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AUTHOR Nelkin, Valerie
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ABSTRACT

The booklet explains ten principles of family-centered health care and six components of community based programs for children with significant medical problems. The principles are: The child and the family have basic rights of self-determination and autonomy. Health care services should be family oriented and maximize family control. Service systems should be community based. Services should be comprehensive and coordinated. Service systems should be accessible and responsive to children with special health care needs and their families. Parents should be early and continuous participants in the long-range planning for their children. Parents should be equal partners with professionals in the care of their children. Normal patterns of living in the home and community should be encouraged. Support services needed to care for children at home should be adequately funded. Families should help shape policies and procedures that affect health care delivery. Components of community-based programs include: increasing professional, family, and community capability; development of a service plan for the child and family through contract negotiation between families and providers; coordination of a plan for care at home; comprehensive service systems with a full continuum of services; quality assurance of services; a child home health care agenda at federal, state, and local levels. (DB)

Family-Centered Health Care for Medically Fragile Children

Principles and Practices

National Center for Networking Community Based Services
Georgetown University Child Development Center

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Family-Centered Health Care for Medically Fragile Children
Principles and Practices

Results of a meeting sponsored by the National Institute on Disability and Rehabilitation Research, U.S. Department of Education and the Division of Maternal and Child Health, U.S. Department of Health and Human Services

Prepared by
Valerie Nelkin

for
The National Center for Networking
Community Based Services
Georgetown University Child Development Center

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FAMILY-CENTERED HEALTH CARE FOR MEDICALLY FRAGILE CHILDREN

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I. INTRODUCTION

"Medically fragile" children are children with complex medical care needs who require technology, special services, or some form of ongoing medical support for survival. This definition includes children with a broad group of chronic and progressive illnesses and severe disabilities.

Increasingly, children are surviving because they receive full or part time assistance from machines and complex appliances that were not available twenty years ago. Other children are surviving through advanced, long-term treatment. Thus, the number of surviving medically fragile children is growing.

The care of medically fragile children has become a matter of national concern. Both parents and providers are talking about the cost and adequacy of care and the long-term quality of the children's lives. This concern extends to all levels of government and many different agencies.

Children with severe disabilities and their families often require long-term multidisciplinary services, such as health care, social services, mental health services, and educational and vocational assistance. Services to these children are best delivered using a comprehensive approach centered on the child, the family, and the community. This approach promotes the placement of medically fragile children in the least restrictive setting, in their own communities, and in their own homes whenever possible.

In recent years, there has been growing recognition of the importance of the family. Lee Schorr, Chair of The Select Panel for the Promotion of Child Health, said in 1980:

> Not only is the family the primary unit for the delivery of health services to infants and children, but the family environment is probably the greatest influence on a child's health....a child is dependent upon his or her mother and other family members not only for the physical necessities of life...but also for the emotional support and intellectual stimulation needed for healthy growth and development....The family is not only the principal influence upon a child's development, it is also the intermediary between the child and the outside world, including the health care system....Health providers can support, encourage, and enhance the competence of parents in their role as caregivers.

Children with chronic illnesses or severe disabilities and their families have special complex needs, desires, burdens, and challenges. Families have the central role in caring for their own children. Families may need assistance in carrying out their responsibilities for nurturing their children and encouraging them to develop as fully as possible. Families are the most important support system for medically fragile children, as for any other children.

In December 1986 a group of parents and professionals met in Bethesda, Maryland to identify critical aspects of family-centered health care for children with significant medical problems. The group identified principles of family-centered health care as well as components of a community-based program to meet the needs of these children and their families. These principles and components all are interrelated.

This meeting, an attempt to build consensus on principles of family-centered health care, incorporated and solidified previous efforts, including the Association for the Care of Children's Health (ACCH)'s "Elements of Family-Centered Care" and the Iowa Health Care Guidelines Project's "Principles of Health Care for Children".

The overall goal of this meeting was to improve services through family-centered care and family involvement in the health care process for children with intense medical needs. This document, a product of the meeting, is designed for use by parents and professionals who provide care and services for medically fragile children. Other groups such as administrators and trainers may also find this useful.

The following sections present principles guiding family-centered health care (Section II) and major components of community-based programs (Section III). Section IV is a summary of the document and Section V contains the meeting participant list.

II. PRINCIPLES OF FAMILY-CENTERED HEALTH CARE FOR MEDICALLY FRAGILE CHILDREN

1. The child and the family have basic rights of self-determination and autonomy.

2. Health care services should be family-oriented and maximize family control.

3. Service systems should be community based.

4. Services should be comprehensive and coordinated.

5. Service systems should be accessible and responsive to children with special health care needs and their families.

6. Parents should be early and continuous participants in the long-range planning for their children

7. Parents should be equal partners with professionals in the care of their children.

8. Normal patterns of living in the home or home-like environment and community should be encouraged.

9. Support services needed to care for children at home should be adequately funded.

10. Families should help shape policies and procedures that affect health care delivery.

Each principle is discussed below.

1. The child and the family have basic rights of self-determination and autonomy.

   Each child is a member of a family. Each child has a right to a home and to a long-term relationship with an adult or adults. Children have the right to live, grow, and play in their own homes and communities. Also, children should be able to participate actively in the intellectual, social, and recreational activities of their peers, and receive health care from their own doctors. They are entitled to live in the setting that provides the best opportunity for development.

   Families have the right to make decisions about their children's care, according to their own values. With accurate information and appropriate support, many parents have the capacity and desire to care for their children. Parents need complete and unbiased information about diagnosis, prognosis, treatment choices, and resources. Parents then can make informed choices about their children's care.

2. Health care services should be family-oriented and maximize family control.

   Since the availability of service systems and providers changes frequently, it is the family that usually remains the constant in the child's life. The family has the pivotal role in the care of the medically fragile child.

Thus, care for the child should involve goals directed toward increasing family capability, effectiveness, and control. Care should be geared to protect the integrity of the family unit.

It is important to recognize family strengths and the diversity of family attitudes, beliefs, and ways of coping. Health care professionals should respect these differences. Also, families are dynamic and experience change, which can affect long-term care for the child. As families have different ethnic backgrounds, religious preferences, and values, all services should be culturally sensitive.

Parents need access to complete information as well as to trained professionals and professional services. A goal of helping professionals should be to increase family control in this process. Finally, family-centered care should have a holistic approach. That is, families are complex and have needs well beyond those revolving around the care of the medically fragile child. The entire family's optimal functioning must be considered and supported by health care professionals.

3. Service systems should be community based.

Service delivery systems capable of providing medical, emotional, educational, and financial support to families as they care for their children in the community should be implemented. Many families and professionals have recognized that services to children are best delivered in their own communities and in their own homes, in their own communities and in their own homes, whenever possible. Support and resources at the community level allow these children to live as independently as possible. Children experience a more normal lifestyle, usually at less cost than institutional care.

The needs of these children and their families are great. To assure a better quality of life for them requires coordination of public, private, and voluntary systems at the community level.

4. Services should be comprehensive and coordinated.

Medically fragile children and their families often require a variety of long-term services, including health care, social services, financial support, and educational and vocational assistance. A range of coordinated services should be available, based on the child's and family's needs.

The child's and family's needs should be determined through comprehensive evaluation with frequent reassessment and ongoing monitoring. Parents caring for children with intense medical needs require ongoing support. Emotional support and stress management for families should be emphasized. Development of natural support networks is helpful and should be encouraged. Parent-to-parent support has proven very valuable.

Support systems are also important for siblings and paid to the emotional support needs of all family members involved in the care of medically fragile children.

5. Service systems should be accessible and responsive to children with special health care needs and their families.

Service delivery systems should be available, appropriate, accessible, and affordable. Families need to have access to services which maximize their child's potential. Accessibility includes issues of location, transportation, and financial support, as well as scheduling and language barriers. In addition, professional attitudes toward rehabilitation and family involvement can facilitate or hinder the provision of services. Also, systems of care should facilitate the participation of both parents.

Responsive community attitudes, such as acceptance of medically fragile children into schools and recreational facilities, are key components of successful community-based programs. Professionals and parents need to be involved in community outreach activities which promote health awareness and education. This will enhance the continuity of care across settings.

6. Parents should be early and continuous participants in the long-range planning for their children.

Family-centered care begins at the birth of the child. Parents need to be early, active participants in the care of their children. Family participation should be facilitated in all aspects of health care, including developing and evaluating the child's health care plan. As these children usually require a range of services over a long period of time, long-range planning for the child and the family must allow for change.

Infants, children, adolescents, and their families have developmental needs which must be assessed and incorporated into their health care plans. Creating an environment that supports developmental progress is essential.

7. Parents should be equal partners with professionals in the care of their children.

Successful family-centered health care depends on mutual respect of all parties involved (family, health care professionals, community agency personnel). Family oriented care encourages the child and the family to become educated health care consumers. Parents and professionals need a common knowledge base that will facilitate successful care at home and in the community.

"Equal partners" does not mean that parents and professionals assume each other's roles, but rather that they respect each other's roles and contributions. While professionals bring technical knowledge and expertise to this relationship, parents offer the most intimate knowledge of their children, and often special skills.

Effective parent participation in health care includes developing and monitoring a program of partnership with professionals. This collaboration is key to "making it work". As all parties learn to value each other, communication and coordination among the child and the family, health care providers, school personnel, and community agencies will be enhanced.

8. Normal patterns of living in the home and community should be encouraged.

   Medically fragile children have the right to live as happily and as normally as possible. Normal patterns of home and community living should be promoted, in an environment that supports and nurtures development.

   Portable respirators, cardiac monitors, and other devices allow children to sleep in their own beds and to be with their families. There is currently a move toward development of less complicated, more accessible equipment to allow the child to participate more fully in activities of daily living.

   A comfortable, loving atmosphere will promote the independence and health of the child and family. Community resources and support also allow these children to live as independently as possible.

9. Support services needed to care for children at home should be adequately funded.

Medically fragile children require many complex services and support personnel. Family-centered care advocates must recognize the tremendous financial burdens parents face, and assist them in their struggles for financial stability.

In addition to services such as direct medical care and equipment, these children and their families often require many auxiliary services, such as transportation, homemaker services, and respite care. Even after funding these services, care at home is less expensive than hospital care.

One of the most significant barriers to care at home for medically fragile children is the refusal of many insurance companies to cover extended care services in the home. This refusal is not logical, as care costs consistently have been much lower in a non-institutional setting. Improving the financing of care for these children and their families is critical to ensure that their needs can be met with limited resources.

10. Families should help shape policies and procedures that affect health care delivery.

As they acquire greater knowledge and understanding, families become educated health care consumers. Families can become active participants in all levels of health care. In addition to participating in their child's care planning and monitoring, and working collaboratively with professionals, families can assist in the development of policies and procedures that affect the overall delivery of health care services in their communities.

Parent participation should be encouraged in the development of programs and policies for the care of children in hospitals, other health care settings, and at home. Parents and professionals must work together to provide health education and awareness in their communities. Family advocacy efforts, coordinated with professional efforts, can strengthen public programs and policies that address the needs of medically fragile children and their families.

III. COMPONENTS OF COMMUNITY-BASED PROGRAMS

A family-focused and community-based approach assumes that there are common problems, requiring common basic support services. These services cut across specific diseases and conditions. This approach is especially relevant in the coordination of community-based systems of care. Comprehensive systems are needed for financing, coordinating and managing services to children with special health care needs.

The major components of community-based programs for medically fragile children are:

1. Increasing professional, family, and community capability.
2. Development of a service plan for the child and family through contract negotiation between families and health care providers.
3. Coordination of a plan for care at home.
4. Comprehensive service systems with a full continuum of services.
5. Quality assurance of services.
6. A child health care agenda at federal, state, and local levels.

Each component is discussed below.

1. Increasing Professional, Family, and Community Capability

Increasing capability must be addressed with professionals, families, and communities.

For Professionals:

Concepts and practice of family-centered care should be incorporated into the curricula for preparation of health professionals. Both pre-service and in-service training should be available for professionals in communication skills; collaboration skills; negotiation skills; medical ethics; confidentiality; processes for adaptation; conflict resolution; coping styles; and managing technology.

For example, a Michigan State University Medical School program provides an in-depth structured experience for learning and understanding family dynamics. Parents are included as teachers in the program to improve physician relationships with families. It is important for parents to participate in developing curricula and teaching.

Professional organization meetings can be used as models of parent-professional collaboration. Special fellowships focusing on working with chronically ill children and their families should be considered. Also, professionals should share effective practices and innovative ideas with other professionals in the field.

For Parents:

Parents need access to trained parent-to-parent support in hospitals immediately after the birth or diagnosis of the child. Parents also need access to current information. Parents should utilize the unique skills of health professionals who are also parents of special needs children. Ways of compensating parents for parent support involvement (stipend, child care, mileage, parking, etc.) need to be developed.

Parent-to-parent skill building should include the following: accessing service systems and negotiating with providers, stress management, time management, and methods for assisting the family in coping and adapting their lifestyle.

For The Community:

Community education will help make the community aware of the presence, needs, and contributions of children with medically complex conditions. Education also is needed on the importance of parent-to-parent support. Training is needed for volunteers who are currently or potentially involved with these children and their families.

State health, education, and social services agencies need to address personnel training on family-centered, community-based care. Development of interagency agreements is one mechanism to accomplish this. Additionally, local political leaders must be educated about the needs of these children.

Systems to provide information should be developed for parents, professionals, and communities. These systems should be current, readily available, understandable, accurate, and updated periodically.

2. Development of a Service Plan for the Child and Family Through Contract Negotiation Between Families and Providers

A comprehensive developmental plan needs to be created for each medically fragile child and his or her family. This plan should include an evaluation of the child's and family's strengths and needs in the areas of physiological functioning, motor functioning, cognitive functioning, and emotional and social interactive functioning. The care plan should focus on outcome objectives.

Creating this plan requires the collaboration of families and many professionals, such as physicians, nurses, physical therapists, occupational therapists, developmental specialists, and educators. Resources must be identified or created to implement and monitor this plan. Periodic reassessments are necessary.

After resources are identified, appropriate information must be provided to the family, other persons designated by the family, and a variety of professionals to monitor potential problems and needs. Case management helps ensure effective coordination of services.

A variety of tools should be developed and tested which include:

- Comprehensive assessment tools for identifying strengths and needs of the child and family
- Comprehensive assessment tools for provider and agency functioning
- Guidelines for contract negotiation with service providers (include physicians, home health agencies, equipment suppliers, funding sources, schools, and social service agencies). Contracts include clarifications or understandings as well as formal payment mechanisms.
- Therapeutic tools for the child and family to ensure optimal development
- Guides about legal rights to care and due process

3. Coordination of a Plan for Care at Home

Coordination of a home care plan requires a commitment to coordinated care at home at a policy level. Coordination of planning and care is needed in several areas: diagnosis; identification of resources; and plan development.

At Diagnosis:

The primary care physician, the child, the family, and other health care professionals need to discuss the child's diagnosis and prognosis. On the basis of available information, a plan for care at home should be developed. Periodic re-evaluation should occur.

Identification of Resources:

Parents can learn to care for and advocate for their children, but they need access to information and resources. Parents need to communicate with various community agencies involved with the care of medically fragile children. Parent-to-parent communication often is very helpful.

The primary care physician should be knowledgeable, accessible, and committed to quality care for families. The physician should be willing to assume responsibility for medical care for the child, including house calls when necessary, and assist parents in making decisions about appropriate care.

An interdisciplinary team is essential for successful care at home. Team members typically include the family, medical personnel (primary care physician, nurses, therapists), medical equipment vendors, nursing agency staff, social workers, educators, interpreters, and other family members or advocates.

The team should meet periodically to review short-term as well as long-term goals, including long-term financial planning, for the child and the family. The team also needs to meet during crises, and whenever the care plan requires revision.

In addition, a home care plan coordinator is needed. The coordinator might be the parents, the primary care physician, or a representative from a community agency. A parent and a professional might also serve as co-coordinators. Funding for coordinating services needs to be available.

Plan Development:

The care plan should include medical needs (both daily care and emergency); daily physical needs; educational and social needs; family needs; and financial needs. Realistic goals must be developed and reviewed periodically.

The commitment to coordinated care includes knowledge, understanding, communication, and collaboration of all parties involved with medically fragile children and their families.

Family input into the care plan must be assured. In a project in Dakota County, Minnesota, the family is the center of the child's program. Project Dakota is an early intervention program serving children with special needs from birth to four years of age. Parents and professionals formed an alliance to assist the family and community in promoting the optimal development of the child.

The project adopted a model in which the parent is an official and equal member of the team. Assessment, program planning, and implementation are collaborative efforts. Facilitators encourage the use of family and community resources to carry out the care plan.

4. Comprehensive Service Systems with a Full Continuum of Services

A successful community-based program must have a wide range of services. It should be flexible and be based on parent-professional collaboration, communication and trust. Service systems should enhance family self-esteem and empower families. Services and follow-up must be available and accessible to families.

The same model of care is not appropriate at every point in a child's and family's development, or for every family. Alternative models should be available. A comprehensive array of choices must be developed, such as alternative living arrangements (e.g., foster/adoptive homes) and respite care.

An effective system of services identifies gaps in care and provides programs or services to meet these needs. For example, educational programs are frequently missing from current service systems for medically fragile children. Several steps can be taken to reach the goal of integrating children into appropriate school systems. Programs can be developed in schools that encourage the acceptance of medically fragile children, and that build the schools' capacity to incorporate these children. School-based health services can be developed. Home-based educational services are an alternative when medically indicated.

The states need to assume leadership in developing these systems, and in bringing existing systems together. Interagency agreements between Departments of Health, Education, Social Services, and Crippled Children's Services can help pull together fragmented service systems. These agencies can jointly provide information, access to services, and monitoring.

5. Quality Assurance of Services

The purpose of quality assurance is to regulate and improve service provision. The quality assurance process should be minimally intrusive. Families should be involved in participatory decision making at all levels.

Quality assurance targets include: equipment and equipment providers; home-based caregivers; external caregivers; case managers; and support services.

A variety of methods are used to assure quality in services. One way is to conduct a survey of family and client satisfaction, to determine whether the services are comprehensive, coordinated, and accessible. Another is to provide a grievance mechanism, a recourse for families. Case management, with its "front line" monitors, also can be a quality assurance mechanism.

Standards are frequently used in quality assurance. Standards concerning the care of medically fragile children include standards for equipment and safety in care settings, and standards for training health care professionals. Standards are based on expectations of safe and effective service, and should focus on best practices. A group of parents and professionals should be convened to review existing standards that apply to the care of children with intense medical problems, and to recommend additional standards that are needed.

Another method of quality assurance is monitoring outcomes to determine improvements in the quality of life and functioning of the child and the family. This may involve review of records, assessment of client satisfaction, and interviews with key informants. Observations and assessments of caretakers also may be used. Aspects of quality assurance which need further study or funding include:

- The need and ability to respond with technical assistance or sanctions
- Monitoring financing of care and resource allocation
- The need for paid parent monitors at the state level.

6. A Child Home Health Care Agenda at Federal, State, and Local Levels

Public policy must be comprehensive, coordinated, and community based. Public policy should demonstrate support for efforts to care for medically fragile children in family settings. Families must be able to participate in the development of policy and procedures that affect health care delivery.

Direction from Federal and state levels is needed to encourage local systems to develop. These systems can be designed and implemented through increased interagency collaboration at local, state, and Federal levels. Collaboration must involve both public and private sectors.

Policy research is needed to develop and evaluate strategies for implementing these principles.

IV. SUMMARY

Services to medically fragile children are best provided using a comprehensive, coordinated approach focused on the child, the family, and the community. The growing recognition of the importance of the family should lead to increased family participation at all levels of health care--including helping to shape policy and procedures that affect service delivery.

Certain principles should guide family-centered health care. Medically fragile children have basic rights, such as living in their own homes and communities. Their families also have rights, such as making informed decisions about their children's care.

Parents and professionals need to develop partnerships in the care of these children. Their positive collaborations -- and cooperation among the public, private, and voluntary sectors -- will help ensure family- centered care.

Because families have different strengths, needs, and values, they require different levels of family support. Alternatives such as respite care should be available in the community. Parent-to-parent support should be encouraged.

Service systems should be flexible and responsive to medically fragile children and their families. Families must have access to services that maximize their child's potential. Responsive community attitudes, such as acceptance of these children into schools and recreational facilities, help ensure successful community-based programs.

All children and their families should have access to adequate health insurance. Health insurance should cover chronic care and care in the community. It should recognize the comprehensive needs of children and their families, and cover supportive services. Both private and public insurers should help improve the financing of care for medically fragile children. Options such as Medicaid waivers and state risk pools should be explored further.

As these principles guide family-centered care, community systems of services can be developed and improved. Major components of effective community-based programs include increasing professional, family, and community capability through education and training; development and coordination of a service plan for the, child and family; comprehensive service systems; quality assurance of services; and a child health care agenda at all levels of government.

Medically fragile children and their families have many challenges and needs. While society must share in providing the services and financial coverage required, family-centered care and family empowerment are key contributors to the best results.

V. PARTICIPANT LIST

Heidelise Als, Ph.D.
Children's Hospital
Enders Pediatric Research Building, M27-29
320 Longwood Avenue
Boston, MA 02115

Julie Beckett
2420 D Avenue, N.E.
Cedar Rapids, IA 52402

Valerie Bradley
Human Services Research Institute
2335 Massachusetts Avenue
Cambridge, MA 02140

Helen Clack
Route 1, Box 1274
Kountze, TX 77625

Molly Cole
117 Harbison Avenue
Hartford, CT 06106

Mary Donar, R.N.
State of Pennsylvania Ventilator Program
Children's Hospital of Philadelphia
34th and Civic Boulevard
Philadelphia, PA 19104

Robert Greenstein, M.D.
Pediatric Research and Training Center
Department of Pediatrics
University of Connecticut School of Medicine
Farmington, CT 06037

Beverley H. Johnson
Association for the Care of Children's Health
3615 Wisconsin Avenue, N.W.
Washington, DC 20016

Roxane Kaufmann
Georgetown University Child Development Center
3800 Reservoir Road, N.W.
Washington, DC 20007

Monica Jones
433 East Pedregosa Street
Santa Barbara, CA 93103

Phyllis R. Magrab, Ph.D.
Georgetown University Child Development Center
3800 Reservoir Road, N.W., CG52
Washington, DC 20007

Margaret Mikol
SKIP of New York
500 East 83rd Street, Suite 1B
New York, NY 10028

Valerie Nelkin
Bear Enterprises, Ltd.
9006 Acredale Court
College Park, MD 20740

Patricia Pierce, Ph.D.
University of Florida
5700 S.W. 34th Street, Suite 323
Gainesville, FL 32603

Cordelia Robinson, Ph.D.
Myer Childrens Rehabilitation Institute
44 South 44th Street
Omaha, NE 68131

Nancy Rosenau
Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, MI 48044

Lynne Rucker
Mental Retardation Services, Region 5
2202 South 11th Street, 4th Floor
Lincoln, NE 68502

Deb Russell
9785 North 30th Street
Richland, MI 49083

Karen Shannon
Sick Kids Need Involved People (SKIP)
216 Newport Drive
Severna Park, MD 21145

May Shayne, A.C.S.W.
Institute for Public Policy Studies
Vanderbilt University
1218 18th Avenue
Nashville, TN 37212

Moiser Simpser, M.D.
Children's Hospital of Miami
Pulmonary Division
6125 S.W. 31 Street
Miami, FL 33155

Patricia McGill Smith
National Information Center for Handicapped
Children and Youth
1555 Wilson Boulevard, Suite 508
Rosslyn, VA 22209

Robin Thomas, R.N., Ph.D.
2855 N.W. Golden Drive
Seattle, WA 98117

Federal Government Participants

G. Thomas Bellamy, Ph.D.
Special Education and Rehabilitation Services
330 C Street, SW, Switzer 3006
Washington, DC 20202

Kathleen Kirk Bishop, D.S.W.
Division of Maternal and Child Health
5600 Fishers Lane, Room 6-40
Rockville, MD 20857

Aaron Favors, Ph.D.
Division of Maternal and Child Health
5600 Fishers Lane, Room 6-40
Rockville, MD 20857

Vince Hutchins, M.D.
Division of Maternal and Child Health
5600 Fishers Lane
Rockville, MD 20857

Naomi Karp
National Institute on Disability and
Rehabilitation Research
330 C Street, SW, Room 3424A
Switzer Building
Washington, DC 20202

Merle McPherson, M.D.
Division of Maternal and Child Health
5600 Fishers Lane, Room 6-40
Rockville, MD 20857

Paul Thomas
National Institute on Disability and
Rehabilitation Research
330 C Street, SW
Switzer 3424 A
Washington. DC 20202

Robert Wardwell
HCFA
East High Rise Building
6325 Security Blvd., Room 429
Baltimore, MD 21207

Robert Wren
HCFA
Room 401, East High Rise Bldg.
6325 Security Blvd.
Baltimore, MD 21207