DOCUMENT RESUME

ED 306 753 EC 212 817

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TITLE	Family Supports in the USA: Current Trends in Policy and Practice.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY	National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE	Aug 88
GRANT	G0085C3503
NOTE	32p.; Paper presented at the International Conference on Family Support (1st, Stockholm, Sweden, August 14-19, 1988).
PUB TYPE	Speeches/Conference Papers (150) -- Information Analyses (070)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Agency Role; *Delivery Systems; *Disabilities; *Family Programs; Family Role; Helping Relationship; Legal Responsibility; Program Development; *Program Effectiveness; Respite Care; Social Change; Social Services; *Social Support Groups

ABSTRACT

Family support services are systematic efforts to support natural, adoptive, or foster families who have a family member with a disability. Programs vary in the types of services offered, goals, and number of families served. The most promising approaches to family support provide services that are flexible and individualized, build on informal sources of support and existing social networks, maximize community participation, provide children with permanent homes, and place control in the hands of families themselves. Barriers that hinder the development of family support services include funding mechanisms that favor institutional care, administrative confusion, role of public agencies versus private responsibilities, traditional service models that substitute for rather than support the family, pressure to maintain the status quo, unequal access to services, and lack of federal policy. Family services can be supported on the grounds that they are based on current service ideology and research-based literature, are consistent with existing legislation, save money, and reflect traditional American family values. To fully implement family support services requires adoption of social change in three spheres: the sphere of ideology, the sphere of practice, and the sphere of legal initiative. (JDD)

FAMILY SUPPORTS IN THE USA:

CURRENT TRENDS IN POLICY AND PRACTICE

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Prepared for the First International Conference
on Family Support Related to Disability,
Stockholm, Sweden, August 1988.

Preparation of this paper was supported in part by the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability Research and Rehabilitation under cooperative agreement no. G0085C3503 awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University. The opinions expressed herein are those of the author and no endorsement by the U.S. Department of Education should be inferred.

ABSTRACT

In the United States, like in so many other countries, families of children with disabilities have historically been faced with two options: either to place their children out of home, or to take care of the child at home, with little, or no external assistance. The third option called "family support" is slowly emerging and there is now a growing commitment to devote more attention and resources to support families of children with disabilities to care for their children at home. The purpose of this paper is to offer an explanation of what is most commonly meant by "family support" in the United States and describe what characterizes some of the most promising practices in family support services. It will also address the major barriers to the development of family supports, review some of the strongest arguments in favor of the provision of such services and discuss public policy issues that influence family support services. The paper draws upon the work of a research team at the Research and Training Center on Community Integration at the Center on Human Policy, Syracuse University. The research team has, for the past three years, conducted qualitative studies of some of the most innovative and promising practices in family supports across the United States.

INTRODUCTION

One of the greatest shortcomings and tragedies of traditional services is that they have undermined families. In the United States, like in so many other countries, it has often been easier for parents to institutionalize their children with disabilities, or place them in other out-of-home settings than to receive support services to keep their children at home. Families have historically been faced with two options: either to place their children out of home, or to take care of the child at home, with little, or no, external assistance. The third option called "family support" is slowly emerging. There is now a growing understanding and commitment to devote more attention and resources to support families of children with disabilities to care for their children at home and the term "family support" has become quite popular in the USA in the last few years. In the past professional human service workers have often urged parents to abandon their disabled children. Today professionals are beginning to realize that even if parents may not be perfect we will never invent anything better for a child than a family. Professionals should support, not supplant the family.(1)

The purpose of this paper is to offer an explanation of what is most commonly meant by "family support" in the United States and describe what characterizes some of the most promising practices in family support services. It will also address the major barriers to the development of family supports, review some of the strongest arguments supporting the provision of such services and discuss some of the public policy issues that influence family support services.

STUDYING THE MOST PROMISING PRACTICES

The size and diversity of the United States of America and lack of a clear federal policy with regards to family supports makes it difficult to talk about family supports in general. Currently most states offer something which they call family supports, or are in the process of initiating their first programs but the types of supports available vary significantly from state to state.

This paper draws upon the work of a group of people who have, for the past three years, been working at the Research and Training Center on Community Integration at the Center on Human Policy. (2). This group has been studying innovative and promising efforts to support people with the most severe disabilities to become part of their communities. We conducted a national search for "model programs" or programs with "exemplary and promising practices." Each nominated program was contacted and interviewed by phone and many were selected for a site visit by project staff members.

During these site visits we spent time with people with disabilities, their families, friends and staff who assist them. The purpose of these site visits was not to evaluate these programs or agencies. Rather the purpose is to identify, document, and learn about innovative ways of supporting people with severe disabilities in their communities. These innovative approaches fall into several categories including family supports. The project staff visited a number of family support services across the United States and spent time with families and the staff who support them, to find out what their life is like and what types of supports receive. We also talked to friends and neighbors, and interviewed administrators and other agency staff.

In this presentation I will share with you some of the things we have learned about the most innovative ways of supporting families. (3)

WHAT IS FAMILY SUPPORT?

Family support services are systematic efforts to support natural, adoptive or foster families who have a family member with a disability. Family support services are designed to assist families who wish to keep a member with a disability at home, but need assistance to do so. Most family support programs in the United States started after 1980. In many places family support services are limited to respite services while other offer a wide range of services to meet the individual needs of each family.

While it varies significantly from state to state what type of services are offered, most family support programs fall into three main categories.

1) Economic support programs, which provide either direct cash subsidies or reimbursement to families to meet the extra costs of having a family member with a disability living at home. Cash subsidy programs are designed to offer families flexibility to pay for services and goods such as specialized equipment, respite care, and diapers. In some states families get a fixed amount of money each month and the family can decide how to spend it, while in other states families are only reimbursed for certain goods or services.

2) Support service programs. The programs that fall under this category offer a range of different services. Some programs offer only one type of service, for example respite care or in-home training. Other programs may offer a variety and combination of services such as in-home nursing, training or attendant care, physical adaptation of the home, consulting and referral, specialized nutrition and clothing, respite care, transportation, specialized equipment and supplies, recreational activities, and many more.

3) Combination programs, that offer both support services and economic support to families. (4)

A nationwide survey conducted in 1983 - 84 showed that the services most frequently offered are respite care and adaptive equipment. (5)

THE GOALS OF FAMILY SUPPORTS

Family support programs usually have three major goals:

1) To prevent (or at least postpone) unnecessary out-of-home placement.

2) To strengthen the family's capacities to care for a family member with a disability.

3) To improve the quality of life of individuals with disabilities and their families. (6)

Some family support programs have the additional goal of providing family supports to encourage families to bring back home children who have been placed in nursing homes or other out-of-home placements. Without these supports families are often forced to seek out-of-home placement for a family member with a disability. By providing the right service at the right time, family supports can prevent or at least delay unnecessary out-of-home placements and make a substantial difference in the quality of life for the family. Appropriate family support has also been a factor in adoption or foster home placements for children with severe disabilities. Families are more likely to adopt a child with a disability if they know they will receive support services such as financial assistance to pay for the extra expenses entailed in taking care of the child.

HOW MANY FAMILIES ARE SERVED?

It is very unusual to find uniformity of any kind across the United States. The U.S. is geographically such a huge country with a population of 240 million people of very different racial, cultural and ethnic background. The size of the country along with its diversity and heterogeneity makes it very difficult to generalize about anything in the U.S. This also applies to human services. There can even be a great diversity in family support services within the same state or service region and the support available for families depends a great deal on where people live. There is no federal policy that guarantees rights to, or equal access to family supports and each state has its own rules and regulations with regard to services for people with disabilities. For example, each state has eligibility criteria of some sort to decide who should get family support services. These criteria vary from state to state and may be related to the severity of disability, type of disability, judgement of the family's ability to cover the cost of care, and other factors.

Currently most states across the United States offer something that they call family supports, or are in the process of initiating their first programs but there is a great variation in the amount of money being spent and the number of people being served. The funding for these services usually comes from local, state and federal funds. In some states, pilot programs can serve as few as fifteen families. (7) In other states, thousands of families receive supports. Similarly there is a great variety in the size of state budgets for family supports. In some states only a few thousands of dollars are available for these services while others spend millions of dollars. The amount of money spent on family support can be placed in perspective by comparing it to the amount spent on institutional placements or what percentage of the total state mental retardation budget is dedicated to family supports. Most states spend only one percent or less of the total developmental disability budget on family supports. (8)

CHARACTERISTICS OF THE MOST PROMISING PRACTICES (9)

This section describes the issues the research team at the Center on Human Policy has identified as positive characteristics of some of the most promising practices in family support services. This is by no means what the typical family support program in the United States looks like. No one program has all of these characteristics, some innovative programs have most of these and other programs have only a few.

Ideological Commitment

The people who are running the most innovative community programs in the United States share a strong ideological commitment. They firmly believe that all people, regardless of the severity of their handicap, belong in the community. This is also true of the people running the most promising family support services. They believe that all children, regardless of their disability, belong in families and are committed to do "whatever it takes" to support families of children with disabilities. This involves the creativity to design individualized supports and respond flexibly to each family's needs rather than requiring the family to fit or adapt to the program.

Parents as Partners

The most innovative programs involve parents in the design, operation and monitoring of services. Parents are not treated merely as clients, but as partners in developing services. Professionals come and go, but parents will always be there. Some professionals have had the tendency to say that parents do not know what is best for their children. These professionals also have the tendency to develop programs and then find families to fit the programs. In designing family support services it is important to think in terms of what families need, and no one knows better than the families themselves what they need to take care of the child.

Family-Centered Approach

The most innovative approach to support families is to define services broadly and in terms of the whole family. The services offered are family-centered where the needs of the child as well as his or her family are taken into account. Supports are targeted not only to the individual child but to assist the whole family. The role of professionals and other service providers is to work with the family, not just to do things for the family.

Individualized Flexible Supports

In many places in the United States, family support services are limited to the provision of respite services. While it is true that families need respite care, family support can encompass much more. Families know best what they need and the most innovative approach is to ask families what they need and allow the family, rather than the professionals, to determine the needs.

The supports families need can vary considerable from one family to the next. Some families may only need a one-time purchase of a piece of adaptive equipment, while others need constant and on-going support services. Some families may need only one type of support, others may need a several. Families may need more intensive supports during certain times and less intensive supports at others. Family supports need to be flexible enough to both meet the unique need of the child and his or her family, and vary as the needs of the child and the family change.

Family supports are generally provided through either direct services, a direct cash subsidy, or a combination of the two. The cash subsidy can offer significant flexibility if adequate supports are available for purchase. Some states have also been able to offer individualized, flexible programs through use of a combination of direct service and cash subsidy.

Empowering Families

Good family support services place the control in the hands of the families themselves and the role of the service provider is to assist and support families, to work with them, rather than just doing things for them. Good agencies recognize that families may need assistance in identifying short- and long-term support needs, gaining access to appropriate support services, and in overall service coordination. However, good agencies function as case managers or service coordinators, not as family managers. They allow the family to be in control.

Natural Community Supports

Whenever possible, many innovative programs use natural, community supports rather than specialized supports to assist families having a child with a disability. These include: use of friends, neighbors, or relatives to help support families, and use of community medical, educational, vocational, recreational and other resources and services. In the most innovative programs professionals see it as their role to increase and strengthen the family's connections to natural community supports. The most promising programs design their services to maximize integration and participation of children with disabilities in community life.

Permanency Planning (10)

The most innovative programs recognize the rights of all children to belong to a family and the needs of all children to have enduring relationships with adults. If children with disabilities cannot remain with their families, for whatever reason, good programs view out-of-home placements initially as a temporary arrangement and direct their efforts toward reuniting the family. When families cannot be reunited or when active parental involvement is absent these programs try to fulfill each child's right to a stable family through adoption or foster family. Many good agencies don't view institutionalization or other group settings as an acceptable option for children.

All children need a permanent home but it has taken a while for the concept of "permanency planning" to make its way into the field of developmental disabilities. The sad fact is that most states and agencies have actually discouraged children with disabilities from having a permanent and stable home. Family support services have only recently been offered to families and children placed out-of-home have often been bounced from place to place; from institution to group home or from one foster home to another and legal and financial barriers have stood in the way of adoption. For example, in an evaluation of one state's specialized family care program for people with developmental disabilities Taylor, et al. (1986) found that seven out of ten families they interviewed had considered adopting children placed in their home, but had been hindered in various ways in doing so. (11)

The most innovative programs are now beginning to take a serious look at permanency planning for children with developmental disabilities to fulfill each child's right to belong to a family and have a permanent stable home.

No One Program is Perfect

One of the lessons we have learned is that there is no such thing as the perfect program and no agency delivers perfect family support services. It was also interesting to learn that the most promising family support programs were very self-critical and conscious of their shortcomings and constantly struggling with how they could provide better services.

To summarize the lessons we have learned about the most promising approaches to family supports in the United States we can say that the best family support services strive to provide services that are: flexible and individualized, build on informal sources of support and existing social networks, maximize community participation, provide children with permanent homes and place control in the hands of families themselves.

BARRIERS TO FAMILY SUPPORT SERVICES (12)

Currently there are a number of barriers that hinder the development and provision of family support services in the United States. Some of these barriers are specific to the United States while others are similar to the barriers to family support services in other countries.

Funding Mechanisms

Current funding mechanisms present major obstacles to family support services. The main federal funding source for long term care of people with disabilities in the U.S. is called Medicaid. This funding source has always focused on medical care and favored institutional care and other out-of-home settings rather than community-based services. During the past five years serious efforts have been made to reform Medicaid, but without success. Still most of the Medicaid dollars go to institutions, group-homes and other segregated services.

Administrative Confusion

It requires complex planning and administration to establish and operate effective and comprehensive statewide family support services. Many states have been reluctant to do this. As a result most states do not provide comprehensive family supports and have not established clear administrative mechanisms to develop or provide such services.

Many states have not yet made decisions about which state department should administer family support programs, what funding sources should be tapped, what type of services should be provided, what families should be eligible, and so on. This often results in confusing administration and funding categories where respite services can, for instance, be provided under the funding category "recreation."

When family support services have not become an integrated part of the state's administration these services have a tendency to be funded by "soft money" which means that states make available time-limited grant money that agencies around the state have to compete for. This is a very insecure funding source and agencies cannot be certain that their funding will be renewed. This unfortunately contributes to the perception of some families that institutions are stable environments and will be there long term and that community services are unstable and "experimental."

A Private Problem or a Public Issue

What is seen as "private" and what is seen as "public" is somewhat different in the United States than in many other countries and there is a strong tendency to protect what is seen as private from public interference.

The family and family affairs are by many Americans seen as private and as a nation Americans have not reached a consensus about what role the public should play in private family matters. Children with disabilities, as well as other children, are seen as the private responsibility of the family where the public should play a limited role. Americans also tend to see disability as a private problem, not as a public issue. (13)

Traditional Service Models

The current professional approach to planning and providing services favors service models that substitute rather than support the family. This may partly be because it is technically easier to substitute the family than to plan a service delivery model that requires a more flexible and individualized approach where a wide range of interacting factors have to be taken into account. In addition, most professionals in the disability field have been trained to develop and work within traditional, facility-based, segregated service models.

Pressure to Maintain Status Quo

While far more people with disabilities live with their families than in institutions or other out-of-home settings, the majority of public dollars are spent on institutions and other residential settings. Policy makers are under a great deal of pressure to maintain this division of funding. Such pressure comes from people who see themselves as benefiting from status quo. These are, for example, people who work in the institutions and parents who have sons and daughters in institutions and fear what happens to them if funding is redirected.

Why Pay for Something that has Always Been Free?

Given the current pattern of funding institutions and community-based programs, the provision of family supports would very likely require additional funds. Even if family support services cost much less than institutional care and it could be argued that family care would be cheaper in the long run, the scarcity of fiscal resources make policy makers reluctant to increase family support services. Besides, from their point of view, family care is something that is already provided at no public cost so why start paying for it now?

Unequal Access to Services

The United States does not have socialized medicine. Instead people have to buy health insurance to cover the cost of medical care. Those who do not have health insurance have to pay for medical care with their personal funds. This situation brings specific problems to those who have a family member with long-term health needs because most health insurance companies do not cover fully extensive long-term health care. This influences families' accessibility to family support services because many of these services are defined as health related. This is true of services such as nursing, physical therapy, speech therapy, dental services, occupational therapy, and many more.

The major public funding options available to families are Supplemental Security Income (SSI) and Medicaid. Both are tied to very complex eligibility criteria that have a built-in institutional bias. If the individual with the disability lives at home the eligibility to this financial assistance is related to the family's income. The family's income is not an eligibility criteria if the individual lives in an out-of-home placement. This is also true of children and attempts to change these eligibility criteria have not been successful. Therefore, to be eligible for family support services or public benefits to pay for such services, families must either be very poor, become very poor, or seek out-of-home placement if they cannot afford to cover the cost of services without external support. This situation primarily affects middle income families because many low income families qualify for SSI or Medicaid and high income families are likely to be able to afford additional costs without assistance from public programs. Middle income families are caught in the position of having too few resources to cover medical costs and too many resources to qualify for government benefits. (14)

Lack of Federal Policy

The single most serious barrier to family support services is the lack of federal policy that requires states to provide such services. Current federal funding regulations do not require states to provide family supports. Instead family supports are only permitted under current Medicaid regulations. For states to be eligible to be reimbursed for part of their spending on services for people with disabilities (50-78% depending on how rich the state is) they have to conform to federal regulations that mandate them to provide certain types and levels of services.

As long as family support services are not mandated, the states will be reluctant to provide such services. Many states find it hard enough to comply with current regulations and will not voluntarily start services that they are not required to provide and may not even be reimbursed for. Until there is a clear federal policy that mandates family support services there will be no equal access to such services and only a few states will provide comprehensive family support services.

ARGUMENTS IN FAVOR OF FAMILY SUPPORT SERVICES

While there are some serious barriers to the development of family support services in the United States, there are also some significant arguments in favor of the development of these services.

Family Support Services are Grounded in Current Service Ideology

Family support services are grounded in the ideology of normalization; the belief that people with disabilities should have the opportunity to lead as normal life as possible. And community integration which emphasizes the rights of people with disabilities to be members of their home communities. What this ideology means has changed in the United States in recent years. For example, a few years back it was common to hear people refer to group-homes as the most innovative practices in community living for children with severe disabilities. What is seen as the most innovative practices today is to support children with disabilities to live with their families.

Family Support Services are Consistent with Existing Legislation

Family support services reflect a new way of thinking about serving people with disabilities. This new way of thinking is consistent with the major legislations that affect people with disabilities in the United States, among them the Developmental Disability Act of 1984, which states it as its overall purpose: "to assure that persons with developmental disabilities receive the care, treatment, and other services necessary to enable them to achieve their maximum through increased independence, productivity, and integration into the community. ...it is in the national interest to strengthen specific programs, especially programs that reduce or eliminate the need for institutional care." (15)

Family Support Services Save Money

One of the major arguments in favor of family support services is that it saves money because it prevents costly out-of-home placement. When researchers have compared the cost of residential out-of-home placement and the cost of home care, they find enormous savings when the care is provided at home. For instance, a recent study of the costs of residential care in Michigan showed an annual cost of $63,722 per person, compared with an annual cost of less than $5,000 for services provided directly to the natural family. (16) Another study of the cost-effectiveness of family support services reported an estimated cost of family support services of $8 per day, while the average out-of-home placement coasted almost $62 per day per person.(17)

Family Support is Supported by the Literature

A growing body of literature and research provides evidence that children with disabilities belong in families and shows that institutionalization has negative effects on children's development while home and community-based care have positive effects. There is also increasing evidence in the literature that parents can, with appropriate supports, meet the extraordinary needs of their children. (18)

Supporting Families Reflects Traditional American Family Values

Another common argument in favor of family support services is that family support recognizes and supports the importance of the family as the cornerstone of society. Without family support services, families are much more likely to be broken up because of the additional stress it brings to the family to have a member with a disability. The goal of family support services is by definition to support the family as a unit, keep families intact and help the family in the traditional role of "taking care of their own."

THREE SPHERES OF SOCIAL CHANGE (19)

The adoption of family support services as a new way of serving children with disabilities and their families is really a question about how social change comes about and how a society conceptualizes, accepts and implements new ideas. When we think about how far the United States have come towards implementing family support services we can answer by looking at three separate but related spheres of social change: the sphere of ideology, the sphere of practice, and the sphere of legal initiative.

Changes in all three spheres result in major social change which in this case would mean that we would have an ideology that reflects the belief that all children should be supported to live with their families, new practical skills to successfully implement this belief, and a legal mandate both requiring that family support services be provided and providing the funds necessary to do so.

Let us now look closer at family support services in the United States today with regard to these three spheres.

Ideology

Supporting families to keep their children with disabilities at home is consistent with the ideology of normalization and community integration. During the past few years this ideology has been refined and articulated in such a way that it now includes the belief that all children with disabilities should live with their families. While there is still some controversy about this belief there is a growing consensus and commitment to define the ideology in this way.

Practice

The past years have seen improvement in professional practices, and the development of new techniques and technologies make it now both possible and practical to support children in their homes and communities. While it is true that relatively few professionals are doing this in practice the fact still remains that we do have the necessary knowledge and techniques to provide family support services.

Legal Initiative

There is no legal mandate that requires that family support services be provided. These services are only permissive under current legislation. Even if family support services are consistent with the spirit of some of the major legislation that influences the lives of people with disabilities there is no legislation that mandates such services or makes available the funds necessary to provide such services. For the past five years members of the US Congress have tried to reform current legislation to mandate family support services. These attempts have not yet been successful.

Conclusion

Looking at these three spheres of social changes shows that the single major hindrance to the development and provision of family support services in the U.S. is the lack of public policy that could lead to a legislation mandating family support services and new funding mechanisms.

FOOTNOTES

1) See Taylor, S., Racino, J.A., Knoll, J.A., and Lutfiyya, Z. (1987): The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities. Syracuse, NY: Human Policy Press. Page 4.

2) The members of the Center on Human Policy's research team are now: Hank Bersani, Douglas Biklen, Robert Bogdan, Dianne Ferguson, Zana Lutfiyya, Julie Racino, Bonnie Shoultz, Steven Taylor, Rannveig Traustadottir, and Pam Walker.

3) For a description of this project as a whole see for example Taylor, S., Racino, J.A., Knoll, J.A., and Lutfiyya, Z. (1987): The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities. Syracuse, NY: Human Policy Press.

Nominated agencies and programs are listed in Programs Demonstrating Model Practices for Integrating People with Severe Disabilities Into the Community (1986). Syracuse, NY: Center on Human Policy. The Center on Human Policy has also published a series of site visit reports and other materials through this project.

4) See for example, Governor's Planning Council on Developmental Disabilities (1987): <u>Supporting Family Care of Persons who are Developmentally Disabled: Family Support/Cash Subsidy Programs</u>. Springfield, Illinois: GPCDD. Page 18.

5) Bradley, V.J. and Agosta, J.M. (1985a): "Keeping Your Child at Home: The Case for Family Support" in <u>Exceptional Parent</u>, November 1985, pp. 10-22.

6) See for example, Bersani, H. (1987): "Timely Answers: What are Family Supports," in <u>Families for All Children</u>, a newsletter on family supports published by the Center on Human Policy, Syracuse University, September 1987. And, <u>Family Support Program: Guidelines and Procedures. Support to Families Who Have a Child with Severe Disabilities</u>. Published by Wisconsin Department of Health and Social Services, November 1987. Page 1 - 3.

7) Bradley and Agosta (1985a) op.cit.

8) Bersani, H. (1987): "Center Provides Timely Answer to Family Support Questions" in the <u>TASH Newsletter</u>, January 1987.

9) This overview is based on various materials on family supports developed by members of the Center on Human Policy's research team. The following three were especially useful: (1) Taylor, S., Racino, J.A., Knoll, J.A., and Lutfiyya, Z. (1987): The Nonrestrictive Environment: On Community Integration for People with the Most Severe Disabilities. Syracuse, NY: Human Policy Press. (2) A Statement in Support of Families and their Children, a policy statement published by the Center on Human Policy, listing principles that should guide public policy toward families of children with developmental disabilities and the actions of states and agencies when they become involved with families. And (3) Information Package on Family Supports (in preparation), especially the introduction by Pam Walker: "Issues in Family Supports."

10) For a full discussion of "Permanency Planning" see Taylor, S. and Lakin, K.C. (in submission) "Permanency Planning for All Children and Youth: Policy and Philosophy to Govern Out-of-Home Placement Decisions."

11) Taylor, S., Lutfiyya, Z., Racino, J., Walker, P., and Knoll, J. (1986): An Evaluation of Connecticut's Community Training Home Program. Syracuse, NY: Center on Human Policy.

12) Agosta and Bradley discuss some of these barriers in Agosta, J.M. and Bradley, V.J. (Eds.) (1985b): Family Care for Persons with Developmental Disabilities: A Growing Commitment. Boston, MA: Human Service Research Institute. Pages 56-69.

13) For an analysis of private problems and public issues see for example C. Wright Mills (1980): The Sociological Imagination. London: Oxford University Press.

14) Agosta and Bradley (1985b) op.cit., pp. 184-200.

15) Developmental Disabilities Act of 1984 (Public Law 98-527) in A Compilation of Federal Laws for Disabled Children, Youth, and Adults. Prepared by the Subcommittee on the Handicapped of the Committee on Labor and Human Resources, United States Senate. Washington, DC: US Government Printing Office. Page 125.

16) Bradley, V.J. (1988): The Medicaid Family and Community Quality Service Act: How Does it Address Research Findings, Quality Assurance, and Family Support? A statement prepared for US Senate Finance Committee, United State Senate. Washington, DC. March 22, 1988. Page 9.

17) From Governor's Planning Council on Developmental Disabilities (1987) op.cit.

18) See Agosta, J., Bradley, V., Rugg, A., Spence, R., and Covert, S. (1985): Designing Programs to Support Family Care for Persons with Developmental Disabilities: Concepts to Practice. Boston, MA: Human Service Research Institute. Page 6-7.

19) Adapted from Bersani, H. (1987): "Principles and Practices of Community Integration for Persons with Severe and Profound Disabilities," in Covert, A.M. and Frederick, H.D.B. (Eds.) Transition for Persons with Deaf Blindness and Other Profound Handicaps: State of the Art. Monmouth, OR: Teaching Research Publications. Page 103-110.