placement in state or private ICFs-MR, admission to nursing homes or the possibility of securing attendant services from the limited program run by Louisiana Rehabilitation Services. Few individualized supports have been available to assist people to live in their own homes -- either by themselves, or with their families.

Recently, the Louisiana State Planning Council on Developmental Disabilities funded two supported living projects that each provide supports to approximately 10 adults with developmental disabilities living in a variety of settings. The two supported living projects are located in Gonzales and Bastrop and are administered by local Associations for Retarded Citizens. Individuals live in apartments or mobile homes or share a house with a roommate. They receive varying amounts of supports from month to month, depending on their need. The services and supports used include specialized equipment, home modifications, medical and dental care, transportation, and service coordination. An emphasis is placed on assisting individuals to become integral parts of their community by participating in typical neighborhood activities and using typical services as much as possible.

Conclusion

This shift toward a service system offering individualized supports to individuals with developmental disabilities and their families can be fully realized with a structured plan of implementation.

V. PROPOSED PROVISIONS

Family Support Services

A cash subsidy should be made available to families with children with developmental disabilities.

Parents who care for their children with severe handicaps at home face many extraordinary costs associated with this care. Medical costs, diapers, sitter services, and specialized equipment are among the items that take a toll on the family budget each month over and above the normal costs of child rearing. Financial support in the form of a monthly cash subsidy will help to offset these costs. The cash subsidy will be available to many families that are not eligible for financial assistance from traditional sources and will enable them to keep their child at home. The family cash subsidy may also help to defray some of the special costs of taking children out of institutions and bringing them back home.

We recommend that the amount of the monthly cash subsidy be \$258 and that eligibility should be limited to families of children with severe handicaps. This amount is equivalent to the monthly maximum Supplemental Security Income payment available in Louisiana for an adult disabled recipient living in the household of another. Increases to this rate will be tied to increasing SSI payments. Additionally, the parent or legal guardian of a family member who is in an out-of-home placement at the time of application may receive a one-time, lump sum advance payment of twice the monthly family subsidy amount for the purpose of meeting the special needs of the family to prepare for the child's return home. The Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and Handicapped Children's Services Program will determine eligibility for the cash subsidy. A uniform application procedure will be used by each agency to ensure consistency in the information collected. The child must be residing, or expected to reside, with his or her parents or legal guardian, or on a temporary basis, with another relative of the family member. A parent means a biological or adoptive parent; a legal guardian means a person appointed by a court of competent jurisdiction to exercise powers over a family member.

Families automatically eligible are those families with children age birth to 18 who meet the Department of Education's Bulletin 1508 criteria for the handicapping conditions of autism, deaf/blind, profoundly mentally handicapped, severely mentally handicapped and multi-handicapped. Children who meet the definitions of severely emotionally handicapped, orthopedically handicapped, health impaired, handicapped infants and toddlers and non-categorical pre-school will be screened to determine the severity of their disability. A standardized assessment tool will be used by the Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and Handicapped Children's Services Program to determine the severity of the handicapping condition. Each of the agencies involved will develop procedures to avoid duplication of subsidy payments. It is estimated that approximately 3000 children statewide will be eligible for a cash subsidy. This includes those eligible children receiving services through the Division of Mental Retardation/Developmental Disabilities in-home and family support program and those children adopted through the Department of Social Services Subsidized Adoption Program.

A system of service coordination to facilitate family support activities should be developed throughout the state.

Service coordination (also known as case management) plays a vital role in the implementation of a family support program. The service coordinator helps the family identify long and short term needs and then helps them gain access to needed services. Knowledge of the system and the services available to the child and his or her family are critical functions of a service coordinator. A service coordinator is responsive to the needs of the family and has the role of empowering the family. The service coordinator will be responsible for coordinating the receipt of the cash subsidy and accessing of appropriate services for each family. There will be a maximum case load of 25 families for each service coordinator.

Service coordination services are best delivered by an agency that does not provide direct services (i.e., infant services, day programs for adults, etc.) and can include regional state offices not providing direct services. A service coordinator should have knowledge of the services and supports that are available to a family and work to move the service system in the direction needed by persons with disabilities and their families. The service coordinator is responsible to the family first and not to any service providing agency. It is very difficult, if not impossible, to advocate for change in the service system when employed by a service provider. In instances where service coordination services are provided by a service providing agency, precautions should be taken to protect the integrity of the functions of service coordination. This should include the separation of service coordination from the provision of services (i.e., the service coordinators should not be located in the same entity that organizes and/or delivers the actual services). Additionally, service coordinators function best when they have a separate office and/or separate staff specifically identified with the family support program.

A range of services should be developed throughout the state to support families with children with developmental disabilities.

Families of a child with a handicapping condition need an array of both specialized and generic services. These services should be flexible in order to allow for the unique needs of each child and their family. Under this provision of the plan, all children ages birth to 18 with a developmental disability will be eligible for services. The Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health, and the Handicapped Children's Services Program will determine the eligibility criteria for services based on disability within the context of the developmental disabilities definition. Children served through the specialized foster care program will be eligible for services if they meet the eligibility criteria.

The services to be provided are those supports that enable a family to keep their child at home and include but are not limited to those listed below. These services can be defined as follows:

- a) **Communication services** are the necessary supports and services for a person with a disability to communicate including but not limited to sign language classes for the child with a disability, family members, and staff working with the child including personal care attendants and teachers; interpreters; braille devices.

- b) **Counseling services** involve professional counseling for the child-and/or his family including siblings; assistance with behavior management; group and individual therapy; parent to parent support.
- c) **Crisis intervention** is the 24-hour, on-call availability of professionals to intervene and deal with crises in the home with the intention of preventing unnecessary out-of-home placement.
- d) **Day care** includes after school and holiday/summer time care for children and adolescents, specialized training for day care providers and staff, and the supports needed to access the typical day care opportunities available to the community.
- e) **Dental and medical care** not otherwise covered through Medicaid services or private insurance.
- f) **Equipment and supplies** are those mobility aids, prosthetics, sensory aids, equipment to maintain medical treatment or health, including disposable supplies and durable items, and assistive technology devices to increase, maintain, or improve function capabilities of persons with disabilities.
- g) **Home and vehicle modifications** include enlarging hallways and doorways to accommodate wheelchairs, adapting bathrooms to accommodate wheelchairs, building ramps for access in and out of the home, and any other home modification needed to accommodate the special needs of a child with a disability. Vehicle modifications include hydraulic lifts to accommodate wheelchairs in vans and any other assistive devices that would enable a child with a disability to be transported in their family vehicle.
- h) **Home health services** involve assistance with medical procedures performed in the home usually by a nurse or trained paraprofessional.
- i) **Homemaker services** provide families with assistance in household chores in order to free family members to provide care to the child with a disability.
- j) **Parent education and training services** are those services which provide guidance to community parenting groups to assist families of children with special needs, are diverse in nature to accommodate the varying schedules of families (i.e., on weekends, evenings, etc.), and offer training on basic as well as specialized skills.
- k) **Personal assistance services** are services that are required by a person with a severe disability to achieve greater physical and communicative independence. Such services include but are not limited to the following: i) routine bodily functions, such as bowel or bladder care; ii) dressing; iii) preparation and consumption of food; iv) housecleaning and laundry; v) moving in and out of bed; vi) routine bathing; vii) ambulation; and viii) any other similar activity of daily living.
- l) **Recreation services** are those supports that provide consultation to community recreation service providers to improve access, organize leisure time activities to the extent necessary, and educate persons who have developmental disabilities and their families in the use of community recreational resources which are available to all community members.
- m) **Respite care** is provided periodically by persons substituting for the usual care giver. Respite services may be used for a few hours or a few days, and may be provided either in

or out of the recipient's home depending upon the family needs. Respite care may be prior arranged or provided on an emergency basis due to family crisis.

- n) **Service coordination** is a lifelong, goal-oriented process for coordination of the range of services needed and wanted by persons with developmental disabilities and their families.
- o) **Sitter services** include care for a child who needs supervision and for whom regular day care is not appropriate. It includes after school care for an adolescent, evening care when a parent has an evening job, or care when a child is ill.
- p) **Specialized diagnosis and evaluation** involves diagnosis and evaluation necessary for assistive devices, therapies, behavior management plans, and any other specialized services.
- q) **Specialized nutrition and clothing** includes supplemental food nutrients and specialized clothing adaptable to physical disabilities.
- r) **Specialized utility costs** are costs related to various extraordinary energy needs, such as electricity and gas, and other utilities, such as water and telephone, to enable a person with a disability to live at home.
- s) **Therapeutic and nursing services** are occupational, physical, speech and language, respiratory, vision and other therapies to increase, maintain or improve the functional capabilities of persons with disabilities.
- t) **Transportation services** are those services that facilitate access to integrated community services, programs and resources; optimize the use of public transportation; provide limited and direct transportation when public transportation is not available (in small groups with no identifying insignia) and provide consultation to providers of public transportation to improve access.

(Equipment financed by the state becomes the property of the person and current state purchasing and inventory procedures are not applicable.)

A sliding fee scale should not be used to generate revenue from families receiving services.

Act 378 calls for the Community and Family Support Plan to address the issue of a sliding fee scale. Based on an analysis of the costs of administering a fee system compared to the revenue that would be generated (see Appendix B for a description of the methodology applied), it is recommended that Louisiana not implement a sliding fee scale for family support services. After 3 years, an analysis of potential income generated through a sliding fee scale will be conducted based on data from families receiving services.

A system of co-payment is recommended for non-Medicaid eligible families to meet the Medicaid requirement of charging for services that are otherwise offered to Medicaid recipients at no charge. Each non-Medicaid eligible family will pay a \$3 fee for Medicaid funded services upon receipt of those services. If required by Medicaid, a sliding fee scale will be implemented.

The same uniform application procedure for services will be used by the Division of Mental Retardation/ Developmental Disabilities, the Division of Mental Health and Handicapped Children's Services Program.

Families often have to go from agency to agency to apply for services and each agency requests similar information. It is recommended the same application procedures for services be used by the Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health and Handicapped Children's Services Program. Information necessary for Medicaid eligibility should be incorporated onto this application and each agency will agree to accept one application and to share the information accordingly.

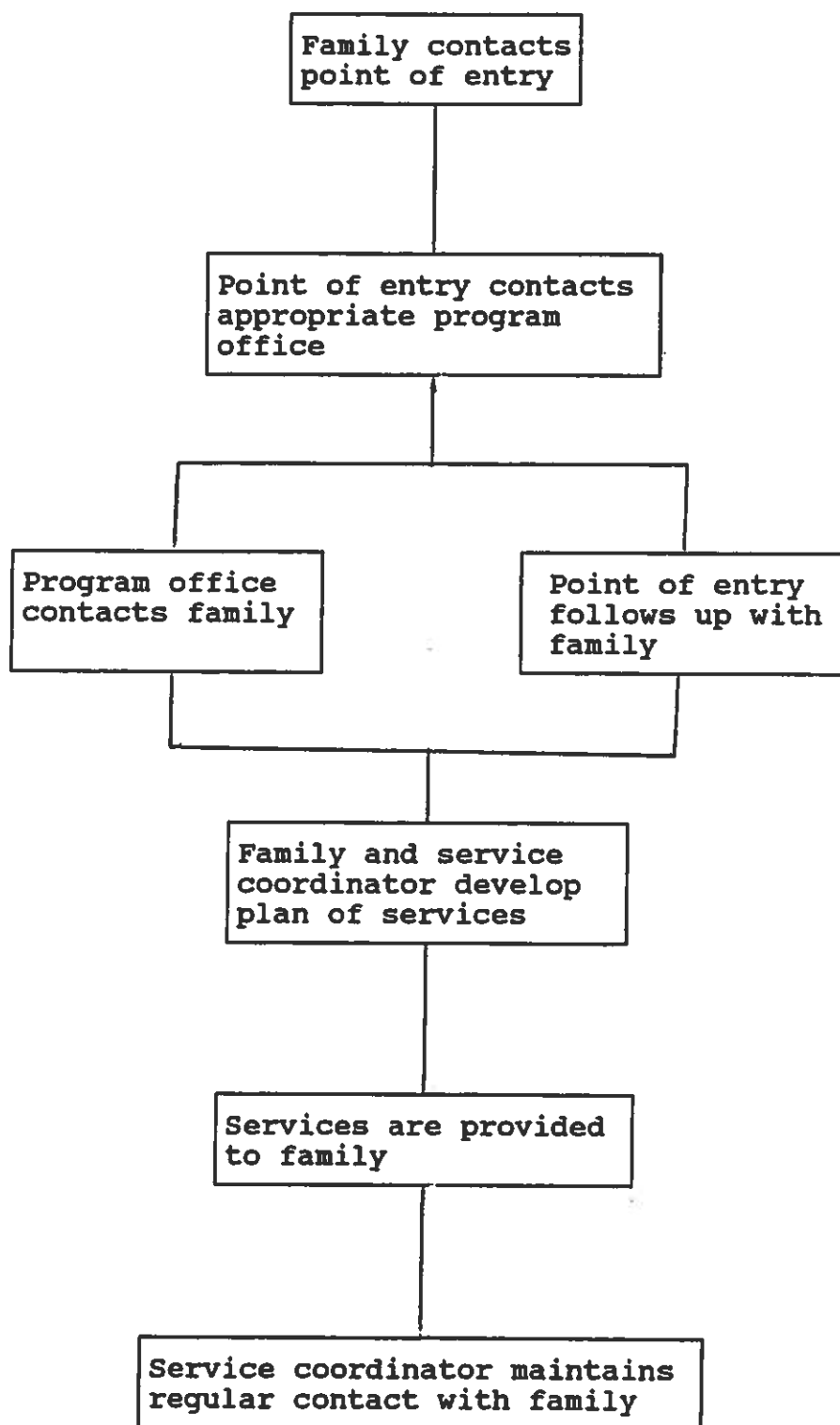
There should be a designated agency in each region that can provide information to families in need.

Currently there is no one source where a family can go to obtain information when they discover their child has a disability. Instead parents who are already experiencing stress, are bounced from agency to agency in their attempt to get information and services. This experience can be extremely confusing, frustrating and ultimately unproductive for family members. Parents around the state have expressed their critical need for a centralized regional agency to go to for assistance.

To address this problem, it is recommended that each region will have a designated point of entry with a toll free number. The appropriate agency can be the regional office of the Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health, Handicapped Children's Services Program, or a local information and referral agency known in the community. The three public agencies mentioned will determine which agency will be the appropriate designated point of entry. The Louisiana State Planning Council on Developmental Disabilities will have the authority to develop guidelines for the selection and to ensure that each region selects the point of entry in a timely manner.

Staff at the regional entry point will do an initial intake and assessment over the telephone or in person. The designated agency will refer the family to the appropriate agency by contacting that agency which will be responsible for contacting the family seeking services. The designated point of entry agency will be responsible for follow up with the family to ensure contact was made and available assistance was offered. (See Table 1.) DIAL (Disabilities Information Access Line), a statewide information and referral system, will act as a back-up to direct families to the appropriate agency in their region. Additionally, the Louisiana Commission for the Deaf will act as a back-up to refer families to the appropriate agency.

Interagency agreements between the agencies responsible for administering family support services will be signed in each region. These documents will outline the roles, responsibilities and time factors agreed to by each agency, and will specify the functions of the designated point of entry. Each designated point of entry will coordinate their efforts with the Handicapped Infant and Toddler Program and other related programs.

TABLE 1

The designated point of entry will be widely publicized in each region. Local school systems will be a primary source of outreach and brochures describing the services available will be disseminated through avenues such as advocacy and parent organizations, hospitals, doctors offices and public and private agencies.

Although called a "designated" point of entry, children who currently receive services or families having knowledge of an agency can directly contact the appropriate agency without going through the designated point of entry.

The implementation of the recommendations in this plan will necessitate the development of a training curriculum.

The development of a statewide system of family support will require a major change in the way services are provided to children with developmental disabilities and their families. A re-direction of resources and comprehensive staff training will be necessary to implement this system successfully. The Developmental Disabilities Council, in conjunction with the Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and Handicapped Children's Services Program will design a training curriculum for agencies involved in family support and will coordinate training with existing agencies.

Act 378 calls for implementation of this system beginning July 1, 1991 with full implementation by July 1, 1993.

Adult Support Services

The eligibility criteria for individualized supports for adults should be based on the definition of developmental disability and should extend to those who were disabled before the age of 55.

Eligibility criteria for individualized residential supports for adults with disabilities will be adults with severe disabilities ages 18 and over whose disability was manifested before age 55. A severe disability means a severe, chronic disability of a person which: a) is attributable to a mental or physical impairment or combination of mental and physical impairments, b) is manifested before the person attains age 55, c) is likely to continue indefinitely, d) results in substantial functional limitations in three or more of the following areas of major life activity: 1) self care, 2) receptive and expressive language, 3) learning, 4) mobility, 5) self direction, 6) capacity for independent living, 7) economic self sufficiency; and e) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

Adults with severe disabilities should receive a range of supports to assist them to live in their own homes and in their own communities.

Individualized residential supports are those services that assist a person find a home and then build in the supports necessary for them to live there. These supports include but are not limited to those listed below. These supports can be defined as follows:

- a) **Communication services** are the necessary supports and services for a person with a disability to communicate including but not limited to sign language classes for the adult with a disability, family members and staff working with the adult including personal care attendants and teachers; interpreters, braille devices.
- b) **Companion and/or roommate services** are services for those individuals needing regular supervision up to 24 hours for daily living.
- c) **Counseling services** involve professional counseling for the individual and/or family including siblings; assistance with behavior management; group and individual therapy; parent to parent support.
- d) **Crisis intervention** is the 24-hour, on-call availability of professionals to intervene and deal with crises in the home with the intention of preventing unnecessary out-of-home placement.
- e) **Dental and medical care** not otherwise covered through Medicaid services or private insurance.
- f) **Equipment and supplies** are those mobility aids, prosthetics, sensory aids, equipment to maintain medical treatment or health, including disposable supplies and durable items and assistive technology devices to increase, maintain, or improve functional capabilities of persons with disabilities.
- g) **Home and vehicle modifications** include enlarging hallways and doorways to accommodate wheelchairs, adapting bathrooms to accommodate wheelchairs, building ramps for access in and out of home, and any other home modifications needed to accommodate the special needs of an adult with a disability. Vehicle modifications include hydraulic lifts to accommodate wheelchairs in vans and any other assistive devices that would enable a person with a disability to be transported in their own or family vehicle.
- h) **Home health services** involve assistance with medical procedures performed in the home usually by a nurse or trained paraprofessional.
- i) **Homemaker services** are in-home supports that assist the person with a disability and/or family to carry out basic household chores.
- j) **Personal assistance services** are services that are required by a person with a severe disability to achieve greater physical and communicative independence. Such services include but are not limited to the following: i) routine bodily functions, such as bowel or bladder care; ii) dressing; iii) preparation and consumption of food; iv) housecleaning and laundry; v) moving in and out of bed; vi) routine bathing; vii) ambulation; and viii) any other similar activity of daily living.
- k) **Recreation services** are those supports that provide consultation to community recreation service providers to improve access, organize leisure time activities to the extent necessary, and educate persons who have developmental disabilities and their families in the use of community recreational resources which are available to all community members.

- l) **Respite care** is provided periodically by persons substituting for the usual care giver. Respite services may be used for a few hours or a few days, and may be provided either in or out of the recipient's home depending upon the individual and/or family needs. Respite care may be arranged prior to the event or provided on an emergency basis due to a crisis.
- m) **Service coordination** is a lifelong, goal-oriented process for coordination of the range of services needed and wanted by persons with disabilities and their families.
- n) **Specialized diagnosis and evaluation** involves diagnosis and evaluation necessary for assistance devices, therapies, behavior management plans, and any other specialized services.
- o) **Specialized nutrition and clothing** includes supplemental food nutrients and specialized clothing adaptable to physical disabilities.
- p) **Specialized utility costs** are costs related to various extraordinary energy needs, such as electricity and gas, and other utilities such as water and telephone, to enable a person with a disability to live at home.
- q) **Therapeutic and nursing services** are occupational, physical, speech and language, respiratory, vision and other therapies to increase, maintain or improve the functional capabilities of persons with disabilities.
- r) **Transportation services** are those services that facilitate access to integrated community services, programs and resources; optimize use of public transportation; provide limited and direct transportation when public transportation is not available (in small groups with no identifying insignia); and provide consultation to providers of public transportation to improve access.
- s) **Vocational and employment supports** are those support services that would enhance employment opportunities for an adult with a disability.

(Equipment financed by the state becomes the property of the person and current state purchasing and inventory procedures are not applicable.)

The agencies responsible for implementing this system of adult supports should be the Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health and Louisiana Rehabilitation Services.

These agencies are currently responsible for providing residential or other support services to adults with disabilities. The programmatic innovations proposed in this plan will provide more flexible options for residential living than are currently available. To facilitate the development of individualized supports, each designated agency should contract with providers to implement the supported living programs. It is anticipated that the providers of supported living programs will be private agencies. State agencies will be used only as a last resort to provide support services after there is documentation of unsuccessful attempts to obtain private providers.

Supported living program providers will provide support services directly or act as a broker to obtain the services necessary from the appropriate private or public agencies. Service coordination will be the primary responsibility of the supported living program provider with external service coordination provided by the appropriate state agency through regional or contract staff.

The Division of Mental Retardation/Developmental Disabilities will provide services to those adults with developmental disabilities; Louisiana Rehabilitation Services will provide services to adults whose severe physical disability occurred before the age of 55; and the Division of Mental Health will provide services to adults with severe mental illness.

Supports for adults should be phased in on a pilot basis.

Providing individualized residential supports to adults with disabilities is a fundamental change in the design of residential services and will be successful if implemented in a deliberate fashion. Implementation of adult community supports will be ongoing.

The Louisiana State Planning Council on Developmental Disabilities is currently funding two pilot supported living projects. Council funding is for a maximum of three years and is designed to demonstrate model programs. The current projects are in their second year and we recommend the Division of Mental Retardation/Developmental Disabilities assume funding of these projects on a permanent basis as a part of the community support system. Each program is developing supports for approximately 10 people a year.

In addition to the 2 pilot projects, we recommend that the Division of Mental Retardation/Developmental Disabilities establish 6 new programs the first year of implementation, 5 new programs during the second year, and 10 new programs the third year. Each of these projects would be allowed ample start up time, including staff training. In addition to establishing programs, support services should be made available to adults with developmental disabilities who choose to remain at home with their family or who already have a home but need additional support to remain there. During year one 100 adults will receive these services, during year two 200 and during year three 300 adults will receive services.

It is recommended Louisiana Rehabilitation Services issue a Request for Proposals for supported living pilot programs for 10 adults with physical disabilities. One pilot will be developed each year for the next three years. After three years, Louisiana Rehabilitation Services will evaluate the success of the pilots and make recommendations for implementation on a statewide basis. A staff person at the central office level will be required to administer the pilot projects.

In keeping with the planning developed through P.L. 99-660, it is recommended the Division of Mental Health administer a pilot program demonstrating capitated, community-based, managed care for 10 adults with severe and persistent mental illness. This has been shown to be a cost effective alternative to continuous or periodic in-patient hospitalization. The Division of Mental Health will evaluate this program based on the costs of serving a control group of like mental health service consumers. After three years, the Division will evaluate the success of the pilot and make recommendations for implementation on a statewide basis.

Each agency should select providers of supported living services through Request for Proposals. Providers should be geographically dispersed throughout the state. Approximately 300 adults will be supported in individualized residential supports over a three year period.

The Developmental Disabilities Council should design a training curriculum for potential supported living providers and will coordinate all training with existing agencies.

The development of supported living services for adults is a major change in the way services are delivered to adults. Comprehensive staff training will be necessary to implement this system successfully. The Developmental Disabilities Council, in conjunction with the Division of Mental Retardation/ Developmental Disabilities, Division of Mental Health and Division of Rehabilitation Services, will design a training curriculum for agencies and will coordinate all training with existing agencies.

Evaluation and Performance Indicators

One of the best indicators of the quality of supports to families and individuals is feedback received from those individuals who are receiving the services. Methods to generate such feedback are included as part of the Community and Family Support System.

Regional and state advisory councils should be established.

Regional family support advisory councils will be formed to provide assistance to the Division of Mental Retardation/ Developmental Disabilities, the Division of Mental Health and Handicapped Children's Services Program on the implementation of family support services. The committee will be comprised of parents representing the geographical areas of the region and will be representative of a variety of developmental disabilities. Parents receiving family support services will be included on the advisory councils. A state family support advisory council will also be formed and will include a representative from each regional council. The state council will have responsibility for advising state agencies on policy issues that arise during the implementation of the family support program.

A state advisory committee on supported living will be formed to provide assistance on the implementation of supported living programs. Membership shall be comprised of persons with disabilities and advocates. Two-thirds of the members shall be persons with disabilities.

An annual evaluation should be conducted based on consumer satisfaction and clear-cut performance indicators.

Both family support and community supports will be evaluated annually. Guidelines and methods used will be different for children and adults. Family support evaluation and performance indicators will be determined by the Regional Family Support Committees with assistance from the Division of Program Support in the Office of Human Services. The external evaluation will include, but not be limited to:

- 1) The impact of the family support program upon children covered by this act in institutions and residential care programs, including, to the extent possible, sample case reviews of families who choose not to participate.
- 2) Case reviews of families who voluntarily terminate participation in the family support program for any reason, particularly when the family member is placed out of the home, including the involvement of the Department of Health and Hospitals in offering suitable alternatives.
- 3) Sample assessments of families receiving family support payments including adequacy of subsidy and need for services not available.
- 4) The efforts to encourage program participation of eligible families.
- 5) The geographic distribution of families receiving subsidy payments and/or services, and to the extent possible, family members presumed to be eligible for and not receiving family support services.
- 6) Programmatic and legislative recommendations to further assist families in providing care for family members.
- 7) Problems that arise in identifying family members through diagnostic evaluations performed pursuant to rules promulgated by the Department of Education.
- 8) The number of beds reduced in state institutions and facilities serving children with disabilities when the children return home to their natural families as a result of the family support program.
- 9) The number of caseload figures by eligibility category for the cash subsidy.

In all cases, parents of children with disabilities will be included in the development and implementation of the annual evaluation.

With respect to the program of individualized supports for adults, quality of life indicators will be developed after convening a group of consumers to serve as an advisory body and to provide input. An external evaluation process will then be designed by the Louisiana Developmental Disabilities Council, with assistance from the Division of Program Support, using factors growing out of the deliberations of the advisory committee as well as the literature on quality of life.

An appeals procedure for families and adults with disabilities should be developed.

Families and adults with disabilities will be notified of the availability of an appeals procedure if a service is denied. The appeals process will have specific time lines and individuals will be informed that assistance can be obtained through the Advocacy Center for the Elderly and Disabled.

<p>Legislation to implement the Plan will be developed.</p>

Legislation will be introduced during the 1991 Regular Legislative Session for implementation of the plan developed through Act 378. Regulations will be developed within 6 months of the passage of the legislation by the appropriate agencies with oversight by the Developmental Disabilities Council and the Advocacy Center for the Elderly and Disabled.

Overall Cost Effectiveness

Family support services and supported living for adults can be shown to be cost effective models when compared to typical service configurations. As these new service models are implemented the evidence mounts that states can be fiscally responsible and meet the needs of their citizens with disabilities by altering their service plan and delivery system. For example, a recent planning document prepared by the Ohio Department of Mental Retardation and Developmental Disabilities concluded that their budget would have to be increased by 174% over the next ten years to meet all of the needs of their constituents. However, by implementing family support, supported living, and other services aimed at decreasing the dependence of individuals on the formal service system, the budget need only increase by 59%. The next section uses analysis of in-state expenditures and research and experience in other states to show the cost effectiveness of the service strategies recommended in this plan.

Family support is a relatively new concept and consequently there are no long term longitudinal studies that demonstrate its outcomes. However, other evidence is available. Family support is cost effective principally because it prevents or delays costly out of home placement of children with severe disabilities. Although the necessary supports to keep a child with serious disabling conditions at home can be quite costly, research has shown that the total costs do not exceed and are usually less than the costs that would otherwise be associated with nursing home or institutional care. In a study that compared the costs of caring for children in an institution versus caring for them in a family setting, care at home showed a savings of one-fourth to one fifth over the former (Knoll & Bersani, 1990).

Michigan has one of the oldest family support and cash subsidy programs in the nation and there is consistent evidence that this program has successfully contributed to the prevention of and return of children from out-of-home placements. Since the inception of the cash subsidy program in 1983, and coupled with an aggressive policy of placing all children either with their natural or adoptive families, Michigan has successfully reduced its population of children living in developmental centers from 175 to 29 (Arneaud & Herman, 1989).

In a study of Michigan parents receiving the subsidy, the proportion of mothers who indicated that they anticipated placing their child out of home at some future time was reduced from 32% to 19% after receipt of the subsidy for up to 10 months. In a different survey of Michigan parents who are receiving the subsidy, nearly 40% of respondents indicated that the subsidy had some degree of influence over their decision to keep their child at home (Meyers & Marcenko, 1989). (This percentage may even be higher were it not for the reluctance of parents to acknowledge the influence of money over decisions concerning their child.)

Previous research has shown that the perceived burden of care associated with the child with disabilities and other life stressors are contributors to a family's decision to seek out of home placement. These studies suggest that family support dedicated to reducing family stress will reduce out of home placement (Tausig, 1985). Indeed, other family support literature has shown that such services do reduce the amount of family stress and increase life satisfaction or contribute to a family's reluctance to seek out of home placement (Meyers & Marcenko, 1989; Bromley & Blacher 1989). Emerging findings from a recent evaluation of a family support pilot in Pennsylvania also show that the subsidy and support received contributed to some families making major life changes such as decisions to pursue education and get off welfare rolls.

Louisiana ranks among the top states in the number of children residing in ICFs-MR. It is estimated that 700 Louisiana children (under the age of 21) live in large and expensive residences, while few other options are afforded to families forced to make the excruciating decision to place a child out of the home. It is anticipated that the proposed family support program together with utilization of a Medicaid waiver to support medically fragile and technology dependent children (described below) will have a substantial impact on reducing and preventing the numbers of children living out of their home. Data from the current pilot administered by the Division of Mental Retardation/Developmental Disabilities, "Family Ties," that brings children out of residential facilities to their home should lend evidence to this assumption.

James is a 16 year old young man with cerebral palsy who is prone to seizures. He is unable to walk or talk. James' family was unable to locate necessary services for him in their community and placed him in an institution two years ago. Last year, the Southwest Louisiana Health Counseling Service's family support pilot program, Project: HOME was able to offer James' family services that would enable him to return to their home in Lake Charles. Through the family support program, his family receives a monthly subsidy and respite care. The project was able to help the family purchase a wheelchair and adaptive equipment. James is now in excellent health and is gaining weight. James goes to public school, uses Medicaid and the health unit for medical care, and his family receives AFDC services. When James lived in the institution the state paid \$39,362 yearly for his care; the annual cost for the family support services he currently needs in order to live in his family home is \$6,420.

Sam is 16 years old and is one of 13 children. He has mental retardation and cerebral palsy. Sam lived in a state institution for 13 years and the state paid \$30,766 annually for his care. Project: HOME offered support to Sam's family and he was able to return to his own home. Sam's family receives a monthly cash subsidy. Additionally, Sam has been able to access a whirlpool, porta lift and a side bar. Sam goes to public school, his parents are a part of a parent support group, and he receives medical care through Medicaid and the local health unit. The annual cost for Sam's care in his family's home is \$6,242.

Family support for children with mental health problems is also a relatively new concept with little longitudinal data. However, it is known that state governments spend millions of dollars on services to these children, usually through a fragmented service delivery network (i.e., juvenile justice, residential educational programs, in-patient hospitalizations, and child welfare and health programs.) Although expensive, these services are often reactive rather than preventive in nature. This problem is heightened by the threatening

specter of rising suicide rates and substance abuse among children. Research and innovative demonstrations across the country indicate that children can be cost effectively treated by enriched community based and family support services (Tarkington-Craig, 1990). Through such an emphasis on prevention, it is expected that costly mental health services for adults can be reduced.

There are also demonstrable cost savings in the adoption of supported living programs for adults with disabilities. Research has shown that the setting or type of residential environment is the greatest predictor of cost, rather than the disabling conditions of the adult (Ashbaugh & Nerney, 1988). ICFs-MR and institutional care are almost always more costly than supported living arrangements for the same population. For example, while the annual per person costs for institutional care in Louisiana range from \$20,910 to \$33,813, and for small ICFs-MR from \$32,120 to \$51,541, the costs for supported living programs in other states range from \$11,000 (Human Services Research Institute, 1990) to \$22,000 (personal communication from Kathy Carmody, Illinois Developmental Disabilities Council, 1990). One of the reasons for the difference in cost lies in the fact that unlike group homes, the state does not compensate for the physical lodging of the person (i.e., the state is not paying for rent, capital costs, building or upkeep in supported living arrangements). Additionally, the individual may be receiving more services than are needed due to the support structure of the facility. The individual, through his or her SSI benefits and other resources is paying for food and lodging, and the overall cost of housing is the responsibility of the private developer or landlord. The annual cost figure for the proposed supported living pilots used here is \$17,000 based on data from a variety of sources.

Judy is a woman in her late-twenties with cerebral palsy. She has severe physical disabilities and uses a wheelchair to get around. She was placed in a state institution when she was three years old and lived there until two years ago. She lived in community homes in Baton Rouge and has recently moved into her own apartment. Judy was thought to have mental retardation but recently passed her GED and will begin Vocational Technical School in the fall. Her apartment has been modified to accommodate her wheelchair and she has a personal care attendant who assists her with her personal needs. She is able to stay alone in her apartment. The cost of Judy's care in a community home was \$51,100 per year; the yearly cost for her services through the supported living program is \$21,400.

Jerry is a gentleman in his mid-thirties who has lived most of his life in a state institution. Jerry was born with spina bifida, uses a wheelchair and was classified as having profound mental retardation. He lived in a community home for one year before moving into his own apartment. When Jerry moved into the apartment he had a roommate to help him with his daily routine. He now lives on his own and has a neighbor who comes in the morning to help him get ready for work. His neighbors visit him often; he belongs to the Jaycees, goes to church, is an avid sports fan and has had a couple of dates since moving into his apartment. The annual cost of Jerry's institutional care was \$46,862; the yearly cost for his supported living services is \$14,400.

As has been shown, the proposed programs are themselves cost effective alternatives to traditional service options. In addition, several other strategies can be employed that either reallocate existing funds to more cost effective or more dignified options or that can be utilized to inexpensively expand service options to other needy groups. These are described in the next section.

Funding Strategies

Additional Medicaid waivers should be submitted and the existing home and community based waiver should be expanded.

Medicaid, the primary federal funding source for services to persons with disabilities, has several community-based options which offer more flexible funding mechanisms to those who may not qualify for traditional Medicaid services due to income or eligibility guidelines. The State of Louisiana can take advantage of these options to fund major portions of the Community and Family Support System.

Home and community based waivers offer services in the home or community and may include expanded medical services and other support services such as habilitation and respite care, which are not normally covered by Medicaid. Additionally, states may select more expansive income eligibility criteria when developing a waiver, thus allowing more children and adults to gain access to specialized services through the waiver.

We recommend the state utilize the home and community based waivers to offer families services in their homes. We recommend Handicapped Children's Services Program develop a Model Waiver for medically fragile and technology dependent children. A Model Waiver targets a specific sub-population, is usually oriented to serving children at home and is offered to a small number of individuals. Very few services are currently available to children with critical health needs and a Model Waiver would enable some children to return to their families from out-of-home placements and enable others to remain with their families. A maximum of 200 children would be served through such a waiver.

A special project administered by the Division of Mental Retardation/Developmental Disabilities called "Family Ties" beginning in July 1990, is designed to initiate a coordinated effort to reunite children who are living in out-of-home settings with their families. Additionally, we recommend the Division develop a waiver to further deinstitutionalize children.

A home and community based waiver can provide the supports necessary for supported living programs and we recommend the state develop a waiver to fund the Division of Mental Retardation/Developmental Disabilities supported living programs across the state. A maximum of 600 adults with developmental disabilities would receive supported living services through such a waiver over a three year period.

The state recently received approval for a Home and Community Based Services Waiver which will provide limited community services to approximately 442 individuals over a three year period. We further recommend the Division of Mental Retardation/Developmental Disabilities amend the existing Home and Community Based Waiver to serve additional persons and to increase the available services, including those defined in the Plan that are Medicaid reimbursable.

The state should take advantage of changes in the EPSDT program to fund important family support services.

The important changes in EPSDT noted above provide a rich opportunity to make significant improvements in services for children with disabilities in Louisiana. Specifically, new EPSDT requirements stipulate that children receiving EPSDT services are also eligible to receive the full array of Medicaid services if needed (whether or not they are included in the state plan). To help take advantage of this new service opportunity, medical care provider participation in the program is being encouraged and made more attractive by raising Medicaid reimbursable fees to 90% of the fees paid by the private insurance industry. In particular, reimbursement for medical screening fees will be increased to \$60. An aggressive program of training screeners is being implemented to ensure availability of screening public and private providers across the state.

The state Medicaid agency has eliminated limits on utilization of various medical services provided through EPSDT, including office visits, hospital and emergency room visits and home health care services. For Medicaid reimbursement purposes, the child's individual educational plan will serve as the basis of determining whether services (such as occupational or physical therapy) are medically necessary. The Individual Family Service Plan, a mandated part of federally funded early intervention programs, will serve as the basis for determining service eligibility for infants and toddlers. It is recommended that the plan for family support services will be used as the basis for determining service eligibility for remaining children ages 0-18.

Louisiana should adopt the TEFRA option to expand Medicaid coverage for children with disabilities at risk of institutionalization.

As described earlier, adoption of a TEFRA amendment to the state Medicaid plan, extends Medicaid eligibility to all children living at home, whose disability meets the criteria for receiving SSI, and who are eligible for institutional care but who would not otherwise be eligible for Medicaid because of family income. Under a TEFRA amendment these children would then become eligible for all of the Medicaid reimbursed services that are ordinarily included in the state Medicaid plan. It is proposed that a TEFRA state plan amendment be adopted in Louisiana. It is predicted that this will extend Medicaid eligibility to 1,125 more children. This is a high estimate based on the following considerations. Most states that have adopted TEFRA have experienced only a small increase in Medicaid rolls of 100 - 300 persons. The two exceptions to this are Minnesota and Wisconsin which have added 950 and 1,515 children respectively (Hall, 1990).

The difference in the experiences of states is largely attributed to how aggressively the state has educated their citizens about the TEFRA opportunity. The estimate of 1,125 children in Louisiana is based on the following: 1) like Wisconsin and Minnesota an aggressive policy of informing the public about TEFRA is advocated; and 2) the number was derived by computing the ratio of Wisconsin households earning over \$20,000 per year (a rough estimate of the income ceiling used to determine SSI eligibility for a child living at home) to the number of children who enrolled in Medicaid through the TEFRA provision. That ratio was applied to the number of households in Louisiana with over \$20,000 income per year. (All figures are based on the 1980 U.S. Census.)

By adopting the TEFRA option, Louisiana will be able to expand support services to families with children with disabilities through the EPSDT program as well as the regular Medicaid program.

Recent changes in the Supplemental Security Income program will expand the number of children eligible for Medicaid in the state.

As noted earlier, recent changes in Supplemental Security Income eligibility determinations will mean an increase in the number of children receiving SSI payments. A recent Supreme Court ruling found discrimination in denials of SSI eligibility for children and ordered the Social Security Administration to broaden their guidelines. Louisiana currently has the second highest number of children receiving SSI payments in the country; we expect a small increase in the number of recipients due to this ruling. These newly eligible children will in turn be eligible for Medicaid and for the EPSDT program.

In order to implement and monitor these recommendations, there will be a need for additional staff at the central office of the Bureau of Health Services Financing, the Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health and Handicapped Children's Services Program.

Resources should be reallocated to community supports based on the state's plan for institutional phase-down.

The Division of Mental Retardation/Developmental Disabilities has developed a plan to downsize its public residential facilities. According to the Division's current state plan, a reduction of 707 beds is planned over the next three years at a savings of \$4.9 million in state funds. This savings can be reallocated to support community-based service options. Additionally, the Division has established a "downsizing" administrative rule which will allow large facilities to "swap" beds for living options of six beds or less.

Estimated Costs and Funding Phases

FAMILY CASH SUBSIDY

The cash subsidy amount proposed is \$258/month per family. This monthly amount is consonant with the subsidies used in the present family support pilots in Louisiana, and it also reflects national averages. Beginning in August 1991, the program will accept 100 persons each month until they reach a maximum of 1000 families in May of 1992. In Year 2 of the program the first 1,000 families will continue to be served and 1,000 more families will be added to the program, at 100 families per month starting in August, 1992. In Year 3, the program will serve the initial 2,000 families enrolled and will increase its rolls by another 1,000 families in the manner described above to total 3,000 families served by the end of Year 3. The annualized costs are calculated as follows:

July = no subsidy

Aug (100 families x \$258) = \$ 25,800

Sept (200 families) =	\$ 51,600
Oct (300 families) =	\$ 77,400
Nov. (400 families) =	\$103,200
Dec.(500 families) =	\$129,000
Jan.(600 families) =	\$154,800
Feb. (700 families) =	\$180,600
March (800 families) =	\$206,400
April (900 families) =	\$232,200
May (1,000 families) =	\$258,000
June (1,000 families) =	\$258,000
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Total families (1000)	\$1,677,000

The following chart outlines the costs for cash subsidy over a four year period.

	Number of Families	Annualized Cost	12 Month Cost	Total
Year 1	1000	\$1,677,000	- 0 -	\$1,677,000
Year 2	2000	\$1,677,000	\$3,096,000	4,773,000
Year 3	3000	\$1,677,000	6,192,000	7,869,000
Year 4	3000	- 0 -	9,288,000	9,288,000

FAMILY SUPPORT SERVICES

In addition to the family cash subsidy of \$258/month, an array of family support services is also proposed. A total of 1500 families per year (enrolled over four quarters) will receive support services at the estimated average cost of \$2,500 per family per year (the figure is based on cost histories from other states). The regional program office will be required to approve requests for services when the services received by a family exceeds \$9600 within a fiscal year. Each request will be reviewed and the family notified of the decision within 30 days of the initial request.

The annualized costs are calculated as follows:

1st quarter: 375 families enrolled @ \$2500/yr = \$937,500

2nd quarter: 375 families enrolled @ \$2000/yr= \$750,000

3rd quarter: 375 families enrolled @ \$1500/yr= \$562,000

4th quarter: 375 families enrolled @ \$1000/yr= \$375,000

Total families (1500) \$2,624,500

The following chart outlines the costs for services over a four year period:

	Number of Families	Annualized Cost	12 Month Cost	Total
Year 1	1500	\$2,624,500	- 0 -	\$2,624,500
Year 2	3000	\$2,624,500	\$3,750,000	6,374,500
Year 3	4500	\$2,624,500	7,500,000	10,124,500
Year 4	4500	- 0 -	11,250,000	11,250,000

STAFFING AND ADMINISTRATION FOR FAMILY SUPPORT PROGRAMS

o **Operation of designated point of entry:**

2 full time employees/region = 20 employees

@ \$25,037 annual salary plus fringe = \$500,740

o **Operation of toll free number for family support:**

Each year: \$7,000 per region= \$70,000

o **Central office costs**

Division of Mental Retardation/Developmental Disabilities

2 full time employees @ \$32,000 each \$64,000

Division of Mental Health

1 full time employee @ \$32,000 \$32,000

Handicapped Children's Services Program

1 full time employee @ \$32,000 \$32,000

Bureau of Health Services Financing

We estimate 75% of the families eligible 210,938
for services will be Medicaid eligible.

We estimate 25% of the services they receive
will be waived services. A 10% administrative
cost is calculated to cover the staff required
to oversee and implement the waivers.

o Service coordinator staff for family support services

We estimate that 25% of the total families receiving services (4,500 after 3 years) would not be Medicaid or Medicaid waiver eligible. Service coordinator costs for these families would not be reimbursed by Medicaid for the federal share. However, the remaining 75% of families could be billed for targeted case management. We estimate 60% of the children served will be served through DMR/DD, 30% through DMH, and 10% through the Handicapped Children's Services Program.

The following calculations reflect the total cost of service coordinator staff for all families. Children needing a wide variety of services are given a service coordination ratio of 1:25. A 1:35 service coordination ratio is used for these purposes to account for those families receiving few services or only the cash subsidy. Yearly costs include 1 supervisor and 1 secretary for every 5 service coordinators and a \$3400 annual overhead cost per service coordinator.

Year one: 43 service coordinator positions= \$1,700,000

Year two: 86 positions \$3,232,000

Year three: 129 positions \$4,940,000

FEDERAL AND STATE SHARE FUNDING FOR FAMILY SUPPORT SERVICES

(Total number of families receiving services is shown in parentheses)

	YEAR 1	YEAR 2	YEAR 3	FULL IMPLE- MENTATION
Cash Subsidy	1,677,000 (1000)	4,773,000 (2000)	7,869,000 (3000)	9,288,000 (3000)
Services	2,624,500 (1500)	6,374,500 (2000)	10,124,500 (4500)	11,250,000 (4500)
Point of entry	570,740	570,740	570,740	570,740
Central office staff	338,938	338,938	338,938	338,938
Service coordination	1,700,000	3,232,000	4,940,000	4,940,000
Total State funds	4,313,553	9,716,053	15,199,928	17,111,334
Total Federal share	2,607,625	5,573,125	8,643,250	9,276,344
Total cost	6,921,178	15,289,178	23,843,178	26,387,678

ADULT SERVICES

To calculate annual per person costs of supported living programs a figure of \$17,000 was derived based on the reported costs of other states relative to their cost of living. This figure reflects costs to the state for provision of rehabilitative and supportive services and does not include the individual's contribution for room and board (usually from the monthly SSI or SSDI check). The figure is equally applicable to programs for persons with physical disabilities and mental illness based on data accrued from several states. For programs serving adults who live with families, a figure of \$7,000 per person is applied to reflect the decreased need for on-site supervision.

It is recommended that the supported living projects for adults continue to be expanded after year three of implementation. New plans for on-going implementation should be developed during year three based on needs identified throughout the state.

Supported Living Costs

YEAR 1:

Continued funding of one supported living model program for 6 months for 15 persons with developmental disabilities	\$127,500
Six new programs serving 36 persons	\$612,000
100 adults living with families	\$ 70,000

Pilot for mental health disabilities serving 10 persons	\$170,000
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Pilot for 10 persons with physical disabilities administered by Louisiana Rehabilitation Services	\$170,000
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YEAR 2:

Expansion of two model programs to serve 50 people (15 existing plus 10 new each program)	\$850,000
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Expansion of programs started Year 1 to serve 72 people	\$1,224,000
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Five new programs serving 30 persons	\$510,000
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200 adults living with families	\$1,400,000
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Pilot for mental health disabilities serving 10 persons	\$170,000
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Two pilots for 10 persons each with physical disabilities administered by Louisiana Rehabilitation Services	\$340,000
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YEAR 3:

Expansion of model programs to serve 70 people	\$1,190,000
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Expansion of programs started year one to to serve 108 persons	\$1,836,000
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Expansion of programs started year two to serve 60 persons	\$1,020,000
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Ten new programs serving 60 persons	\$1,020,000
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300 adults living with families	\$2,100,000
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Pilot for mental health disabilities serving 10 persons	\$170,000
------------------------------------------------------------	-----------

Three pilots for 10 persons each with physical disabilities administered by Louisiana Rehabilitation Services	\$510,000
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STAFFING AND ADMINISTRATION FOR ADULT SUPPORTED LIVING SERVICES

o Service Coordinator staff for adult supported living programs

(Costs include \$3400 annual overhead cost per service coordinator)

Division of Mental Retardation/Developmental Disabilities

Year 1: 10 Service coordinator positions (average 1 per region) = \$320,560

Year 2: 20 Service coordinator positions (average 2 per region) = \$641,120

Year 3: 30 Service coordinator positions (average 3 per region) = \$961,680

Louisiana Rehabilitation Services

Year 1: 1 Service coordinator \$32,056

Year 2: 2 Service coordinators \$64,112

Year 3: 3 Service coordinators \$96,168

o Central Office Costs

Division of Mental Retardation/Developmental Disabilities

1 full time employee \$32,000

Louisiana Rehabilitation Services

1 full time employee \$32,000

Bureau of Health Services Financing

10% of the total cost of waived services \$716,600
for administrative costs

FEDERAL AND STATE SHARE FUNDING FOR SUPPORTED LIVING SERVICES

(Total number of adults receiving services is shown in parentheses)

	Year 1	Year 2	Year 3
DMR/DD programs	809,500 (151)	3,984,000 (355)	7,166,000 (598)
LRS pilot	170,000 (10)	340,000 (20)	510,000 (30)
DMH pilot	170,000 (10)	170,000 (10)	170,000 (10)
Service Coordinators	356,616	705,232	1,057,848
Central office/staff	780,600	780,600	780,600
Total State funds	1,021,829	2,072,608	3,126,262
Total Federal share	1,264,887	3,907,224	6,558,186
Total cost	2,286,716	5,979,832	9,684,448

A regional program office cost breakdown on family support and adult supported living services will be made available to the appropriate program offices for Fiscal Year 1991 budget planning purposes.

Phases of Implementation

October, 1990 through June 1991

A task force will be created by October 1990 and will meet quarterly through 1994 to oversee implementation of the Plan. (Developmental Disabilities Council)

The TEFRA option under Medicaid will be submitted by October 1990. (Bureau of Health Services Financing)

Agencies will develop the budget requests necessary by October 1990 to implement the Plan. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Bureau of Health Services Financing and Louisiana Rehabilitation Services)

A waiver for supported living for adults and for the deinstitutionalization of children and an amendment to the Division of Mental Retardation/Developmental Disabilities existing waiver will be written and submitted for approval by January 1991. (Division of Mental Retardation/ Developmental Disabilities and the Bureau of Health Services Financing)

A waiver for medically fragile and technology dependent children will be written and submitted for approval by January 1991. (Handicapped Children's Services Program and the Bureau of Health Services Financing)

Designated points of entry will be agreed upon by January 1991. (Division of Mental Retardation/ Developmental Disabilities, Handicapped Children's Services Program, Division of Mental Health and the Developmental Disabilities Council)

Requests for proposals will be developed for supported living programs for adults and will be disseminated by January 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and La. Rehabilitation Services)

A plan of service coordination will be developed by January 1991. (Division of Mental Retardation/Developmental Disabilities task force)

Family support policy procedures will be developed by March 1991. (Division of Mental Retardation/Developmental Disabilities, the Division of Mental Health, and Handicapped Children's Services Program)

Legislation to implement the plan will be drafted and introduced in the 1991 Regular Legislative Session. (Developmental Disabilities Council and Department of Health and Hospitals)

Training curricula on family support and supported living will be developed by April 1991. (Developmental Disabilities Council, Division of Mental Retardation/Developmental Disabilities, Handicapped Children's Services Program and Division of Mental Health and La. Rehabilitation Services)

Appropriate agencies will draft and sign interagency agreements by April 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Louisiana Rehabilitation Services, and Department of Education)

Providers will be selected for supported living programs for adults by May 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and La. Rehabilitation Services.)

Regional and state family support advisory committees will be formed by June 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Program Services)

State and regional agency staff and providers will receive training on family support and supported living concepts by June 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Bureau of Health Services Financing, La. Rehabilitation Services, Department of Education, Office of Eligibility Determinations and private providers)

Appeals procedures will be developed by June 1991. (Community and Family Support System Plan Task Force and the Department of Health and Hospitals)

The Community and Family Support System Task Force will report to the Developmental Disabilities Council quarterly on the implementation of the Plan. (Task force)

July 1991 through June 1992

Regional service coordinators and designated point of entry staff will be hired by July 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services)

Providers of supported living services will begin implementation of programs in July 1991. (Private providers)

Families will receive subsidies and services beginning August 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program)

Staff training on family support and supported living programs will continue throughout the year. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education, Office of Eligibility Determinations, private providers)

Agencies will develop the necessary budget requests by October 1991 to implement the Plan. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Bureau of Health Services Financing, La. Rehabilitation Services)

Regulations to legislation will be developed before December 1991. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, and La. Rehabilitation Services)

Performance indicators for the family support program will be designed by December 1991. (Regional family support advisory committees and the Division of Program Support)

A consumer satisfaction survey instrument will be developed by December 1991. (Developmental Disabilities Council and the Division of Program Support.)

Requests for proposals will be issued for providers of supported living programs by December 1991. (Division of Mental Retardation/Developmental Disabilities and La. Rehabilitation Services)

Providers will be selected for supported living programs for adults by May 1992. (Division of Mental Retardation/Developmental Disabilities and La. Rehabilitation Services)

An external evaluation of the family support program will be conducted in June 1992. (Human Services Research Institute)

A state supported living advisory committee will be formed by June 1992. (Developmental Disabilities Council)

Consumer satisfaction surveys of supported living programs will be conducted in June 1992. (Private providers)

Interagency agreements will be reviewed and necessary modifications will be made by June 1992. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education)

The Community and Family Support System Task Force will meet quarterly throughout the year and report to the Developmental Disabilities Council on the implementation of the Plan.

July 1992 through June 1993

New supported living programs will begin providing services in July 1992. (Private providers)

Additional families will be enrolled to receive subsidies and services beginning August 1992. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program)

Staff training on family support and supported living programs will continue throughout the year. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education, Office of Eligibility Determinations, private providers)

The Developmental Disabilities Council will report on the implementation of the Plan to the House Committee on Health and Welfare, Senate Committee on Health and Welfare, secretary of the Department of Health and Hospitals, the secretary of the Department of Social Services by September 1992.

Agencies will develop the necessary budget requests by October 1992 to implement the Plan. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Bureau of Health Services Financing, La. Rehabilitation Services)

Based on results from annual evaluations and reports from the task force, the Community and Family Support System Plan will be revised as needed in October 1992. (Developmental Disabilities Council)

Requests for proposals will be issued for providers of supported living programs by December 1992. (Division of Mental Retardation/Developmental Disabilities and La. Rehabilitation Services)

An external evaluation process for supported living services will be developed by December 1992. (State supported living advisory committee, the Developmental Disabilities Council, and the Division of Program Support)

Providers will be selected for supported living programs for adults by May, 1993. (Division of Mental Retardation/Developmental Disabilities and La. Rehabilitation Services)

An external evaluation will be conducted on family support and supported living programs by June 1993. (Human Services Research Institute)

Consumer satisfaction surveys of supported living programs will be conducted in June 1993. (Private providers)

Interagency agreements will be reviewed and necessary modifications will be made by June 1993. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education)

The Community and Family Support System Task Force will meet quarterly throughout the year and report to the Developmental Disabilities Council on the implementation of the Plan.

July 1993 - June 1994

New supported living programs will begin providing services in July 1993. (Private providers)

Additional families will be enrolled to receive subsidies and services beginning August 1993.
(Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program)

Staff training on family support and supported living programs will continue throughout the year. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education, Office of Eligibility Determinations, private providers)

The Developmental Disabilities Council will report on the implementation of the Plan to the House Committee on Health and Welfare, the Senate Committee on Health and Welfare, the secretary of the Department of the Health and Hospitals and the secretary of the Department of Social Services by September 1993.

Based on results from annual evaluations and reports from the task force, the Community and Family Support System Plan will be revised as needed in October 1993. (Developmental Disabilities Council)

Agencies will develop the necessary budget requests by October 1993 to implement the Plan. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, Bureau of Health Services Financing, La. Rehabilitation Services)

Plans for implementation of additional supported living programs will be developed by January 1994.
(Division of Mental Retardation/Developmental Disabilities, Division of Mental Health and La. Rehabilitation Services.)

An external evaluation will be conducted on family support and supported living programs by June 1994.
(Human Services Research Institute)

Interagency agreements will be reviewed and necessary modifications will be made by June 1994. (Division of Mental Retardation/Developmental Disabilities, Division of Mental Health, Handicapped Children's Services Program, La. Rehabilitation Services, Department of Education)

The Community and Family Support System Task Force will meet quarterly throughout the year and report to the Developmental Disabilities Council on the implementation of the Plan.

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APPENDICES

APPENDIX A

ACT 378

Regular Session, 1989

HOUSE BILL NO. 1380

BY REPRESENTATIVES HAIK, ANSARDI, FORSTER, GARRITY, HERRING, JETSON,
LEMOINE, S. J. THERIOT, DEWITT, AND IRVIN AND SENATORS NELSON,
CROSS, FIELDS, HINTON, LANDRY, AND MCPHERSON

AN ACT

To enact R.S. 28:752(13) and Chapter 13 of Title 28 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 28:821 through 824, relative to services for developmentally disabled children and adults and their families; to provide for legislative intent and definitions; to provide for principles of care; to provide for the development of a Community and Family Support System plan by the Louisiana State Planning Council on Developmental Disabilities; to provide for implementation of the plan by the Department of Health and Hospitals with the cooperation of the Department of Social Services, and to provide for related matters.

=====ORIGINATED=====

=====IN THE=====

House of Representatives

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BY SECRETARY OF STATE

JUN 30 1989

W. FOX MCKEITHEN
SECRETARY OF STATE

[Signature]

Clerk of the House of Representatives

Regular Session, 1989

HOUSE BILL NO. 1380

BY REPRESENTATIVES HAIK, ANSARDI, FORSTER, GARRITY, HERRING, JETSON, LEMOINE, S. J. THERIOT, DEWITT, AND IRVIN AND SENATORS NELSON, CROSS, FIELDS, HINTON, LANDRY, AND MCPHERSON

AN ACT

To enact R.S. 28:752(13) and Chapter 13 of Title 28 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 28:821 through 824, relative to services for developmentally disabled children and adults and their families; to provide for legislative intent and definitions; to provide for principles of care; to provide for the development of a Community and Family Support System plan by the Louisiana State Planning Council on Developmental Disabilities; to provide for implementation of the plan by the Department of Health and Hospitals with the cooperation of the Department of Social Services, and to provide for related matters.

Be it enacted by the Legislature of Louisiana:

Section 1. R.S. 28:752(13) and Chapter 13 of Title 28 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 28:821 through 824, are hereby enacted to read as follows:

§752. Responsibilities

The responsibilities of the council shall include but not be limited to the following:

* * *

(13) To develop and monitor implementation of the Community and Family Support System plan (R.S. 28:821 et seq.).

* * *

CHAPTER 13. COMMUNITY AND FAMILY SUPPORT SYSTEM

§821. Findings and purpose

A. The Legislature of Louisiana finds that services for persons with developmental disabilities should be responsive to

the needs of the individual and his family, rather than fitting the person into existing programs. The legislature further finds that it is more cost effective to provide services to adults and children with developmental disabilities living in their own homes or with their families rather than in out-of-home placements.

B. The legislature declares that the purpose of this Chapter is to establish that:

(1) Children, regardless of the severity of their disability, need families and enduring relationships with adults in a nurturing home environment. As with all children, children with developmental disabilities need families and family relationships to develop to their fullest potential. Parents of children with developmental disabilities shall be afforded freedom of choice as to placement of their child, in accordance with R.S. 28:380 et seq.

(2) Adults with developmental disabilities should be afforded the opportunity to make decisions for themselves and to live in typical homes and communities where they can exercise their full rights and responsibilities as citizens.

C. It is the intention of the legislature that the state of Louisiana adhere to the principles contained in this Chapter in program planning, development, funding, and implementation for persons with developmental disabilities and their families. It is the further intention of the legislature that the Department of Health and Hospitals and the Department of Social Services work cooperatively to implement the Community and Family Support System plan developed by the Louisiana State Planning Council on Developmental Disabilities pursuant to this Chapter.

§822. Definitions

The following definitions shall apply:

(1) "Adult" means an individual eighteen years of age or older.

(2) "Cash subsidy" means a monetary payment to eligible families of children with developmental disabilities to offset the costs of services and equipment.

(3) "Child" means an individual under the age of eighteen.

(4) "Community supports" means those supports and services that enable an adult with developmental disabilities to live in the residence of his choice. Community supports shall include but not be limited to the following:

(a) Dental and medical care that are not otherwise covered.

(b) Respite care.

(c) Recreation.

(d) Homemaker services.

(e) Transportation.

(f) Personal assistance services.

(g) Home health services.

(h) Therapeutic and nursing services.

(i) Home and vehicle modifications.

(j) Equipment and supplies.

(k) Counseling services.

(l) Communication services.

(m) Crisis intervention.

(n) Specialized utility costs.

(o) Vocational and employment supports.

(p) Specialized diagnosis and evaluation.

(q) Specialized nutrition and clothing.

(r) Service coordination.

(5) "Developmental disabilities" means a severe, chronic disability of a person which:

(a) Is attributable to a mental or physical impairment or combination of mental and physical impairments.

(b) Is manifested before the person attains age twenty-two.

(c) Is likely to continue indefinitely.

(d) Results in substantial functional limitations in three or more of the following areas of major life activity:

- (i) Self care.
- (ii) Receptive and expressive language.
- (iii) Learning.
- (iv) Mobility.
- (v) Self-direction.
- (vi) Capacity for independent living.
- (vii) Economic self-sufficiency.

(e) Reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

(6) "Equipment and supplies" means mobility aids, prosthetics, sensory aids, equipment to maintain medical treatment or health, including disposable supplies and durable items, and assistive technology devices to increase, maintain, or improve functional capabilities of persons with disabilities.

(7) "Family supports" means those supports that enable a family to keep their child with developmental disabilities at home. Family supports shall include but not be limited to the following:

- (a) Dental and medical care that are not otherwise covered.
- (b) Respite care.
- (c) Recreation.
- (d) Homemaker services.
- (e) Transportation.
- (f) Personal assistance services.
- (g) Home health services.
- (h) Therapeutic and nursing services.
- (i) Home and vehicle modifications.
- (j) Equipment and supplies.
- (k) Counseling services.

- (l) Communication services.
- (m) Crisis intervention.
- (n) Specialized utility costs.
- (o) Day care.
- (p) Specialized diagnosis and evaluation.
- (q) Specialized nutrition and clothing.
- (r) Parent education and training.
- (s) Service coordination.

(8) "Personal assistance services" means services which are required by a person with a severe disability to achieve greater physical and communicative independence. Such services include but are not limited to assistance related to the following:

- (a) Routine bodily functions, such as bowel or bladder care.
- (b) Dressing.
- (c) Preparation and consumption of food.
- (d) Housecleaning and laundry.
- (e) Moving in and out of bed.
- (f) Routine bathing.
- (g) Ambulation.
- (h) Any other similar activity of daily living.

(9) "Service coordination" means a lifelong, goal-oriented process for coordination of the range of services needed and wanted by persons with developmental disabilities and their families.

(10) "Specialized utility costs" means costs related to various extraordinary energy needs, such as electricity and gas, and other utilities, such as water and telephone, to enable a person with a disability to live at home.

(11) "Substitute family" means placement of a child in a family other than his natural or adoptive family.

(12) "Therapeutic services" means occupational, physical, speech and language, respiratory, vision, and other therapies to

increase, maintain, or improve the functional capabilities of persons with disabilities.

§823. Principles

The following ideals shall be the guiding principles for the development of a Community and Family Support System plan:

(1) The family of each child with developmental disabilities shall be provided the support necessary so that the child may live in a stable family environment in an enduring relationship with one or more adults regardless of the severity of the disability of the child or the degree of support necessary.

(2) Adults with developmental disabilities should receive the supports necessary to enable them to achieve their maximum potential through increased independence, productivity, and integration into the community.

(3) The family support system shall be flexible, individualized, and family centered.

(4) The needs of the entire family shall be considered in the development of the individualized family supports.

(5) The family support system recognizes that families are best able to determine their own needs, rather than having their needs determined by the state or an agency.

(6) Adults with developmental disabilities should have supports and services provided in the community to meet their needs wherever the individual chooses to live and work.

(7) The system shall have a program of outreach so that families may obtain family support at the time they learn of their child's disability, and so that people are aware of the availability of community supports when the need arises.

(8) The system shall support and strengthen existing informal social networks and natural supports in addition to professional support services.

(9) The system shall promote the use of existing community resources.

(10) Out-of-home placement of children shall be used only after parents are given the option of choosing family support services.

(11) The system shall be flexible to insure that unanticipated needs are met and that the provision of supports and services is not limited to the location and types of existing services.

(12) A cash subsidy should be made available to eligible families for any of the purposes contained within the plan in order to enhance the family support system.

§824. Community and Family Support System plan

A. The Louisiana State Planning Council on Developmental Disabilities shall develop a plan to implement a Community and Family Support System in accordance with the principles contained in this Chapter. The secretary of the Department of Health and Hospitals shall allocate funds from existing resources to provide staff support to the council for the development of the plan. The council may appoint an advisory committee as necessary to assist in the development of the plan. The advisory committee shall include representation of parents of children or adults now residing in an intermediate care facility for the mentally retarded.

B. The plan shall address the following issues:

(1) Budgetary recommendations with specific emphasis on cost effectiveness in providing services to those who qualify.

(2) Eligibility criteria.

(3) Methods of service provision.

(4) Sliding fee scale.

(5) Application procedures.

(6) Service coordination system.

(7) Performance indicators that will measure the effectiveness of the Community and Family Support System.

C. The plan shall be coordinated with the plans of the Mental Retardation and Developmental Disabilities Services

H.B. NO. 1380

System (R.S. 28:380 et seq.), the Handicapped Infants and Toddlers Program (P.L. 99-457 Part H), the Child and Adolescent Service System Program (R.S. 28:801 et seq.), the Comprehensive Mental Health Plan Act of 1986 (P.L. 99-660), and other activities of the Louisiana State Planning Council on Developmental Disabilities (R.S. 28:750 et seq.).

D. The council shall submit the plan to the secretary of the Department of Health and Hospitals and the secretary of the Department of Social Services by August 1, 1990. The secretaries shall review and approve the plan and submit it for review and approval to the House Committee on Health and Welfare and the Senate Committee on Health and Welfare and submit the plan to the Joint Legislative Committee on the Budget by September 1, 1990. Any changes made in the plan by the secretaries shall be so indicated.

E. The secretary of the Department of Health and Hospitals, with any necessary cooperation from the secretary of the Department of Social Services, shall begin implementation of the Community and Family Support System plan by July 1, 1991.

F. The council shall monitor the implementation of the plan, and shall report its findings annually to the House Committee on Health and Welfare and the Senate Committee on Health and Welfare, for review and approval, and to the secretary of the Department of Health and Hospitals and the secretary of the Department of Social Services until the plan is fully implemented.

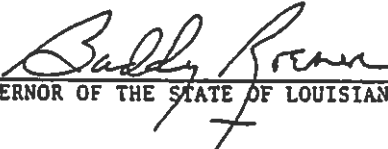
G. The plan shall provide for full implementation of the Community and Family Support System by July 1, 1993.

H. The council shall submit a report evaluating the effectiveness of the plan and its implementation to the House Committee on Health and Welfare, for review and approval, the Senate Committee on Health and Welfare, for review and approval, the secretary of the Department of Health and Hospitals, and the

secretary of the Department of Social Services prior to the
convening of the 1998 Regular Session of the Legislature.


SPEAKER OF THE HOUSE OF REPRESENTATIVES


PRESIDENT OF THE SENATE


GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: 6-29-89

Appendix B

Sliding Fee Scale Methodology

We estimate the total net income the state would generate would be \$100,000 upon full implementation of a sliding fee scale applied to families who were not Medicaid eligible and whose income is above 200% of the poverty level (\$24,000 for a family of four). The income for the state is derived as follows:

4500 families will receive services upon full implementation of the family support plan. 17% of total Louisiana families have an income of \$25,000-\$35,000, therefore, 765 of families eligible for services will earn \$25,000-\$35,000. They would contribute 18% of the cost or \$450 each. This totals to \$344,250 in contributions (\$450 x 765 families).

9% of total Louisiana families have an income of \$35,000-\$50,000, therefore, 405 of families eligible for services will earn \$35,000-\$50,000. They would contribute 27% of annual costs or \$675 each. This totals \$208,125 in contributions.

5% of total Louisiana families have an income of \$50,000 or more. Therefore, 225 of eligible families for services earn \$50,000 or more. They would contribute 37% of costs or \$925 each. The total contribution would be \$208,125.

The total contribution would be \$825,750 to the state. However, only 25% of total families would not be eligible for Medicaid or waived services and would therefore be contributing. 25% of \$825,750 is \$206,438 which would be the total gross income to the state.

We approximate that 50% of that income would be used in administrative overhead; case management time to administer eligibility initially and yearly to confirm income; administration of accounting section to handle incoming funds; and supervisory costs, resulting in a net income to the state of only \$100,000, a rather small amount, making implementation of a sliding fee scale unwarranted.

The 1980 census figures were used to estimate annual income. The attached contribution chart is used by the pilot projects and the above calculations were made using these figures.

FAMILY SUPPORT PROJECTS SLIDING FEE SCALE

<u>Taxable Income</u>	<u>Percentage of Co-Payment</u>
up to \$661	0
662-773	2
774-1019	4
1020-1229	6
1230-1413	8
1414-1626	10
1627-1900	13
1901-2187	16
2188-2544	19
2545-2959	23
2960-3442	27
3443-4003	31
4004-4656	35
4657-5415	40