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ABSTRACT

The bibliography and resource guide summarizes relevant research and information on home care for children with disabilities and chronic illnesses, including those with such diagnoses as spina bifida, cerebral palsy, severe mental retardation, acquired immune deficiency syndrome (AIDS), hemophilia, sickle cell anemia, autism, or failure-to-thrive syndrome. Section I provides a narrative overview of three main themes addressed in the resources listed: (1) the values involved in making home care available; (2) the needs of children and their families; (3) financing issues related to home care. Section II offers a list of published resources, arranged by subtopic areas such as siblings, prevention, financing, federal policy, employer initiatives, case management, conceptual framework, research and evaluation, and policy development. After identifying a specific subtopic and the corresponding list of resources, the reader locates relevant bibliographic summaries in Section III, an alphabetical list of citations with annotations. Four appendices list journals and newsletters focusing on the care of children with chronic illnesses, published directories identifying services nationwide, names and addresses of relevant organizations, and other published bibliographies that relate to children with special health needs.
 (JW)

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HOME CARE FOR CHILDREN WITH CHRONIC
ILLNESSES AND SEVERE DISABILITIES:
A BIBLIOGRAPHY AND RESOURCE GUIDE

November 15, 1987

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A BIBLIOGRAPHY AND RESOURCE GUIDE

November 15, 1987

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TABLE OF CONTENTS

INTRODUCTION.....	i
HOW TO USE THE BIBLIOGRAPHY AND RESOURCE GUIDE.....	ii
I. SUMMARY OF MAIN THEMES	
A. Overview of Values and Governing Principles....	I - 1
B. Overview of Families and Home Care.....	I - 3
C. Overview of Financing Issues.....	I - 8
II. CROSS REFERENCE GUIDE	
A. The Cross Reference Guide.....	II - 1
B. Substantive Sub-Topics.....	II - 3
C. Generic Sub-Topics.....	II - 16
III. SELECTED LITERATURE	
A. Alphabetical List of Annotated Citations.....	III - 1
IV. APPENDICES	
A. Journals and Newsletters.....	IV - 1
B. Directories.....	IV - 3
C. Associations.....	IV - 6
D. Bibliographies.....	IV - 11

INTRODUCTION

This bibliography and resource guide summarizes relevant research and information on home care for children with serious medical problems. The document addresses three areas: 1) the values involved in making home care available; 2) the needs of children and their families; and 3) financing issues related to home care. The document is intended to assist parents and professionals to understand current issues and trends in home care.

The bibliography does not represent an exhaustive review of the literature. It does, however, contain material that addresses most of the pertinent issues relating to home care and is written in a style that is accessible to lay as well as professional readers. Human Services Research Institute is continuing to collect materials for another bibliography volume which will focus in greater depth on financing issues.

This bibliography is one product of a three year grant from the National Institute of Disability and Rehabilitation Research (NIDRR) in the Department of Education. The overall goal of this project is to identify effective mechanisms to support and sustain family care for children with severe disabilities and chronic illnesses and to disseminate material relevant to families, policy-makers, service providers, and others concerned with the well-being of children with disabilities and their families.

HOW TO USE THE BIBLIOGRAPHY AND RESOURCE GUIDE

This Bibliography and Resource Guide can be used in several ways. First, the reader can review the brief summaries of the three main topic areas that grew out of the literature search and review. These areas include: Values, Family Needs, and Financing.

Next the reader can use the two cross reference guides to find a list of articles related to specific subjects. The Substantive Sub-Topics section categorizes the annotated articles by subject areas such as siblings, prevention and financing. The Generic Sub-Topics section categorizes the annotated reviews by activities such as research, policy development and conceptual framework. After finding a specific subtopic and the corresponding list of articles, the reader can locate annotated summaries of the articles in the Alphabetical List of Annotated Citations.

The user of this volume can also choose to use one of the appendices. Appendix A contains journals and newsletters that are concerned with the care of children with chronic illnesses. Appendix B contains published directories that identify services nationwide. Appendix C contains names and addresses of organizations concerned with a wide range of children's health and disability issues. Appendix D contains other published bibliographies that relate to children with special health needs.

I. SUMMARIES OF MAIN THEMES

- A. Overview of Values and Governing Principles
- B. Overview of Families and Home Care
- C. Overview of Financial Issues

A. OVERVIEW OF VALUES AND GOVERNING PRINCIPLES

The values that influence policy decisions affecting families and their children with chronic illnesses and severe disabilities are explored in the literature reviewed in the bibliography. "Values" refer to principles or standards that are considered worthwhile or desirable. Every policy decision is affected by particular values although they are not always explicit. That is, decision makers do not regularly identify the principles that direct their efforts. Nonetheless, knowledge of the values that influence or should influence policy makers will assist in an understanding of why particular decisions are made and how to structure future decisions.

The literature highlights three sets of values that are put forward to support the the desirability of home care. The first value or principle is that home care contributes to growth and development and improved health status. A child's own home provides a familiar setting, as well as the loving support and stability of the family unit. These factors are believed to add to the well-being of the child. Faster developmental progress and better psychological development are also shown to be increased by being in a home.

A second related value is that home care promotes better family integrity and cohesiveness. Parents report that they want their children to be at home. These parents like being directly responsible for their children's lives. Parents also report that having the child at home promotes a continued

commitment to the future well-being of the child. Though families recognize that it is not always easy to have the child at home -- given the level of emotional, physical and financial resources required -- most families have opted to care for their child at home.

Another value expressed in the literature is that home care for children with chronic illnesses and severe disabilities is desirable because it is cost effective. Studies have shown that it is usually less expensive to keep these children at home than it is to maintain them in hospital settings.

What is missing in the literature is a better discussion of the values that should govern professional and parent relationships and the delivery of services to families. The literature does suggest that values play an important role in the relationships between professionals and parents of children with chronic illness and disabilities, and that professional care providers who work with families must be aware of the unique needs and desires of the family. Issues such as confidentiality and respect for the privacy of the family, truth telling, informed consent and locus of responsibility for decision making are discussed. However, what is lacking is a carefully woven analysis that knits together the overarching values of home care, family empowerment and self-sufficiency, individualized planning and community integration into a coherent vision of the benefits of family support and the characteristics of a comprehensive family support system.

B. OVERVIEW OF FAMILIES AND HOME CARE

Description of Children

A review of the literature pertaining to home care of children with disabilities and chronic illnesses reveals two sometimes overlapping trends. The overwhelming majority of published materials in this area addresses children with specific diagnoses and may discuss their typical course of treatment in hospitals or other care facilities and their homes. The children may have any of a lengthy list of conditions or disabilities such as: bronchopulmonary dysplasia, spina bifida, cerebral palsy, mental retardation, AIDS, hemophilia, sickle cell anemia, autism or failure-to-thrive syndrome. These are children who may have functional

limitations when compared with peers who do not have a disabling or chronic illness. They may also be children who are considered at risk for developing disabilities due to factors such as premature birth and/or various family circumstances.

On the other hand, there is an evident attempt to document the commonalities in the children's experience and those of their families. Examples of such commonalities include: the emotional and psychological impact of the disability or illness on the child and family, the functional limitations that the child may have, and the expenses involved in providing home

care. Implications of this latter approach for treatment are discussed and have relevance for policy and program developers alike. While much has been written about the impact of a child with a disability or chronic illness upon his or her family, the literature seems to lack documentation regarding the child's adjustment at various ages and stages of his or her condition and the factors that mediate this adjustment.

Description of Families

Central to the literature about families of children who have disabilities or chronic illnesses is the assumption that the child influences the entire family unit. Not only must parents and siblings deal with the emotional impact of having a child with a disability or illness, but they must also assume new responsibilities and roles, both towards the child and service providers, in order to obtain and provide care to the child.

How the families experience and deal with the impact of a child's disability or illness is frequently addressed in the literature, and reactions have typically been attributed to a combination of factors such as: the severity of the child's disability or illness, the amount of care the child requires in comparison with other children of the same age, the family's socioeconomic status, the family's social network, the expenses involved in caring for the child. While research seems to indicate that these parents tend to experience more stress than parents of children who do not have disabilities or chronic illnesses, research has also found these families demonstrate a

range coping strategies. There is a paucity of documentation, however, of the factors that contribute to the latter.

The literature in this area also suffers from a lack of overall demographic information about families of children with specific types of disabilities or chronic illnesses. Finally, due to the nature of the sampling which does occur when such information is obtained, there is undoubtedly a certain percentage of families who may not be included. These families may not routinely be receiving formal services and may therefore be neither adequately documented nor served, for reasons such as lack of information, transportation, cultural beliefs or practices, language barriers and/or a multitude of other, higher priority needs.

Needs for Formal Services

Given the ecological perspective on child health and development that pervades the literature on home care, amelioration or maintenance of a child's condition is generally assumed to depend on resources available to both the child and his or her family. Efforts are therefore increasingly being undertaken to examine and meet the needs of the family that are related to their care of the child, as well as the child's needs.

The literature pertaining to services for children and their families can be roughly divided into two broad categories: that which includes discussions of family needs based on surveys given to them and second, studies that examine the implementation and effects of particular interventions

(e.g., cash assistance) or combinations of interventions on children or families. Children's needs are typically better documented: special education, physical therapy, counseling, early intervention, respiratory therapy, adaptive and medical equipment, health insurance, transportation, evaluations and special diets. The formal services required by their families may include: respite care, financial assistance, prenatal care, education related to home care, counseling, information and referral and assistance in planning for the child's future.

In addition to discussions about specific services needed by families, the literature also contains several major themes, despite methodological limitations such as typically small samples and the paucity of longitudinal data and control groups. Foremost is the need for the service delivery system to be flexible to the individual needs of families since such needs may vary with the level of resources of the family and may also change over time. Further, there is an increasing trend toward empowering families to articulate their needs to providers and to mobilize resources that may be available to them outside of the formal service delivery system. Additionally, given the proper combination of resources, many children with special needs can do at least as well, if not better, in their own homes, as they would if cared for in hospitals or other residential settings.

Finally, the maintenance of these children in their homes and communities requires a concerted effort and commitment on the part of professionals and family members within the home, as

well as in the broader community and society (e.g., throughout broad-based legislation and outreach to under- and unserved families). While the needs of the families of children with specific disabling conditions may be delineated with time, it is apparent that a flexible service system which can respond to individual families needs, is necessary.

Needs for Informal Services

The literature frequently mentions that these families often characterize themselves as being socially isolated, due apparently to the presence of the family member with a disability or chronic illness. In view of the utility of an ecological approach to understanding and providing services to families, the literature has begun to include discussions about the informal supports available to and/or needed by these families. The emotional as well as concrete support which is provided by neighbors, friends and family members is increasingly recognized, as is that which other parent in similar circumstances can give.

While some writers briefly mention the value of these supports, others have sought to evaluate the adequacy of families' social networks. Still others, though few in number, have actively undertaken to assist families in increasing and mobilizing these informal supports.

Though the importance of informal support networks in mediating the impact of the child on the family has not yet been adequately documented formally, their significance is perhaps most apparent in their frequent mention in literature written by parents for parents and professionals.

C. OVERVIEW OF FINANCING ISSUES

Major Themes

The literature concerning costs and financing issues reviewed for this bibliography contains several themes. First, there is recognition that home care for children with chronic medical problems is less expensive than institutional care. The American Association of Respiratory Therapy, for instance, states that the average cost of caring for a ventilator-dependent child in a hospital is \$271,000.00 per year.

Concurrent with cost savings is the second theme. Namely, current insurance policies do not fully support the care of children with serious medical problems at home. Even with the reduced cost of family care over hospital care, there is considerably more family financial responsibility when the child moves home. The higher out-of-pocket expenses stem from the fact that private as well as publicly subsidized health insurance mechanisms make it difficult, if not impossible, to get full reimbursement for care at home. Private and public insurance programs are oriented toward hospital care and physician services, rather than alternative supports in the home. Consequently, children with disabilities and chronic illnesses must frequently stay in institutional settings in order to be eligible for third party insurance payments. Only recently has there been any movement by private insurance carriers to support children with chronic illnesses at home -- at least on an ad hoc if not systematic basis.

A third theme in the literature concerns the need to reorganize financing mechanisms in order to allow families to keep their children at home if they wish to do so. Provisions must be made to pay for adequate outpatient and home care services. Financing schemes must be sufficiently flexible to pay for non-physician services from psychologists, social workers and others -- well as for other needed supports such as home adaptation. Similarly, family support services, such as respite care, must be an allowable expense for families and must be delivered in a flexible fashion.

One concern about any new financial scheme is that it must account for the multiple diagnoses and complexity of care required by the range of children with chronic illnesses and severe disabilities. Some writers suggest that costs should be determined by the actual amount of the services required based on an individualized plan rather than on a capitated or flat fee basis. Unless costs are individually tailored, the idiosyncratic needs of these complex children may not be met. According to one writer, flat fees per visit may not encourage private service providers to take all of the time that is required to properly care for the children. Irrespective of the payment system(s) adopted, many individuals urge the need to insure access to services and to maintain an acceptable quality of care level.

A fourth theme in the literature on financing is that families need help in securing support for the care of their children at home. They not only need help with locating specific medical and social services, they also need help in

understanding and securing access to the funding options available to them. It is not easy to know which decisions to make concerning how to spend money unless all of the alternatives are understood. To assist with this, a number of guides have been written to help families to understand the private and public funding options that are available to them.

Specific Mechanisms

Although the literature does not include a large body of information on funding streams, some general categories or approaches emerge:

1. **Risk Pools and Subsidized Insurance Premiums:** These are programs designed by states to provide health insurance for residents who are ineligible for adequate health insurance from private insurers because of pre-existing and/or the current medical problems of family members. Eligibility for the pool generally includes being a resident of the state and being rejected by at least one private insurance carrier. While these plans provide some families with support, there are many families who will be unable to pay the premiums which range between 125 and 200 percent of the average comparable plan available in the state. Other states have chosen to subsidize uninsured individuals in order to supply insurance support. While this provides basic health care, the limitations attendant on commercial health insurance -- such as constraints on home care coverage -- still pertain.

2. **Title XIX Community Services Waiver:** States have the option of extending their Medicaid coverage to include an array

of community services (including family support) for eligible individuals who, without these services, are at risk of institutionalization. The community services waiver, however, has not been used extensively for home care.

Moreover, there is concern that the complex regulatory requirements discourage states from applying for the waiver and expanding health care coverage to include home care. Such complexities, likewise, deter many families from applying for waived services.

Another concern about the waiver program, and Medicaid in general, is that the delivery of services varies too markedly across the country. Benefits available in some states are not available in others. Still another concern about Medicaid is that the service specifications are not flexible enough to provide the type of individualized attention required by children with disabilities living at home. In other words, specific services are denied by Medicaid because the service requested does not comply with specific Medicaid guidelines regarding that service.

3. Model 50 Waivers: States also have the option to provide Medicaid support for home care for families whose income is too high to qualify for Medicaid providing that such home care is less costly than continued hospitalization and that the child's disability qualifies. Again, such waivers have been used only sparingly in most states.

4. Family Subsidy: Several states have developed programs to disburse cash subsidies or cash vouchers to qualifying families. This cash is usually provided in

combination with certain core services -- for example, information and referral, and parent education. Some states provide funding up front for designated purchases. Other states reimburse for purchases after the fact. One state, Michigan, provides a cash grant which can be spent at the discretion of the family.

5. Health Maintenance Organizations (HMOs): These organizations provide comprehensive health care for members for a fixed premium. All health care is coordinated through the HMO and members must usually use only the medical personnel provided by the HMO. One draw back for families with a child with a chronic illness or disability is that a HMO may not offer all of the specialized medical services required by children with complex needs and may be reluctant to refer the family elsewhere.

6. Private Insurance: This is health coverage purchased from a traditional insurance company either individually or through a group plan. The extent of coverage depends on the policy. Some companies deny membership on the basis of health status. Other companies restrict benefits for treatment of a chronic illness for up to three years from the date of enrollment.

Conclusion

The overarching theme in the literature on financing issues is that if home care is to be a reality, both public and private funding streams must be restructured to reverse the current orientation to more institutional forms of care. Much of this

restructuring, particularly in the private sector will be predicated on the generation of additional information on the efficacy of alternative forms of care, as well as more careful assessments of the relative costs of caring for children in a range of settings. In general, the literature suggests that innovative, yet practical, alternatives need to be considered.

II. CROSS REFERENCE GUIDE

- A. The Cross Reference Guide
- B. Substantive Sub-Topics
- C. Generic Sub-Topics

THE CROSS REFERENCE GUIDE

The articles cited in the bibliography have been categorized into substantive and generic sub-topics. The lists below describe what is in each section.

SUBSTANTIVE SUB-TOPIC HEADINGS

1. Historical Overview -- background information on home care and children's health concerns.
2. Governing Principles and Values -- values underlying the importance of home care.
3. Description of Children -- information on disabilities and medical condition of the children.
4. Impact on Children -- the effect that chronic illness has on children.
5. Incidence and Prevalence -- information on the number of individuals effected.
6. Prevention -- programs and research on prevention strategies.
7. Description of families -- information on the nature of the families and issues that they face.
8. Impact on Families -- the effect of a child with a serious medical problem on the family.
9. Siblings -- issues relating to brothers and sisters of children with chronic illnesses.
10. Costs to Families -- the monetary costs to the families.
11. Financing -- issues relating to financing mechanisms for care of the children.

12. Program Models and Practices -- review of programs that exist to care for the children and to support the families.
13. Informal Supports -- issues concerning who assists families other than formal organizations.
14. Medicaid -- issues relating to Medicaid.
15. Federal Policy -- federal policies which impact the children and their families.
16. State Policy -- state policies which impact the children and their families.
17. Federal Programs -- programs for the children or their families that are sponsored by or receive federal support.
18. State Programs -- programs for the children or their families which are sponsored by or receive state support.
19. Private Insurance -- issues relating to private insurance carriers
20. Employer Initiatives -- initiatives by employers to support employees with children who have serious medical problems
21. Case Management -- issues relating to case management for their children and families.

GENERIC SUB-TOPICS HEADINGS

1. Conceptual Framework -- Articles that establish a framework to understand the issues relating to home care fo the children.
2. Policy Development -- Articles that describe policies or programs that have been implmented or which are being considered for care of the children and their families.
3. Research and Evaluation -- Articles that demonstrate the effectiveness of particular program models.

SUBSTANTIVE SUB-TOPICS

HISTORICAL OVERVIEW

Agosta & Bradley, Family care...persons with developmental disabilities...
 Andrews, Child health care in America.
 Donnellan & Miranda, Issues...families of individuals with autism...
 Dybwad, Raising children in modern America...
 Gallo, Spina bifida..medical management.
 Hardman, ..withholding of treatment from seriously ill newborns...
 Magee & Pratt, 1935-1985: Federal support to promote health...
 Maybanks & Bryce, Home-based services for children and families...
 Meisels, Children in transition...public policy...handicapped children.
 NICHD, An evaluation...state of science...m.r. and dev. disabilities.
 Perlman, Family home care: Critical issues for services and policies.

GOVERNING PRINCIPLES & VALUES

Agosta & Bradley, Family care...persons with developmental disabilities...
 Agosta, et al., Designing programs to support family care...
 American Academy of Pediatrics, Treatment of critically ill newborns.
 Ctr. on Hum. Policy, Statement in support of families and...children.
 Dunst, Helping relationships...enabling...families.
 Dunst & Trivette, Enabling and empowering families...
 Dunst & Trivette, A family systems model of early intervention...
 Dunst & Trivette, Helping, helplessness and harm.
 Dybwad, Raising children in modern America...
 Freedman, Supporting...Families of the chronically mentally ill.
 Gallagher & Vietze, Families of handicapped persons...
 Gardner & Markowitz, Maryland family support services consortium...
 Gittler & Colton, Alternatives to hospitalization...
 Goldfarb, et al., Meeting the challenge of disability...
 Griss, The role of vouchers and informal help networks...
 Healy & Lewis Beck, Improving health care...Guidelines for families.
 Hobbs, et al., Chronically ill children and their families.
 Koepke & Thyer, Behavioral treatment of failure-to-thrive...
 Magrab, et al., Community workbook for collaborative services...
 Magrab, et al., Developing a community team.
 Miller, Patient power resources.
 NCCIP, Infants can't wait.
 NICHD, An evaluation...state of science...m.r. and dev. disabilities.
 Skarnulus, Support not supplant the natural home...
 Sparer, The legal right to health care: Public policy and equal access.
 Starr, et al., The contribution of handicapping conditions to child abuse.

DESCRIPTION OF CHILDREN

- Agosta & Bradley, Family care...persons with developmental disabilities...
- Agosta, et al., Designing programs to support family care...
- Aitken & Aday, A multi-method, multi-source evaluation model...
- Als, A synactive model of neonatal behavioral organization...
- Als, et al., ...care for the very low birth weight preterm infant...
- Batshaw & Perret, Children with handicaps: A medical primer.
- Batshaw & Perret, ...The family of a child with handicaps.
- Blackman, Warning signals...tracking at-risk infants and toddlers.
- Blackman, et al., Screening children at risk: The Iowa experience.
- Crnic, et al., Adaptation of families with mentally retarded children...
- Donnellan & Miranda, Issues...families of individuals with autism...
- Friedman, Major issues in mental health services for children.
- Friedman, Serving seriously emotionally disturbed children...
- Gallagher & Vietze, Families of handicapped persons...
- Gallo, Spina bifida...medical management.
- Gardner & Markowitz, Maryland family support services consortium...
- Garfunkel, Hospital care for children and youth.
- Gittler & Colton, Alternatives to hospitalization...
- Goldfarb, et al., Meeting the challenge of disability...
- Gortmaker & Sappenfield, Chronic childhood disorders: Prevalence...
- Gurdin & Anderson, ...AIDS-specialized foster care family homes.
- Harel & Anastasiow, The at-risk infant: Psycho/social/medical aspects.
- Healy, et al., Early services for children with special needs...
- Heying, Family-based...services...severely emotionally disturbed child.
- Hobbs, et al., Chronically ill children and their families.
- Holtzman, Newborn screening for genetic metabolic diseases.
- Hunter, Children's hospice advisory panel report.
- Kellam, et al., Family structure and the mental health of children.
- Koepke & Thyer, Behavioral treatment of failure-to-thrive...
- Lapham & Sherlin, The impact of chronic illness on...human development.
- Lubin, et al., Projected impact...functional definition of dev. dis...
- Massie, The constant shadow: Reflections...chronically ill child...
- Mattson & Gross, ...studies on hemophilic children and their families.
- McPherson, Systems approach to care of technology-assisted children.
- Miller, Patient power resources.
- NCCIP, Program evaluation...
- NCCIP, Infants can't wait: The numbers.
- NICHHD, An evaluation...state of science...m.r. and dev. disabilities.
- NICHHD, Maternal and child health.
- NICHHD, Mental retardation.
- NICHHD, Sudden infant death syndrome.
- Pless & Ferrin, Issues common to a variety of illnesses.
- Rosen & Gerring, Head trauma educational reintegration.
- Rosetti, High risk infants: Identification, assessment...intervention.
- Schopler & Mesibov, The effects of autism on the family.
- Stroul, A system of care...disturbed children and youth.
- U.S. Congress, O.T.A., Technology-dependent children: Home care...
- U.S. Senate, Committee on Labor and Human Resources, ...hearings.
- Van Dyck, et al., Creating an info. base for program collaboration.
- Watkins & Melnick, Infant mortality...Psychosocial factors.
- Weisfeld, The Robert Wood Johnson...report...rural infant care program.
- Wikler, Chronic stress of families of mentally retarded children.

IMPACT ON CHILDREN

- Aqosta & Bradley, Family care...persons with developmental disabilities...
- Aitken & Aday, A multi-method, multi-source evaluation model...
- Assoc. for Retarded Citizens, How to provide for their future.
- Assoc. for the Care of Children's Health, Child health care facilities.
- Batshaw & Perret, Caring and coping...
- Batshaw & Perret, Children with handicaps: A medical primer.
- Beckman, Influence of selected child characteristics on stress...
- Bilotti, Getting children home: Hospitals to community.
- Subolz & Whiren, The family of the handicapped: An ecological model...
- Casey & Bradley, The impact of the home...on children's development...
- Castro, Plasticity and the handicapped child.
- Frates, et al., Outcome of home mechanical ventilation in children.
- Friedman, Major issues in mental health services for children.
- Friedman, Serving seriously emotionally disturbed children...
- Gallagher & Vietze, Families of handicapped persons...
- Gardner & Markowitz, Maryland family support services consortium...
- Gittler & Colton, Alternatives to hospitalization...
- Greenstein & Hudd, Home care of the pediatric patient.
- Gurdin & Anderson, ...AIDS-specialized foster care family homes.
- Harel & Anastasiow, The at-risk infant: psychosocial medical aspects.
- Healy, et al., Early services for children with special needs...
- Healy & Lewis-Beck, Improving health care...Guidelines for families.
- Heying, Family-based...services...severely emotionally disturbed child.
- Hobbs, et al., Chronically ill children and their families.
- Hobbs & Perrin, Issues in the care of children with chronic illness.
- Hunter, Children's hospice advisory panel report.
- Kellam, Family structure and the mental health of children.
- Lapham & Sherlin, The impact of chronic illness on...human development.
- Lubin, et al., Projected impact...functional definition of dev. disabil...
- Magrab, et al., Developing collaborative services
- Massie, The constant shadow: Reflections..life...chronically ill child.
- Meisels, Children in transition...public policy...handicapped children.
- Miller, Patient power resources.
- NCCIP, Infants can't wait.
- NCCIP, Program evaluation...
- NICHHD, An evaluation...state of science...m.r. and dev. disabilities.
- NICHHD, Family planning and population research...
- NICHHD, Mental Retardation.
- Rosen & Gerring, Head trauma educational reintegration.
- Schilling, et al., Coping and social support...
- Starr, et al., ...contribution of handicapping conditions to child abuse.
- Turnbull, et al., The wise family plans...aspects of future planning.
- Van Dyck, et al., Creating an information base for program collaboration.
- Walker, Care of chronically ill children in schools.
- Walker, Report of a national conference: School-age children...
- Warren & Dickman, ...issues in development of community respite care...
- Watkins & Melnick, Infant mortality, ... Psychosocial factors.

INCIDENCE & PREVALENCE

Gortmaker & Sappenfield, Chronic childhood disorders: Prevalence...
 Hobbs, et al., Chronically ill children and their families.
 NICHD, An evaluation...state of science...m.r. and dev. disabilities.

PREVENTION

Andrews, L., Legal liability and quality assurance in newborn screening.
 Andrews, L., State laws and regulations governing newborn screening.
 Blackman, Screening children at risk: The Iowa experience.
 Blackman, Warning signals...tracking at-risk infants and toddlers.
 Hall, et al., The family: A critical factor in prevention.
 Harel & Anastasiow, The at-risk infant: psychosocial medical aspects.
 Lennie, et al., Low birth-weight reduced by obstetrical access project.
 NICHD, An evaluation...state of science...m.r. and dev. disabilities.
 NICHD, Family planning and population research. Special report...
 NICHD, Maternal and Child Health.
 NICHD, Mental retardation.
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 Gallo, Spina bifida... medical management.
 Gardner, Implementation of the home and community based care waiver.
 Gardner & Markowitz, Maryland family support services consortium...
 Garfunkel & Evans, Hospital care for children and youth.
 Gittler & Colton, Alternatives to hospitalization...
 Gittler & Colton, Community-based case management...
 Goldfarb, et al., Meeting the challenge... disability or chronic illness...
 Gortmaker & Sappenfield, Chronic childhood disorders: Prevalence...
 Griss, The role of vouchers and informal help networks...
 Guardianship & Advocacy, A future planning guide for parents...
 Gurdin & Anderson, ... AIDS-specialized foster care family homes.
 Hall, et al., The family: A critical factor in prevention.
 Hardman, ... withholding of treatment from seriously ill newborns...
 Harel & Anastasiow, The at-risk infant: psychosocial medical aspects...

POLICY DEVELOPMENT (continued)

- Healthy Mothers, Healthy Babies Coalition, ...serving low-income women.
- Healy, et al., Early services for children with special needs...
- Healy & Lewis-Beck, Improving health care...Guidelines for families.
- Healy & Lewis-Beck, Improving health care...Guidelines for physician.s
- Heying, Family-based...services...severely emotionally disturbed child.
- Hobbs, et al., Chronically ill children and their families.
- Hobbs & Perrin, Issues in the care of children with chronic illness.
- Holtzman, Newborn screening for genetic metabolic diseases.
- Hunt, A common sense guide to health insurance.
- Hunter, Children's hospice advisory panel report.
- Hutchinson & Nelson, How pub. agencies...provide family-centered services.
- Information Sciences Research, Workshop on financing health care...
- Jones, Home care for the chronically ill or disabled child.
- Jones, Teaching and educating your child.
- Jones, Paying for the medical help you need.
- Kaufman & Lichtenstein, The family as care manager...
- Kimmich, America's children who cares? Growing needs...
- Knollmueller, Funding home care in a climate of cost containment.
- Lennie, et al., Low birth-weight reduced by obstetrical access project.
- Magee & Pratt, 1935-1985:...federal support to promote health...
- Magrab, et al., Developing a community team.
- Meisels, Children in transition...public policy...handicapped children.
- Merila, Liability insurance: The purchaser's guide.
- NCCIP, Program evaluation...
- Noyes, Children: A priority?
- Project Serve, New directions: Serving children with special...needs...
- Shelton, et al., Family-centered care...
- Strauss & Munton, Common concerns of parents with disabled children.
- Stroul, A system of care for...children and youth.
- Tuszynski & Dowd, Home-based services to protective service families.
- Upshur, Developing respite care: A support service for families...
- U.S. Congress, O.T.A., Technology-dependent children: Home care...
- U.S. Senate, Committee on Labor and Human Resources, ...Hearings.
- Van Dyck, et al., Creating an information base for program collaboration.
- Walker, Care of chronically ill children in schools.
- Walker, Report of a national conference: School-age children...
- Warren & Dickman, ...issues in the development...community respite care...
- Warren & Gordon, Transition practices for handicapped youngsters...
- Weisfeld, The Robert Wood Johnson...report...rural infant care program.
- Wickler, Chronic stress of families of mentally retarded children.

RESEARCH AND EVALUATION

- Agosta & Bradley, Family care...persons with developmental disabilities...
- Agosta, et al., Designing programs to support family care...
- Akabas & Krauskopf, Families & work:...employees with disabled children.
- Als, A synactive model for neonatal behavioral organizations...
- Als, et al., ...care for the very low birth weight preterm infant...
- Anderson, The social construction of illness experience...
- Bates, States family support/cash subsidy programs.
- Beckman, Influence of selected child characteristics on stress...
- Blackman, et al., Screening children at risk: The Iowa experience.

RESEARCH AND EVALUATION (continued)

- Brooten, et al., ...a randomized clin. trial of early hos. discharge...
- Burwell, et al., Medicaid recipients in intermed. care facilities...
- Campbell, Family's impact on health: A critical review...
- Casey & Bradley, The impact of the home env. on children's development...
- Castro, Plasticity and the handicapped child.
- Colton & Gittler, The Title V state program and...case management...
- Crnic, et al., Adaptation of families with mentally retarded children...
- Dunst & Trivette, A family systems model of early intervention...
- Dunst & Trivette, A guide to measures of social support...
- Dunst, et al., Towards an experimental evaluation...
- Epenshade, Investing in children. New estimates of parental expenditures.
- Frates, et al., Outcome of home mechanical ventilation in children.
- Gallagher & Vietze, Families of handicapped persons...
- Gardner & Markowitz, Maryland family support services consortium...
- Garfunkel & Evans, Hospital care for children and youth.
- Giele, A delicate balance: The family's role...care of handicapped.
- Gittler & Colton, Community-based case management...
- Gittler & Colton, Alternatives to hospitalization...
- Gortmaker & Sappenfield, Chronic childhood disorders: Prevalence...
- Herman, Plan for evaluation of the family support subsidy program.
- Heying, Family-based...services...severely emotionally disturbed child.
- Hobbs, et al., Chronically ill children and their families.
- Hobbs & Perrin, Issues in the care of children with chronic illness.
- Holtzman, Newborn screening for genetic metabolic diseases.
- Kellam, et al., Family structure and the mental health of children.
- Koepke & Thyer, Behavioral treatment of failure-to-thrive...
- Kupst, et al., Family coping with childhood leukemia...
- Longo & Bond, Families of the handicapped child: Research...
- Lubin, et al., Projected impact...functional definition of dev. dis...
- Mattsson & Gross, ...studies on hemophilic children and their families.
- Maybanks & Bryce, Home-based services for children and families...
- McDonald, Med. needs of...disabled persons...in the community.
- McPherson, Systems approach to care of technology-dependent children.
- Merila, Liability insurance: The purchaser's guide.
- Moore, et al., Extending family resources.
- NCCIP, Infants can't wait: The numbers
- NICHHD, An evaluation...state of science...m.r. and dev. disabilities.
- NICHDD, Family planning and population research...
- NICHHD, Mental retardation.
- NICHDD, Sudden infant death syndrome.
- Pine, The new human genetics...how gene splicing helps...
- Project Serve, New directions...Serving children with special needs...
- Rosen & Gerring, Head trauma educational reintegration.
- Rosetti, High risk infants: Identification, assessment...intervention.
- Sherman & Coccozza, Stress in families of the developmentally disabled...
- Snell & Beckman-Brindley, Family involvement in interve-tion...
- Specht & Nagy, Social supports research project: Report of findings.
- Stein & Jessop, Does pediatric home care make a difference...
- Suelzle & Keenan, Changes in family support networks...?...
- Tausig, Factors in family decision making...
- U.S. Congress, O.T.A., Technology-dependent children: Home care...
- Van Dyck, et al., Creating an information base for program collaboration.
- Watkins & Melnick, Infant mortality...psychosocial factors.
- Zimmerman, The mental retardation family subsidy program...

III. SELECTED LITERATURE

Alphabetical List of Annotated Citations

ALPHABETICAL LISTING OF ANNOTATED CITATIONS

Agosta, J.M. & Bradley, V.J. (Eds.) (1985). Family care for persons with developmental disabilities: A growing Commitment. Cambridge, MA: Human Services Research Institute.

This monograph describes the importance of the provision of support services to families of persons with developmental disabilities, the nature of existing services, alternative means for providing family support, and policy options. Much of the material was stimulated by a national conference that brought together experts in the area of family support.

Agosta, J., Bradley, V., Rugg, A., Spence, R. & Covert, S. (1985). Designing programs to support family care for persons with developmental disabilities: Concepts to practice. Cambridge, MA: Human Services Research Institute.

Family support efforts nationwide and a specific program for families of persons with developmental disabilities, including children with emotional disabilities, in Virginia are presented. In addition to a national survey of existing services, an analysis of administrative options, a comprehensive discussion regarding programs available in six states, and a survey of the needs of caregiving families in Virginia, the report also describes efforts to weave administrative options and conceptual preferences into viable policy and provides a plan for initiating a family support program.

Aitken, M.J. & Aday, L.A. (1986). A multi-method, multi-source evaluation model: Assessing home care for the chronically ill and/or technology assisted child Illinois: University of Illinois.

In this paper, literature on home care for chronically ill and technology-assisted children is reviewed and a conceptual model for evaluating home care programs is proposed. The model incorporates a descriptive component for collecting data and an evaluative component, focusing on the program's attainment of intermediate and ultimate objectives. The model is applied to the analysis of three demonstration projects designed to develop programs to permit home placement of hospitalized ventilator-assisted children.

Akabas, S.H. & Krauskopf, M.S. (1984). Families and work: Creative workplace responses to employees with disabled children. New York: Columbia University School of Social Work, Industrial Social Welfare Center.

This paper presents research concerning the needs of families who are at risk of disrupting their work roles due to having children with disabilities and the services necessary to help family members continue working. Procedures to identify such families using company insurance data banks are discussed. The results from interviewing and surveying identified families are presented. Many of the work-place related and other social/emotional needs of parents who have a child with disabilities are not very different from those experienced by any new parent. Program models for work-place assistance and a state and local resource directory are also presented.

Als, H. (1986). A synactive model of neonatal behavioral organization: Framework for the assessment of neurobehavioral development in the premature infant and for support of infants and parents in the neonatal intensive care environment. In J.K. Sweeney (Ed.), The high risk neonate: Developmental therapy perspectives. Physical and Occupational Therapy in Pediatrics, 6, 3-55.

In an attempt to decrease the stresses to which premature infants are typically subjected and the preponderance of developmental impairments found among them, the author advocates using specific behavioral observations to develop individualized treatment plans. Instruments designed to assess neurobehavioral development are presented, along with a discussion of how the results may be utilized to determine treatment. This material, as well as the discussion on ways neonatal intensive care unit staff can actively include and support parents in the care of their infant is very useful.

Als, H., Lawhorn, G., Brown, E., Gibes, R., Duffy, F.H., McAnulty, G., & Blickman, J.G. (1986). Individualized behavior and environmental care for the very low birth weight preterm infant at high risk for bronchopulmonary dysplasia: Neonatal intensive care unit and development outcome. Pediatrics, 78 (6), 1123-1132.

A highly controlled study was conducted in order to test the hypothesis that improvement in the respiratory and functional status of hospitalized very low birthweight

infants with bronchopulmonary dysplasia can be made through the restructuring of the sensory input provided to the infant. Specifically, the investigators intended to examine whether modifications in caregiving procedures could reduce an infant's need for oxygen. Systematic behavioral observations and physiological measures were conducted at specific times of infants in the intervention and control groups. Based on these results, modifications in the care provided to intervention group infants were made. Substantial improvements in the medical and developmental status of the intervention group infants, and significant between-group differences were found both during and after hospitalization. The results and possible reasons for them are discussed in detail.

American Academy of Pediatrics, Committee on Bioethics. (1983). Treatment of critically ill newborns. Pediatrics, 72(4), 565-566.

This official policy regarding the treatment of critically ill newborns was developed in response to controversies surrounding the treatment of these infants. In recognition of the difficulties involved in determining the best interests of the infant, the Committee recommends a thorough review of the patient's situation before any decisions are made regarding the withdrawal or withholding of treatment. This review should occur in consultation with other professionals, before institutional ethics committees developed within hospitals.

Anderson, J.M. (1981). The social construction of illness experience: Families with a chronically ill child. Journal of Advanced Nursing, 6, 427-434.

Four families of children with chronic illnesses were interviewed and observed in an effort to determine how parents understand and explain their child's sickness and how this understanding affects their interactions with their children. These observations were compared with those of 12 families of "well" children. The author contends that a parent's understanding of a sickness affects her/his compliance with treatment regimes. Implications for practice, including the utilization of family intervention are presented.

Andrews, D. (1976). Child health care in America. (DHEW Publication No. (HSA) 76-5015). Rockville, MD: U.S. Department of Health, Education, and Welfare, Health Services Administration.

This publication is designed to acquaint the general public with highlights of the five-volume documentary history, Children and Youth in America, by the Harvard School of

Public Health. Specific developments in the area of maternal and child health care in the United States from the 19th century through the 1960's are discussed, together with their historical and social context. Photographs and original source material are used throughout to illustrate the attitudes and events which helped shape current programs.

Andrews, L.B. (1985). Legal liability and quality assurance in newborn screening. Chicago, IL: American Bar Foundation.

Some of the legal issues surrounding metabolic screening of newborns are presented. In addition, the importance of quality assurance and other mechanisms designed to protect the family, child and provider are discussed.

Andrews, L.B. (1985). State laws and regulations governing newborn screening. Chicago, IL: American Bar Foundation.

This volume presents a state-by-state analysis of state-mandated programs to screen newborn babies for various metabolic disorders. The volume also presents a comparative overview of all the states' programs, a description of related sickle cell screening laws, and a chart of disorders for which screening is supposed to occur. For each state the following items are discussed: (1) the statute mandating services and its components; (2) the screening tests that are administered; (3) quality assurance; (4) parties responsible for the screening activities; (5) the costs; and (6) sanctions for non-compliance. The author discusses the controversy surrounding testing for sickle cell anemia, current laws addressing sickle cell anemia, and the prevention of stigmatization and discrimination. The author concludes that 48 states and Washington, D.C. have statutes governing newborn screening. The legal guidelines vary considerably from one state to another in the level of detail, the substantive provisions, the types of disorders they address, and in quality assurance requirements.

Association for the Care of Children's Health. (1984). Home care for children with serious handicapping conditions. (A report on a conference held on May 27, 1984, in Houston, Texas). Washington, DC: Association for the Care of Children's Health.

This is a summary of the presentations at the May 27, 1984 conference entitled "Home Care for Children with Seriously Handicapping Conditions" sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health. Presentors, who include parents and professionals, discuss a wide variety of topics including: a definition of home care and its components, criteria for

home care program admission, family assessment, support services, coordination of educational activities for the children, continuing education for providers, and financing home care. Case examples are provided throughout. Ten recommendations for further development of home care are discussed. Permeating all the presentations are commitments to home care, wherever feasible, and to parent-professional collaboration. The practical nature of much of the material, combined with the personal perspectives provided by parents, make this a valuable resource for both parents and professionals.

Association for Retarded Citizens National Insurance and Benefits Committee. (1984). How to provide for their future. Arlington, TX: Association for Retarded Citizens, National Headquarters.

This booklet is designed to assist parents of persons with mental retardation deal constructively with their concerns about the future. This edition is the fifth major revision since the first edition was published in 1963. The interrelationship is shown between the child's prospective needs for social and/or economic supports, as individually assessed, and the formal mechanisms which can be brought to bear on them (e.g., insurance, trust provisions, governmental benefits for persons with disabilities and guardianship). State and federal laws which provide for all these financing mechanisms, along with private sector responses, continue to be in a state of flux.

Bates, M.V. (1984). State family support/cash subsidy programs. Madison, WI: Wisconsin Council on Developmental Disabilities.

This report summarizes the family support services and/or cash assistance programs in 26 states that are available to families of children with disabilities. Information is included on: 1) type of program, 2) appropriations, 3) number of persons served, 4) goals and objectives of programs, 5) administering agencies 6) eligibility criteria, 7) expense limits, 8) services offered, and 9) implementation strategies.

Batshaw, M.L. & Perret, Y.M. (1986). Caring and coping: The family of a child with handicaps. In M.L. Batshaw & Y.M. Perret (Eds.), Children with handicaps: A medical primer. (Second Edition). Baltimore, MD: Paul H. Brookes Publishing Company, 351-364.

The book in which this chapter is found is designed for parents and professionals, and is devoted primarily to providing information about the birth and development of infants and children and comprehensive descriptions of

various handicapping conditions. Topics covered in this chapter include: the impact of a child's disability upon his or her family over the course of the family life cycle; the effects of the family's and society's attitudes upon the child's development; child abuse and neglect of children with disabilities; and the role of the professional working with these children and their families. Despite the challenges which face these families, the authors conclude that most family members develop positive relationships amongst themselves and cope effectively with their extra responsibilities.

Batshaw, M.L. & Perret, Y.M. (1986). Children with handicaps: A medical primer. (Second Edition). Baltimore, MD: Paul H. Brookes Publishing Company.

Written for professionals and parents, this book serves as a reference on the etiology and treatment of disabilities. Chapters on fetal development, birth and infant development precede others which address prematurity, specific disabling conditions, the effects of a child with a disability on the family, ethical dilemmas, and financial issues. Appendices include: a glossary of medical terms; description of over 50 syndromes; lifesaving techniques, and bibliographies. Direct implications for assessing home care needs and designing programs to address such needs can be found throughout.

Beckman, P.J. (1983). Influence of selected child characteristics on stress in families of handicapped infants. American Journal of Mental Deficiency, 88, 150-156.

This paper summarizes the results of research concerning the extent to which the characteristics of a child with disabilities are related to the stress reported by mothers. Five characteristics of the child were examined: rate of progress, responsiveness, temperament, repetitive behavior patterns, and the need for additional or unusual caregiving demands. All characteristics of the child, except rate of progress, are significantly related to the amount of stress experienced by family caregivers. Single mothers reported more stress than mothers in intact homes.

Bilotti, G. (1984). Getting children home: Hospitals to community. Washington, D.C.: Georgetown University Child Development Center.

This volume provides a conceptual model for placing a chronically ill child in the home. The first section describes the three phases from initial planning to the placement in the home. The next section outlines the roles of various participants involved in the placement process,

including parents, the physicians and the interdisciplinary team. The third section details the actual discharge plan and home care plan. The final section centers upon using the community resources which assist the placement effort. Throughout, the book incorporates checklists, charts, diagrams and sample documents to aid the parent-planners.

Bilotti, E. & Kettrick, R. (1984). Innovative approaches to financing home care. In Association for the Care of Children's Health, Home care for children with serious handicapping conditions: A report of a conference sponsored by the Association for Care of Children's Health. Washington, DC: Association for the Care of Children's Health, 86-91.

In their presentation at a conference entitled "Home Care for Children with Serious Handicapping Conditions," the presentors provide an overview of a variety of actual and potential sources of financial assistance for home care, including federal and state programs, private insurers, and local community organizations. The presenters advocate that parents actively seek out allies in the media and the legislature in order to obtain assistance for specific individuals while also working to affect legislative changes in the financing of home care for large numbers of children. The parent or advocate who reads this paper will be encouraged and well informed about how to proceed in the struggle to obtain financial assistance.

Blackman, J.A. (1986). Warning signals: Basic criteria for tracking at-risk infants and toddlers. Washington, DC: National Center for Clinical Infant Programs.

This monograph was developed in response to findings that the percentages of infants and children in the U.S. who are identified as having discernible disabling conditions jumps from 1%-2% at birth to 10%-12% of those entering school. The purpose of this monograph is to provide criteria for identifying very young children who are at-risk for developing a disabling condition so that they may be included in a tracking system and referred to appropriate resources for treatment. These criteria include: parental and psychosocial variables, health maintenance, familial disorders, evidence of growth deficiency, and severe chronic illness. Although no statistical information is provided regarding the frequency with which specific factors and/or combinations of factors tend to actually result in the development of specific disabilities, the monograph does point out the multiplicity of factors which influence a child's development and the need for multifaceted assessments of infants and their families.

Blackman, J.A., Hein, H.A., & Healy, A. (undated). Screening children at risk: The Iowa experience. Iowa City, IA: University Hospital School, Division of Developmental Disabilities.

This publication describes the Iowa High-Risk Infant and Follow-up Program, one component of a statewide system designed to identify and serve children (birth-5 years) at-risk for developing disabling conditions and their families. Findings generated from the analysis of data describing children enrolled in the program from 1978-1983 are also included. Further research is necessary to identify children at risk of disabilities due to non-medical causes. The issues raised in this monograph are particularly relevant for people responsible for developing and directly operating follow-up programs for high-risk infants.

Bradshaw, K. (Ed). (1984). Conference proceedings: The use of case-mix based prospective payments for inpatient pediatric hospital care. Merrifield, VA: Cardinal Publishing Company.

This volume is a compilation of papers presented at a conference on case-mix based prospective payment systems for pediatric hospitals. The volume presents discussions on alternative classifications systems, including Diagnosis Related Groups (DRGs), severity of illness index, and disease staging. The implications of case-mix reimbursement for financing graduate medical education, maintaining quality services, and accurately identifying the components of hospital costs were explored. The conference participants concluded that: 1) DRGs should be modified to enable equitable payment for levels of severity within pediatric case mixes; 2) prospective pricing places teaching hospitals at a competitive disadvantage (because they have a higher price per case than non-teaching hospitals and therefore there is a need for additional funding for education); and 3) efforts should be directed towards safeguarding service access and quality.

Brazner, K. & Gaylord, C.L., et al. (1986) Medicaid, HMO's and Maternal and Child Health. Madison, WI: Community Based Maternal and Child Health Project and Center for Public Representation, Series #3.

This research paper reports on a study of Wisconsin's mandatory Health Maintenance Organization (HMO) enrollment program for families who receive Aid for Families with Dependent Children (AFDC). The study assessed the effect that the enrollment program had on access to quality health care for the clients. In the study, 180 AFDC heads of households enrolled in HMOs were interviewed. The study identified several problems in the implementation of the

policy. In general, the study showed that the enrollees do not like the new enrollment program because they cannot access the health care system as well as they could with the old system.

Brooten, D., Kumar, S., Brown, L., Butts, P., Finkler, S., Bakewell-Sachs, E., Gibbons, A. & Delivoria-Papadopoulous, M. (1986). Special article: A randomized clinical trial of early hospital discharge and home follow-up of very-low-birth-weight infants. The New England Journal of Medicine, 315,(15), 934-939.

To assess the safety, costs and feasibility of early discharge of very low birthweight infants, the authors of this study divided infants into control (n=40) and treatment (n=39) groups. Infants from both groups had to meet a set of criteria prior to discharge. Treatment group infants were discharged at lower weights, and were provided with extensive follow-up services (e.g., counseling, home visits, availability of a nurse on-call at all times) over an 18-month period. Costs incurred by infants in the early discharge group were significantly lower than those of the control group infants. No differences between the groups were found in the number of rehospitalizations, acute care visits or the growth and development. Results are discussed in detail as are implications for national health care costs. The authors also note that such follow-up programs reduce child abuse. This study warrants the attention of other researchers, public health professionals, hospital staff and health insurance policy makers.

Bubolz, M.M. & Whiren, A.P. (1984). The family of the handicapped: An ecological model for policy and practice. Family Relations, 33, 5-12.

An ecological systems model for the analysis of the family is presented. In this approach the family is viewed holistically, recognizing that behavior of any part of the system affects the entire system. Implications for policy and practice are presented.

Burr, K. (1985). Impact on the family of a chronically mentally ill child. In N. Hobbs & J.M. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco, CA: Jossey-Bass.

To provide the reader with a broad perspective on the relationship between the child with a chronic illness and his or her family, this chapter reviews major research findings on the impact of the child on the family, and the relationship between family functioning and the child's psychosocial adjustment. Drawing on these and related findings, the author presents implications for the

development of public policy which would enhance the functioning of families. In providing a concise overview of the challenges these families face, the author communicates respect for these families and their capacities to function effectively given appropriate resources.

Burwell, B., Clausen, S., Hall, M.J. & Simon, J. (1987). Medicaid recipients in intermediate care facilities for the mentally retarded. Health Care Financing Review, 8(3), 1-12.

This study examined Medicaid utilization and expenditure patterns of Medicaid recipients in intermediate care facilities for the mentally retarded (ICF/MR) in three states: California, Georgia and Michigan. Data were obtained from uniform Medicaid data files. Most recipients in ICF/MRs were adults with severe or profound mental retardation who were in an ICF/MR for the entire year. The average annual cost of care ranged from \$26,617 per resident in Georgia to \$36,128 per resident in Michigan. The vast majority of recipients were utilizers of other Medicaid services. Approximately one-third of the recipients were also covered by Medicare.

Campbell, T.L. (1986). Family's impact on health: A critical review and annotated bibliography. Washington, DC: National Institute of Mental Health. Series DN No. 6, DHHS Pub. No. (ADM) 86-1461.

This manuscript reviews policy and research concerning the complex relationships between family systems and mental illness. In addition to evaluating empirical research studies, the report also presents a comprehensive annotated bibliography.

Casey, P.H. & Bradley, R.H. (1982). The impact of the home environment on children's development: Clinical relevance for the pediatrician. Developmental and Behavioral Pediatrics, 3, 146-151.

This paper selectively reviews the literature which demonstrates the major impact of the environment on children's development in three developmental high-risk categories. Specific aspects of the home environment which optimize or impede developmental progression are discussed. Finally, the various instruments which are available to screen the home environment are presented. Information regarding the environment increases accuracy of developmental predictions, facilitates more appropriate treatment plans, and serves as a basis for specific counseling.

Castellani, P.J. & Puccio, P.S. (1984). The development of family support services for the developmentally disabled: An administrative and political perspective. Albany, NY: New York State Office of Mental Retardation and Developmental Disabilities.

This paper is a review of steps that have been taken in New York to develop a family support services program for families with children who have developmental disabilities. The specific actions taken to generate support, gain access to the policy agenda, and to build bureaucratic and legislative consensus are described within the historical context of the issues. Implementation problems such as eligibility criteria, needs assessment, service delivery mechanism, funding mechanisms, service management and accountability are also discussed.

Castro, G. (1987). Plasticity and the handicapped child. In J.J. Gallagher and C.T. Ramey (Eds.), The Malleability of children. Baltimore, MD: Paul Brookes Publishing, 103-113.

Seventy-four studies that addressed the issue of the efficacy of early intervention for children with handicaps were statistically analyzed using a meta-analysis approach. Analysis provided information about the correlation between specific study characteristics with outcomes and findings related to four key variables (e.g., parent involvement) are discussed. The overall conclusion was that early intervention did provide relatively immediate benefits to the children. Given the paucity of data, it was not possible to determine the duration of these effects nor the age at which early intervention should begin in order to maximize the benefit to the child. Implications relevant to advocates, researchers and early intervention staff are discussed.

Center for Law and Sciences. (1982). Estate planning for parents of persons with developmental disabilities. Boston: Developmental Disabilities Law Center of Massachusetts, Inc.

This booklet is written to assist parents of children with disabilities in planning their estates. It reviews various estate planning mechanisms that can help assure that money left for a child will be appropriately spent and will not make the child ineligible for governmental assistance (e.g., trusts, morally obligated gifts). Further, it reviews mechanisms to assure a lifetime protector/advocate of the child's legal rights. An appendix of governmental benefits is included.

Center on Human Policy. (1986). Statement in support of families and their children. Syracuse, NY: Center on Human Policy.

This statement was prepared by the Center on Human Policy Research and Training Center on Community Integration at Syracuse, New York. It is the result of a two day "Policy Institute" on families and homes for people with severe disabilities. It addresses the philosophy and services that should underlie a comprehensive family support program. The following propositions are listed and discussed: 1) primary planning should be based upon a guiding philosophy, 2) families should receive supports in order to maintain their children at home, 3) supports should build on existing social networks, 4) families should have maximum control over services and supports, 5) the entire family is the target of support, 6) support should encourage community integration of children, 7) out-of-home placements should be viewed as temporary, 8) adoption should be aggressively pursued when families cannot be reunited and, 9) foster care should be pursued when children cannot live with their own families or with adoptive families.

Cina, S. & Caro, F. (1984). Supporting families who care for severely disabled children at home: A public policy perspective. New York: Community Service Society of New York.

This report reviews data concerning the adequacy of current efforts to support New York City families caring for children with severe disabilities. In addition to presenting the major public policy initiatives and funding streams relevant to children with disabilities, this monograph also describes the stresses experienced by families in caring for their children at home and alternative approaches such as: strategies to increase a family's purchasing power, model respite care programs, case management, and the use of a voucher system to purchase family support services.

Colton, M. & Gittler, J. (1986). The Title V state program and the provision of case management services for children with special health needs. Iowa City, IA: National Maternal and Child Health Resources Center.

The Future Directions project, administered by the National Maternal and Child Health Resource Centers, is conducting research to determine the future direction of services for children with special health care needs. One component of this project, described in this publication, was a 1986 nationwide survey of case management activities of state Title V programs. Factors such as the administration, organization and financing of programs are examined. In addition, the programs' use of case management services was

explored by analyzing their treatment of three hypothetical cases. Findings are discussed in narrative and presented in charts and tables.

Crnic, K.A., Friedrich, W.N. & Greenberg, M.T. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency, 88 (2), 125-138.

Research concerned with the families of children with mental retardation has often yielded inconsistent, and at times, contradictory findings. No succinct model has been presented to explain family adaptation and the range of possible outcomes. In this paper, a comprehensive conceptual model is proposed that accounts for the range of possible familial adaptations to stress associated with the presence of a child with mental retardation, the family's coping resources, and ecological environments that serve to mediate the family's responses to stress.

Donnellan, A. & Mirenda, P. (1984). Issues related to professional involvement with families of individuals with autism and other severe handicaps. Journal of the Association for the Severely Handicapped, 9, 16-25.

The combination of social, cognitive and communicative deficits associated with autism has contributed to a unique and complex relationship between parents and professionals who serve these individuals. This relationship has changed over time from one in which parents were "blamed" for their children's autism to the present situation in which no blame is assigned and emphasis is placed on building an effective parent-professional partnership. This paper addresses some of the roots of non-productive parent-professional interactions related to individuals with autism and offers standards which might lead to more fruitful and positive relationships.

Duggar, B., et al. (1986). Final report: Financing care of chronically mentally ill and disabled children in home and other ambulatory settings. (DHHS Task Order No. 240-85-0503). Rockville, MD: La Jolla Management Corporation.

This volume reports on a study to examine the costs and services associated with serving chronically ill children in alternative care settings under the Medicaid waiver program. To complete the study, nine states serving chronically ill and/or disabled children were visited and client level data were abstracted from each site. Data for each person were collected on demographics, care plan and case management, the care setting prior to program admission, principal diagnosis, functional level, services

currently receiving, costs prior to and after entry into the waiver program. In general, the study concludes that Medicaid waiver programs serving chronical / ill children in home care settings result in lower costs to Medicaid.

Dunst, C.J. (1986). Helping relationships and enabling and empowering families (unpublished manuscript). Morgantown, NC: Human Development Research and Training Institute, Western Carolina Center.

An examination of various models of helping relationships and an in-depth discussion of one model which stresses the role of the professional in enabling and empowering the person seeking help is provided. The basic underlying assumption of this model is that changes in people are most likely to occur and to endure when the help seekers are actively involved in developing solutions to their problems. A social-systems perspective is used in developing the concept of empowerment and ten principles designed to guide professionals in enabling and empowering families are discussed. A practical application of the model is described as is an illustrative early intervention program.

Dunst, C.J. & Trivette, C.M. (1987). A family systems model of early intervention with handicapped and developmentally at-risk children. (unpublished manuscript). Morgantown, NC: Human Development Research and Training Institute, Western Carolina Center.

This manuscript presents a family systems-oriented early intervention program, including research and intervention components and an in-depth analysis of its theoretical base, guiding principles, and format. In addition, current research to isolate factors which affect family functioning and adjustment in raising a child with or at-risk of a developmental disability are discussed. The professional's role revolves primarily around empowering families--assisting them with identifying their needs and helping them to mobilize their informal social support networks in order to meet these needs. This model is contrasted with traditional early intervention programs. Preliminary findings of ongoing research provide support for an individualized, needs based social support model of intervention. Findings and their impact on program design are examined.

Dunst, C.J. & Trivette, C.M. (1985). A guide to measures of social support and family behaviors. Chapel Hill, NC: University of North Carolina, Frank Porter Graham Child Development Center, Technical Assistance Development Systems.

This monograph presents a selective list of measures of social support and a number of different outcome measures that support has been found to mediate. Section I provides definitions of key terms (e.g., social networks, stress, coping) and a brief review of evidence that substantiates the contention that providing support prompts beneficial outcomes. Sections II and III are comprised of two large charts. The first displays a list of family support measures and the corresponding types of social support (e.g., kinship, extra-familial) and measures of well-being that the instrument addresses. The second chart cites reliability and validity data for selected measures. The final section provides references for the instruments and cited literature.

Dunst, C.J. & Trivette, C.M. (1987). Enabling and empowering families: Conceptual and intervention issues. Morgantown, NC: Western Carolina Center, Family Infant and Preschool Program.

A social systems model of family functioning is used to examine the concept of empowerment and the role of helping professionals in facilitating or hindering an increased sense of empowerment in help-seekers. The authors discuss various models of helping relationships and focus on the one approach which they believe is the most viable. This model emphasizes the role of the help seeker in developing solutions to problems and serving to promote positive change and a sense of empowerment in him/herself.

Dunst, C.J., Trivette, C.M., McWilliam, R.A., & Gallant, K. (In press). Toward an experimental evaluation of the family, infant and preschool program. In H. Weiss & F. Jacobs (Eds.), Evaluating family programs. New York: Aldine Publishing Co.

The Family, Infant and Preschool Program (FIPP), an early intervention program which utilizes a proactive, family- and systems-oriented approach, is described, with a particular focus on its integral research and evaluation components. Examples of evaluation projects, their findings, and the impact of the latter upon program design are discussed. Findings provide support for the FIPP model of services which emphasizes helping families to mobilize their informal social support networks. A discussion about the ongoing exchange between research and practice would be valuable for professionals working with people with disabilities and their families.

Dunst, C.J. & Trivette, C.M. (1987). Helping, helplessness and harm. Morgantown, NC: Human Development Research and Training Institute, Western Carolina Center.

In this paper, a discussion of helping relationships, based on social systems theory, is provided. Factors influencing the help seeking process and the potential positive and negative consequences of help seeking are reviewed. To maximize the potential positive effects of these relationships, the authors maintain that the help-seeker must be held responsible for the solution of the problem for which help is sought, though not for the problem's development. Ten principles designed to guide the professional in enabling and empowering the help seeker are outlined as are implications for public policy and practice in the areas of family support programs and behavior therapy.

Dybwad, G. (1976). What should be national policy toward handicapped children? In N.B. Talbot (Ed.), Raising children in modern America -- problems and prospective solutions. Boston: Little, Brown and Company.

This chapter identifies major areas of concern in the care and treatment of children with handicaps. It offers an historical perspective of the key issues and suggestions for the future direction of national policy. The article discusses the definition of the term "handicap" and the criteria used in determining whether a person is to be considered handicapped. It also addresses the expenditures made on behalf of children with handicaps, the range of services, the role of the federal government, and the impact of the state and federal courts on the rights of these children. The article makes recommendations for national policy in the following areas: (1) the right to compensatory assistance; (2) early intervention; (3) home-based care; (3) post-school transitional programs; (4) access and fuller participation in a wide range of generic services; and (5) equal protection under the law.

Edna McConnell Clark Foundation. (1985). Keeping families together: The case for family preservation. New York: Edna McConnell Clark Foundation.

This monograph presents background information concerning the factors contributing to the increase in out-of-home placements of at-risk children. Alternative state-level and local-level approaches for supporting and empowering families including the Court-Appointed Special Advocates (CASA) model and interagency coordination strategies are described.

Epenshade, T.J. (1984). Investing in children. New estimates of parental expenditures. Washington, DC: The Urban Institute Press.

The purpose of the study is to provide estimates of expenditures that parents make in rearing their children from birth through 18 years old. Data collected in 1972-73 by the U.S. Bureau of Census was examined to estimate the level of expenditures made by parents and the results are expressed in 1981 dollars. The study calculates the total expenditures on each child and presents data on ten separate categories of consumption including: food at home, shelter, utilities, household furnishings, clothing, transportation, and entertainment. In general, the study found expenditures ranging from \$58,000 to \$135,000 per child. These figures are affected by the parents' socio-economic status, wife's employment status and the number of children in the family. Expenditures are also affected by the region of the country which the family lives and whether or not the family lives in a large metropolitan area. The author concludes that: information on family expenditures is needed to inform legal and other policy decisions, facts about the financial child rearing should be included in parent education programs for high school students, and this type of information will be useful to courts faced with setting child support payments.

Frates, R.C., Splaingard, M.L., Smith, E.O. & Harrison, G.M. (1984). Outcome of home mechanical ventilation in children. The Journal of Pediatrics, 106(5), 850-856.

In an effort to evaluate the efficacy of home care for these children, the outcomes for 54 children with respiratory insufficiency who were dependent on ventilators to varying degrees and were cared for at home, were analyzed in a retrospective study. The children ranged in age from 4 months to 16 years at hospital discharge, which had occurred between 1962 and 1983. Seventeen children died over the twenty-year period and causes of death are discussed. Recommendations for improving the outcomes for children who are dependent on ventilators and living at home are provided. Given the benefits of home care for the child and family, home care is seen as a viable alternative, provided the necessary supports are available.

Freedman, R.I. (1984). Supporting the supports: Families of the chronically mentally ill (draft). Cambridge, MA: Harvard University, Division of Health Policy Research and Education, Mental Health Policy Working Group.

Research studies examining family issues in gerontology, mental health and developmental disabilities are reviewed to present: 1) the roles of families in providing care to members having chronic mental illness, 2) the impact of chronic mental illness on families, and 3) the services and

supports needed by families. The implications of federal policies affecting family caregiving are also discussed.

Friedman, R.M. (1986). Major issues in mental health services for children. Tampa, FL: Research and Training Center for Improved Services for Seriously Emotionally Disturbed Children; University of South Florida; 13301 N. 30th Street.

This paper offers discussion on some of the major policy issues facing the federal and state governments with regard to services for children with emotional disturbances. Information is presented to document the neglect this group has endured, the services they may require, and the steps that must be taken to provide effective community services.

Friedman, R.M. (1985). Serving seriously emotionally disturbed children: An overview of major issues. Florida: Florida Mental Health Institute, University of South Florida.

This report, concerning the development of services for children with serious emotional disturbances, presents the goal of these services and related concepts, and then lays the groundwork for an in-depth discussion of the design and implementation of such services in the least restrictive environment. Existing programs are cited. The author concludes that community-based services are being effective and are reducing the need for utilizing more restrictive alternatives.

Gallagher, J.J. & Vietze, P.M. (Eds.) (1986). Families of handicapped persons: Research, programs, and policy issues. Baltimore, MD: Paul H. Brookes Publishing Co.

Despite the focus on families of children with mental retardation, this multidisciplinary collection of research and policy articles is a very useful source of background information concerning family systems theory, research on the impact of children with disabilities on the family, and current state and federal based approaches to supporting families who provide home care.

Gallo, A. (1984). Spina bifida: The state of art of medical management. The Hastings Center Report, February, 10-13.

In an effort to address controversies surrounding the treatment of Baby Jane Doe and other infants born with spina bifida, the author provides information on factors which influence treatment decisions. Spina bifida, and its effects on bodily functions and intelligence and its medical

management are described. The history of the treatment of children with spina bifida and the evolution of today's treatment philosophy are discussed. The author points out that, though much remains yet to be done, advancements in medical technology and in treatment have improved the prognosis for many of these children. He argues that decision-making regarding the treatment of infants with spina bifida could be facilitated through the uniform and universal dissemination of information about current treatment practices to physicians.

Gardner, J.F. (1986). Implementation of the home and community-based care waiver. Mental Retardation, 24(1), 18-26.

This article examines the success of states in developing home and community-based service waivers authorized by the 1981 amendments to the Social Security Act contained in PL 97-35, the Omnibus Reconciliation Act. Many states submitted waiver proposals that provided a range of community-based services to persons who would otherwise require care in an Intermediate Care Facility for the Mentally Retarded. Most states integrated the waiver services into the existing pattern of service delivery. Difficulties in complying with federal requirements, however, have delayed implementation of the waiver program in many states.

Gardner, J.F. & Markowitz, R.K. (1984). Maryland family support services consortium: Data analysis and summary. Baltimore, MD: Maryland Developmental Disabilities Planning Council.

The purpose of this document is to summarize the major findings from the first project year (July 1983 - June 1984) of the Maryland Family Support Services Consortium. The report consists of three sections: section one provides a brief overview of the organization and methodology for the Consortium project; section two highlights the major findings of an analysis of the program; and section three includes a series of vignettes written about families in the Consortium. The vignettes identify the needs of the families as they entered the Consortium, the services provided by the Consortium and the changes that have occurred in the families as a result of participating in the Consortium project.

Garfunkel, J.M. & Evans, H.E. (Eds.). (1986). Hospital care for children and youth. Elk Grove Village, IL: American Academy of Pediatrics.

Recognizing the importance of information concerning recent developments in medical technology, financing and cost containment, the American Academy of Pediatrics routinely publishes this book which covers new developments in hospital care for children and youth. The appendices include information concerning patient isolation procedures, technical considerations relating to intensive care units, and resuscitation. The authors indicate that the compilation is a resource for physicians and not a set of standards covering hospital care for young children.

Giele, J. (1984). A delicate balance: The family's role in care of the handicapped. Family Relations, 33, 85-94.

Available studies of family care of the elderly and the 1976 Survey of Income and Education are used to examine the relationships of families to individual members with disabilities. Interactions between the person with disabilities, the family, and the community reveal a delicate balance of outside help and family resources.

Gittler, J. & Colton, M. (1987). Alternatives to hospitalization for technology dependent children: Program models. Iowa City IA: National Maternal and Child Health Resource Center.

This report deals with the creation of alternatives to long-term hospitalization for technology dependent children. The report describes five programs (located in Illinois, Iowa, Louisiana, Maryland and Pennsylvania) that are designed to promote and facilitate the transfer of technology-dependent children from a hospital/institution setting to a home setting and to prevent hospitalization of technology-dependent children who are already being cared for in a home setting. The following aspects of each program are described: (1) the program mission, goals and organizational structure; (2) eligibility criteria and population served; (3) service provisions; (4) financing mechanisms; (5) program budget, personnel resources and costs. The report indicates that there is no generally accepted definition of "technology dependent children." Thus, the populations served by the programs vary. The programs also differ by their organizational structure. Exhibits, forms and other documents relating to each of the programs, appear in the appendix of the report.

Gittler, J. & Colton, M. (1986). Community-based case management programs for children with special health care needs. Iowa City, IA: National Maternal and Child Health Resource Center.

As one component of the "Future Directions of Services for Children with Special Health Care Needs" project, administered by the National Maternal and Child Health Resource Center, this publication provides detailed information about four case management programs which serve children with special health care needs and their families. Each program's organization, eligibility criteria, services, personnel and costs are described and related materials (e.g., assessment tools, case management guidelines) are included, as are two case studies. While there were variations between the programs, they share a commitment to improving and expanding family-oriented, community-based case management services. The material illustrates the complexity of the needs of many of these children and their families, the multidisciplinary nature of the services they may require and the role of case management in facilitating the delivery of appropriate services to families.

Goldfarb, L.A., Brotherson, M.J., Summers, J.A. & Turnbull, A.P.. (1986). Meeting the challenge of disability or chronic illness: A family guide. Baltimore, MD: Paul H. Brookes Publishing Company.

Written for family members, the material presented in this book is designed to facilitate home care of individuals with chronic illnesses or disabilities. Specific strategies are presented for assessing and solving problems families may encounter along with examples to illustrate their applications. An annotated bibliography and a list of organizations relevant to people with disabilities or chronic illnesses and their families are included.

Gortmaker, S.L. & Sappenfield, W. (1984). Chronic childhood disorders: Prevalence and impact. Pediatric Clinics of North America, 31 (1), 3-18.

This article reviews what is known about the prevalence of a variety of childhood chronic disorders with emphasis upon disorders showing significant change in prevalence rates. The authors indicate that one review of incidence and survival concerning 11 chronic childhood disorders showed little evidence for significant change in incidence. In contrast, estimates of the survival of children has shown considerable change over time. One key result is that the prevalence of some chronic childhood diseases, such as leukemia, has increased during recent decades. Such developments signal a need for service systems to respond in kind. For instance, the responsibilities of the primary physician may increase since children with chronic illnesses

utilize a broader range of health-related services. Similarly, because children are living longer, service providers must be prepared to offer appropriate services to adolescents and adults as well as very young children.

Greenstein, R.M. & Hudd, S.S. (undated). Home care of the pediatric patient. Monograph Series No. 2, Connecticut Pediatric Research and Training Center.

The purpose of this article is to acquaint the primary care medical provider with the essential elements of home-based care for children and their families. The specific focus is on the physician's role in long term care for the children with multiple-handicaps and/or disabilities. A model for providing home care for the many needs of a pediatric patient is described and the model is described and the model is applied to a number of practical treatment situations. The authors believe that the primary care physician should be a leader in the development, implementation and maintenance of home-based care programs for handicapped children.

Griss, R. (1984). The role of vouchers and informal help networks in long term support. East Lansing, WI: Department of Health and Social Services, Division of Community Services, Office of Program Initiatives.

This is a two paper collection. The first offers descriptions of the cash assistance programs (i.e., vouchers) available to families who provide home care to persons with disabilities and discussion of several issues that must be considered concerning this category of family supports. The second focuses on means for promoting natural personal support groups for families providing home care, offering a conceptual overview of this approach and examples of how natural supports can be used to enhance family efforts.

Guardianship, Advocacy and Protective Services Board. (1981). A future planning guide for parents of developmentally disabled persons. Salem, OR: Association for Retarded Citizens of Oregon.

This booklet provides parents of children with disabilities essential information about ways to plan for their futures. This material should not substitute for the expertise of qualified estate planning professionals. Rather, it is designed to serve as a first step in a comprehensive planning process which, with the involvement of those professionals, should lead to future personal and financial security of children with disabilities.

Gurdin, P. & Anderson, G.R. (1987). Quality care for ill children: AIDS-specialized foster care family homes. Child Welfare, 66(4), 291-302.

This article describes a special foster care demonstration project for infants with AIDS. The article describes the children served, the recruitment and selection of foster parents and the services provided to the foster parents. One conclusion of the project is that foster parents can be recruited, but the number of children in need will likely exceed the number of available homes. Furthermore, children with AIDS and related disorders will add a new challenge to the child welfare system to provide appropriate services.

Hall, W.T., St. Denis, G. & Young, C.L. (Eds.). (1985). The family: A critical factor in prevention. Proceedings of a workshop sponsored by the University of Pittsburgh, Graduate School of Public Health, May 1 - 4, 1983. Pittsburgh: University of Pittsburgh, Graduate School of Public Health.

This manuscript contains papers presented at a 1983 interdisciplinary workshop on the prevention of disability and disease. The focus of all of the papers was the family, since the family is the agent of care and cure. The workshops sought to develop multidisciplinary, family-oriented strategies for health promotion and disease prevention. In addition, presentations also concerned substance abuse and research relating to family stress.

Hardman, M.L. (1984). The role of Congress in decisions relating to the withholding of medical treatment from seriously ill newborns. The Journal of the Association for the Severely Handicapped, 9, 3-15.

This article provides a history (1974-1983) of Congress' role in medical decisions affecting the lives of seriously ill newborns. Major initiatives are identified and discussed beginning with the hearings in 1974 concerning research about withholding medical treatment. Then, responding to the famed "Baby Doe" case in 1982, the executive branch warned against discrimination of those with disabilities. Congress considered several resolutions acknowledging the right to life of the disabled newborn, including the Handicapped Infant Protection Act in 1982. Other initiatives are described as well, ending with S.B. 1009 which forbids discrimination against the person with disabilities. The author identifies ways in which Congress can maintain involvement in this issue, and suggests the need for a general statement of national intent, substantive civil rights legislation, the establishment of a Congressional commission and expanded funding for research.

Harel, S. & Anastasiow, N.J. (Eds.). (1985). The at-risk infant: Psycho/social/medical aspects. Baltimore, MD: Paul K. Brookes Publishing, Company, Inc.

Chapters in this book were originally presented at an international workshop on infants at risk of disability or illness. The 46 chapters of the book are separated into three major sections, each dealing with prevention of risk factors. Section I addresses ecological and environmental factors that place infants at risk. Section II deals with specific conditions arising during pregnancy and perinatal period, while Section III focuses on infancy and early childhood. The multidisciplinary and international perspective undertaken in developing these chapters provide a valuable cross-disciplinary examination of factors contributing to childhood illness and disability.

Healthy, Mothers, Healthy Babies Coalition. (1986). Healthy mothers, healthy babies: A compendium of program ideas for serving low-income women. Division of Maternal and Child Health, Washington, DC: U.S. Public Health Service.

This report summarizes a survey of maternal and child health programs directed toward low income women and their families. The report contains descriptions of selected programs and a summary of responses about educational efforts and the need for educational materials. Three common goals of all of the programs emerged from the survey: 1) commitment to helping low-income women have healthy babies; 2) commitment to the physical well-being and development of children born into low income families; and 3) commitment to supporting the total family. To help reach these goals, respondents articulated a need for increased networking among programs. Professional, para-professional and voluntary training models and effective methods for evaluating programs and materials were also needed. A brief review of the literature concerning health information and education for groups with low incomes is also included.

Healy, A., Keese, P.D., & Smith, B.S. (1985). Early services for children with special needs: Transactions for family support. Iowa City IA: University Hospital School, Division of Developmental Disabilities.

This volume addresses current issues in early intervention programs for very young children who have or are at risk of disability. Three questions are addressed: 1) what is known about at-risk and disabled children and their families? 2) what are the barriers to translating this knowledge into program practice? and 3) what concrete steps can be taken to improve this transition? This book includes chapters concerning: parent-professional interactions; early intervention programs, and child development. The

book also includes an extensive annotated bibliography covering child development, social support, family issues, and early intervention programs. The authors suggest that: 1) family support must become a core service and a primary goal of early intervention services; 2) the terminology used in early intervention must be clear and understandable to facilitate communication and evaluation of services, and 3) the development of interdisciplinary, coordinated services will require important changes in traditional professional agencies' concepts of territorial roles each plays.

Healy, A. & Lewis-Beck, J.A. (1987). Improving health care for children with chronic conditions: Guidelines for families. Iowa City, IA: University of Iowa, University Hospital School.

This manuscript presents guidelines, developed by parents of children with chronic health problems, which are designed to help families cope more effectively when a child becomes ill. These guidelines suggests means for maintaining a supportive home life for other children in the family; establishing collaborative relationships; identifying problems in health, cognitive, social, psycho-social, environmental, and developmental areas; determining strengths and needs in developing individualized plans; securing follow-up services to promote needed care; and participating in outreach and advocacy activities.

Healy, A. & Lewis-Beck, J.A. (1987). Improving the health care for children with chronic conditions: Guidelines for physicians. Iowa City, IA: University of Iowa, University Hospital School.

These guidelines, developed by physicians, are designed to assist physicians work more effectively with families and children with chronic illness. Like the guidelines these authors designed for families, major areas requiring intervention are identified and specific activities targeted to each are described.

Herman, S. E. (1984). Plan for evaluation of the family support subsidy program. Michigan Department of Mental Health, Research and Evaluation Division.

This report presents research on the characteristics, effects, and costs of family support services in four counties in Michigan. Tables display the types of services received, family outcomes in terms of changes in quality of life, perceived changes in the severity of problems, satisfaction with services, changes in behavior, and costs of services.

Heying, K.R. (1985). Family-based, in-home services for the severely emotionally disturbed child. Child Welfare, 64, (5), 519-527.

The staffing patterns, admission criteria, funding, therapeutic approaches and impact of an experimental, family-centered program providing in-home services to families with children labeled as aggressive, psychotic and/or incorrigible are presented. Outcome data suggest that this San Diego-based program is effective in reducing family disruption and out-of-home placements.

Hobbs, B. (1986). News Digest. Washington DC: National Information Center for Handicapped Children and Youth.

This issue is devoted to family support services. Relevant federal and state policy issues are outlined as well as various funding options.

Hobbs, N. & Perrin, J.M. (1985). Issues in the care of children with chronic illness. San Francisco: Jossey-Bass Publishers.

This comprehensive text examines a broad array of topics concerning children with chronic illness and their needs for services. In addition to introducing basic concepts concerning childhood chronic illnesses, the book provides a comprehensive orientation to epidemiological and demographic information concerning 11 different types of severe childhood chronic health conditions. In addition, contributors also discuss special populations and the unique characteristics of rural and inner-city children. The text also includes discussions concerning the involvement of children with chronic illnesses in the public education system and offers some suggestions for improving medical and social services for these children.

Hobbs, N., Perrin, J.M., & Ireys, H.T. (1985). Chronically ill children and their families. San Francisco: Jossey-Bass Publishers.

In presenting the results of a Vanderbilt University study concerning children with chronic illness, the authors present ways to develop a comprehensive system of care for these children. Current medical and social services, educational programs as well as training programs for health and social services professionals are evaluated. In conclusion, the authors make recommendations to improve the current organization and financing of services for these children and their families.

Holtzman, N.A. (1978). Newborn screening for genetic metabolic diseases. (DHEW Publication No. (HSA) 78-5207). Rockville, MD: U.S. Department of Health, Education and Welfare, Health Services Administration.

The purpose of this monograph is to discuss developments which have occurred in the screening of infants for genetic-metabolic disorders since the guidelines for these tests were issued in 1966. Topics addressed include: new developments in PKU screening; related ethical and legal issues; regionalized screening programs; factors which affect the routine use of screening tests for other disorders, and financial issues. Recommendations regarding the use of other screening tests (the benefits of which are not yet sufficiently documented) are discussed.

Hunt, M. (May 3, 1987). A common sense guide to health insurance. New York Times Magazine.

An overview of available health insurance plans is provided to assist the consumer in choosing a plan which meets his or her needs. Variables such as cost, freedom of choice, major medical protection, comprehensiveness and foreseeable medical needs are discussed. A separate section on Medicare is included. Of relevance to family members providing home care to children with chronic illnesses or disabilities are components about catastrophic illness protection and pre-existing conditions. While the article provides useful background information, people concerned with coverage for these conditions would need to seek assistance from individuals familiar with specific policies.

Hunter, M.M. (1984). Children's hospice advisory panel report. Washington, D.C.: Department of Health and Human Services, Division of Maternal and Child Health.

This report is based on a conference held by the Pediatric Hospice Advisory Panel in 1984. The topics covered include: 1) the problems and special burdens faced by families of children with a life-threatening condition; 2) the complex network of services required to respond effectively to the seriously ill child and their family; and 3) strategies to stimulate the implementation of the pediatric hospice philosophy in the United States, using available public and private resources.

Hutchinson, J. & Nelson, K. (1985). How public agencies can provide family-centered services. Social Casework, 367-371.

This paper assesses some of the components involved in a public, "family-centered" child welfare service program. Topics reviewed are: intake and family service components,

social work staff allocation models based on case mix, and funding constraints.

Information Sciences Research Institute. (1984). Workshop on financing health care for handicapped children. Vienna, VA: Information Sciences Research Institute.

This volume contains papers presented at the Workshop on Financing Health Care for Handicapped Children held in May 1983. The objectives of the conference were: 1) to provide a basis for State Title V Programs to use in reviewing their role in financial counseling for families; 2) to identify gaps in public and private insurance coverage; 3) to define new ways to improve the availability of care for children with handicaps. The workshop generated recommendations which identified the need for leadership to change existing reimbursement systems and the importance of improving the systems providing care while containing costs.

Isensee, L.C. & Campbell, N.D. (1987). Dependent care tax provisions in the states: An opportunity for reform. Washington, D.C.: National Woman's Law Center.

This report is addressed to policy makers in their efforts to address dependent care needs through tax policy. The manuscript begins with an examination of the provisions of the federal dependent care tax credit and then provides an overview of state dependent care tax credit provisions. Finally, the report examines the effect of federal tax reform on state dependent care tax provisions and sets forth specific revisions in state tax codes that would increase state support for dependent care.

Jones, M.L. (1985). Home care for the chronically ill or disabled child. New York: Harper and Row.

This is a practical how-to guide for family members providing home care to children with chronic illnesses or disabilities. Written by the mother of a child who had a degenerative neurological condition, it provides detailed information about the daily care of a child's physical, educational and social needs. The book is replete with drawings which illustrate specific techniques and equipment discussed in the text. The comprehensive and well-organized nature of this book contribute to making it an invaluable resource for families.

Jones, M.L. (1985). Paying for the medical help you need. In M.L. Jones, Home care for the chronically ill or disabled child. Cambridge, MA: Harper and Row, 228-243.

This chapter is written for parents who are providing home care to a child with a chronic illness or a disability. Using the same straightforward, practically-oriented approach found throughout the book, the author provides the reader with information about potential sources of financial assistance for costs incurred in home care. Ms. Jones reviews various government programs (e.g., Medicaid, SSI, Crippled Children's Services) and also provides detailed information about maximizing the benefits of private health insurance policies. Some creative approaches to seeking financial assistance from other sources are offered.

Jones, M.L. (1985). Teaching and educating your child. In M.L. Jones, Home care for the chronically ill or disabled child. Cambridge, MA: Harper and Row, 185-209.

Written for parents of children with chronic illnesses or disabilities, this chapter addresses the educational needs of the child. Basic principles of teaching, which parents may use in order to teach skills at home, are discussed. The major focus of the chapter is a discussion of the federal law (P.L. 94-142) which entitles all children to an education and the ways which parents may advocate for that education. Parents will find the content of this chapter invaluable as they work with school administrators and individual educators on behalf of their children.

Kaufman, J. & Lichtens*ein, K. (1984). The family as care manager: Home care for medically fragile children. Washington, D.C.: Georgetown University Child Development Center.

This workbook is designed to help families become experts in the roles and responsibilities of the "parent as case manager." It outlines five major roles and/or tasks that might be assumed by parents who provide home-based care for medically fragile children: medical manager, financial planner, educational advocate, resource specialist, employer, and maintainer of records. Each task is discussed and worksheets are included to assist parents in planning these activities. The financial workshee* includes a monthly budget, a listing of the child's medical expenses, financial programs for which a child or family might be eligible, details on insurance coverage and a discussion of

basic insurance practice. This is a useful, direct and clear treatment of the myriad of responsibilities faced by parents who assume care and case management of their chronically ill or disabled child at home.

Kazak, A. & Marvin, R. (1984). Differences, difficulties, and adaptations: Stress and social networks in families with a handicapped child. Family Relations, 33, 67-77.

This paper discusses differences in 100 families with and without a child having handicaps with respect to three types of stresses (individual, marital, and parenting) and three structural characteristics of their social support networks (size, density, and boundary density). Generally, higher levels of stress and distinct network structures are found in the families having a child with handicaps. Despite the presence of high levels of stress, the families are found to have successful coping strategies. The results are discussed in terms of recognizing family strengths and incorporating existing adaptational patterns in clinical interventions.

Kellam, S.G., Ensminger, M.E. & Turner, R.J. (1977). Family structure and the mental health of children. Archives of General Psychiatry, 34, 1012-1022.

This research report details the results of an empirical study of the relationship between poverty and the mental health of children. Results suggest that poor mental health of children may result from the child's limited social adaptation and from the social isolation of the mother.

Kimmich, M.H. (1985). America's children who cares? Growing needs and declining assistance in the reagan era. Washington, D.C.: The Urban Institute Press.

This book analyzes the behavior of state and local governments in coping with federal cutbacks. Although existing federal programs and the nature of the reductions are described, the primary emphasis of this booklet is how cutbacks affect the provision of services to children. The author suggests that although states and localities have been able to replace some of the federal funds, most children's services have suffered reductions. Nonprofit agencies serving children have been able to recover from government funding reductions by increasing fees and services. These agencies have become less able to serve nonpaying persons. Most programs have had changes in service offerings such as favoring crisis assistance over prevention and basic services over specialized ones.

Knollmueller, R.N. (1984). Funding home care in a climate of cost containment. Public Health Nursing, 1(1), 16-22.

While home care is often proposed as a less costly alternative to institutional care, in an era of rapidly escalating health care costs, the author contends that the expansion of these services under the current fragmented reimbursement systems is not a viable plan. An overview of current public and private financing programs and the model by which costs are currently determined diagnosis related groups (DRGs) are presented. An alternative method, under which costs would be determined according to services actually provided is proposed. The author emphasizes the need to further examine the DRG system and alternative prospective reimbursement systems prior to their utilization for home health care.

Koepke, J.M. & Thyer, B.A. (1985). Behavioral treatment of failure-to-thrive in a two year old. Child Welfare, 64(5), 511-516.

This is a description of the behavioral treatment of a two year old hospitalized with non-organic, severe failure-to-thrive syndrome and rumination. Techniques to decrease voluntary behaviors which interfered with eating and to increase socially appropriate eating behaviors were taught to the child's mother. Improvements in the child were maintained above baseline levels over the first seven months following hospitalization and regurgitation was absent. Findings provide support for further exploration of this approach, which is less aversive, intrusive and time consuming for the child and family members than those often used to treat self-rumination in children with failure-to-thrive syndrome.

Kupst, M.J., Schulman, J.L., Honig, G., Maurer, H., Morgan, E. & Fochtman, D. (1982). Family coping with childhood leukemia: One year after diagnosis. Journal of Pediatric Psychology, 7(2), 157-174.

Sixty-four families of children with leukemia participated in a study designed to assess coping, and the effects of psychosocial intervention on coping. The authors hypothesized that most families would be coping well at one year following diagnosis and that their coping levels at one year would be related to previous coping. Families were randomly assigned to two treatment groups and one control group. The first hypothesis was supported, while the second was not. Possible reasons for these and other findings, including methodological limitations are discussed and implications of the findings for treatment are suggested.

Lapham, V.E. & Sherlin, K.M. (1986). The impact of chronic illness on psychosocial stages of human development. Washington, DC: Georgetown University Hospcial and Medical Center, Department of Social Work.

The purpose of the book is to address critical issues regarding the impact of chronic illness and disability on human development. Erik Erikson's theoretical framework concerning the stages of human development is used to explore the crises caused by chronic illness. The book discusses each developmental stage: infancy, early and late adolescence, young adulthood, mature adult and retiring adult. There is a review of of Erickson's "anticipated crises" associated with the developmental stages as well as a discussion of "unanticipated crisis" associated with stage. Questions are raised about how individuals in each developmental stage can resolve the occurring crises.

Lennie, J.A., Klun, J.R. & Hausner, T. (1987). Low birth-weight reduced by the obstretrical access project. Health Care Financng Review, 8(3), 83-86.

This article describes the efforts of a demonstration project in improving both access to care and birth outcome to a group of 7,000 low-income and Medicaid patients in California. The project provided prenatal care, including psychosocial, health education and nutrition serviecs with the use of a modified fee for service financing mechanism and a specified maternity benefit package. The results of the project were: 87% of the registrants started prenatal care during the first trimester, 84% of the registrants completed the project.

Longo, D.C. & Bond, L. (1984). Families of the handicapped child: Research and practice. Family Relations, 33, 57-65.

Children who have chronic illnesses or disabilities and their families regularly come to the attention of community professionals. Measures of successful family functioning, along with models of practice to promote healthy family adaptation need to be identified. In this review, studies that support the notion of successful family functioning are used as the basis for discussing clinical implications.

Lubin, R.A., Jacobson, J.W. & Kiley, M. (1982). Projected impact of the functional definition of developmental disabilities: The categorically disabled population and service eligibility. American Journal of Mental Deficiency, 87, 73-79.

Indicators of substantial limitation in seven life activity areas defined in P.L. 95-602 were generated from a comprehensive needs assessment/screening instrument used in

New York State. These indicators were then applied to a data base of over 35,000 individuals having one or more of the categorical developmental disabilities of autism, cerebral palsy, epilepsy, mental retardation, or other neurological impairments. Results of this analysis suggest that potential inclusion of persons eligible for services within the functional developmental disabilities definition of P.L. 95-602 varies as a function of categorical disability, age, and level of intellectual functioning. Implications of these findings for access to services are also presented.

Magee, E.M. & Pratt, M.W. (1985). 1935-1985: Fifty years of U.S. federal support to promote the health of mothers, children and handicapped children in America. Vienna, VA: Information Sciences Research Institute.

This volume reviews federal appropriations and allocations to states for health and related programs of the Social Security Act of 1935 and the Omnibus Budget Reconciliation Act of 1981 and includes a brief history of the Maternal and Child Health Program from 1935 through 1985. Information is given about the earliest organization, Children's Bureau, formed in 1912. A discussion of the impact of the block grants implemented in the 1981 U.S. budget is also presented. State-by-state allocations of Maternal and Child Health Block Grants are listed for each year from 1935 to 1985.

Magrab, P., Elder, J., Kazuk, E., Pelosi, J. & Wiegerning, R. (undated). Developing a community team. Washington, D.C.: Georgetown University Child Development Center.

This book identifies issues involved in developing a team approach in providing services to children with handicaps in the community. The book has four how-to chapters which identify issues and offer concrete suggestions for addressing problems. This book is a companion to Community Workbook for Collaboration Services to Preschool Handicapped Children.

Magrab, P., Kazuk, E. & Greene, L. (1981). Community workbook for collaborative services to preschool handicapped children. Washington, D.C.: American Association of University Affiliated Programs for the Developmentally Disabled.

This workbook presents procedures for initiating a cooperative effort to coordinate the activities of the individuals and agencies serving preschool handicapped children and their families. The workbook is divided into five sections: 1) Identifying Participating Groups, 2) Collecting Numerical Data, 3) Determining Needs of Target Populations, 4) Surveying Service Providers, 5) Finalizing

Community Needs. Each section contains a narrative explaining what should happen at each stage of the entire process. There are worksheets which can be used to assist community groups in accomplishing the tasks involved.

Magrab, P., Young, T. & Waddell, A. (1985). Developing collaborative services for seriously emotionally disturbed children. Washington, DC: Georgetown University Child Development Center.

This is a concise, step-by-step guide for cooperatively planning comprehensive community services to benefit children with emotional handicaps and their families. The practical techniques presented for group problem solving and program implementation strategizing are useful for planning a wide variety of services.

Massie, R.K. (1985) The constant shadow: Reflections on the life of a chronically ill child. In N. Hobbs & J.M. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco, CA: Jossey-Bass, 13-29.

The intent of this chapter is to provide the reader with a personal account of life with chronic illness. The author, who has hemophilia, discusses his own experiences and the commonalities among children with different chronic illnesses and their families. The psychological and emotional challenges which face these children are discussed, as are ways in which doctors and nurses can assist youngsters in addressing these challenges. The author argues that chronic illnesses and handicaps in one family member affect the entire family unit. Given the crucial role which parents can play in the condition of the child's health, their involvement in treatment planning is essential. The need to support families through legislative changes leading to a more equitable health insurance system for American citizens is emphasized. The chapter provides the reader with insights into the experiences of a child with chronic illness, while also sensitively challenging him or her to explore ways in which to connect with that child, despite the potential of pain.

Mattson, A. & Gross, S. (1966). Social and behavioral studies on hemophilic children and their families. The Journal of Pediatrics, 68(6), 952-964.

A study was conducted to assess coping behavior of boys with hemophilia and their families and any relationship which might exist between parental attitudes towards the disease and the child's psychological development and clinical course. Thirty-five boys and their twenty-two families were interviewed and observed on multiple occasions over a two-year period. The majority of boys, their families and

siblings demonstrated satisfactory adaptation to the disease. Correlations between parental behavior and attitudes and the boy's adjustment are discussed. The specific recommendations are geared toward supporting the family.

Maybanks, S. & Bryce, M. (Eds.). (1979). Home-based services for children and families: Policy, practice and research. Springfield, IL: Charles C. Thomas, Publisher.

This collection of essays by researchers and administrators provides a theoretical foundation for the provision of preventive and rehabilitative services to the family in the home. The first section traces the historic, economic and theoretical perspectives of the return to home-based care. Section II examines many of the assumptions regarding service delivery to families. Section III consists of 19 descriptions of social, educational, health and specialized programs for persons with developmental disabilities. One chapter discusses home-based services for families who receive protective services. The final section discusses evaluation of home-based social and educational programs.

McDonald, E.P. (1985). Medical needs of severely developmentally disabled persons residing in the community. American Journal of Mental Deficiency, 90, 171-176.

This research reports needs for medical services by 27 persons with severe developmental disabilities who were living in the community. Although the purpose of the research was to examine use of services in order to formulate recommendations for developing a generic services network, the authors report a low incidence of acute illnesses and emergencies among these individuals. The authors concluded that living in the community was advantageous and that these individuals had access to highly specialized medical services that had previously been unavailable to them.

McKeever, P.T. (1981). Fathering the chronically ill child. Maternal Child Nursing, 6, 124-128.

Ten fathers of children with chronic illnesses under the age of 12 were interviewed in order to gain an understanding of the impacts of their child's chronic illness upon them. All of the children lived at home in intact families. All families had health insurance. The interviews took place in the father's home and focused on the following topics: communication with health professionals, impact of the illness on the father, father's involvement with the child, coping mechanisms; and the father's main concerns. Findings compared favorably with results from other studies. Implications for nurses revolve primarily around the need to

be alert to father's concerns and to assist parents in obtaining relief from their daily caretaking responsibilities.

McPherson, M. (1986). Systems approach to care of technology assisted children. Testimony presented to the Secretary's Task Force on Technology Dependent Children.

This testimony to the Secretary of Health and Human Services Task Force on Technology Dependent Children provides information about Maternal and Child Health (MCH)-sponsored programs and the population served by the programs. The author points out that the major issues surrounding technology-dependent children are high costs and the lack of a comprehensive system for coordinating, managing and financing care. The author identifies projects which focus on future needs, case management, family-centered care, and financing.

Meisels, S.J. (undated). Children in transition: The evolution of public policy for handicapped young children (unpublished manuscript). Ann Arbor, MI: University of Michigan.

This paper presents an analysis of public policy governing intervention programs for very young handicapped and at-risk children in Massachusetts. Public policy for early intervention programs underwent major changes between 1980 and 1984. This paper describes the state-wide constraints on policy, administration and finances that influenced early intervention services prior to 1984. The process of policy change and formulation is analyzed by focusing on the principal catalysts for change: key individuals and constituency groups, critical documents and research studies, and important political and economic events. In addition, other general factors that were critical to the transformation of early intervention policy are identified. These include the compelling logic of early intervention and the readiness of key individuals and organization with vision and political influence to act. The potential long-term effects of these changes are discussed and placed within a broad policy framework.

Merila, E. (1986). Liability insurance: The purchaser's guide. Madison, WI: The Center for Public Representation.

This booklet presents information for small businesses, non-profit organizations and local governments to use when making decisions about buying insurance. The information is written in the form of a purchaser's checklist and provides a basic introduction to concepts often discussed in insurance purchases. The appendices include a glossary of insurance terms and a list of insurance commissioners in all states.

Miller, J.F. (1983). Patient power resources, Coping with chronic illness, pp. 3-13.

An overview of the power resources model as it pertains to people with chronic illnesses is presented in this introductory chapter. The focus is on the ways in which chronic illnesses compromise people's power resources (e.g., physical strength, self-concept, motivation). Based on evidence that a person's ability to cope with a chronic illness and to achieve optimal therapeutic results are improved if one's control is maximized, the author argues that nurses must assist patients in identifying and maximizing their intact resources and suggests ways in which this may be done.

Moore, J.A., Hamerlynck, L.A., Barsh, E.T., Splieker, S. & Jones, R. (1982). Extending family resources (2nd Ed.). Seattle, WA: Children Clinic and Preschool.

This report documents a two phase demonstration project undertaken by the University of Washington. Phase I included an assessment of the barriers families face in providing home care. Phase II involved the provision of family support services to 17 families of children with either cerebral palsy or other neurological impairments. The service approach focused on empowering families to decide what services or goods they needed, and to strengthen the natural supports available to families (e.g., extended family, neighbors), using such supports whenever possible. An evaluation of program effects is also described.

National Center for Clinical Infant Programs. (1986). Infants can't wait. Washington, DC: National Center for Clinical Infant Programs.

The authors of this publication suggests that the responsibility for ensuring the healthy development of children rests with families and with those individuals who design public policies which can either facilitate or hinder parents' abilities to provide for their children. The needs and developmental stages of infants and toddlers are reviewed. This is followed by a discussion of supports available to enhance child development and a review of unmet needs. Two initiatives designed to address gaps in services to all children, including those at risk for or identified with health or developmental programs, are discussed. The authors present detailed strategies for implementing these initiatives, utilizing a combination of public and private resources. Related training and research needs are also described.

National Center for Clinical Infant Programs. (1986).
Infants can't wait: The numbers. Washington, D.C.:
National Center for Clinical Infant Programs.

This report presents national data concerning characteristics of at-risk children, their families and neighborhoods relevant to program planning and development.

National Center for Clinical Infant Programs. (1986).
Program evaluation: Issues, strategies and models.
Washington, D.C.: National Center for Clinical Infant
Programs.

This volume discusses issues, strategies and models of program evaluations for early intervention programs. The first section addresses the purpose and process of conducting evaluations for early intervention programs. The second section addresses process evaluations, outcome evaluations and active evaluations. The third section gives an example of an evaluation which helped to improve clinical practice and supervision in an early intervention program.

National Institute of Child Health and Human Development. (1986). An evaluation and assessment of the state of the science. Report of the study groups on mental retardation and developmental disabilities. Washington, DC: U.S. Department of Health and Human Services, National Institute of Health.

This volume represents an update and an expansion of the National Institute of Child Health and Human Development's Research Plan addressing issues in the area of mental retardation. It includes such areas as: epidemiology, developmental neurobiology, genetics, nutrition, obstetrics, psychological processes, psychobiological processes, behavior analysis, communicative processes, early diagnosis and early intervention, socio-ecological processes, family and community and resource and training needs. For each area, there is discussion of the major issues and recommendations for research priorities and action.

National Institute of Child Health and Human Development. (1986). Family planning and population research. Special report to Congress. Washington, D.C.: National Institute of Health.

The responsibilities of National Institute of Child Health and Human Development and selected activities of the Center for Population Research (CPR) are described. Major findings of research supported by CPR in the following areas are summarized: reproductive sciences, contraceptive development and evaluation, and demographic and behavioral sciences (e.g., effects of teen parenthood on school-related

achievement). Specific projects include: the effects of family and household structure on child health and development; impact of the costs of child care and the availability of employment on childbearing; and the factors related to infant mortality.

National Institute of Child Health and Human Development. (1986). Maternal and child health. Washington, D.C.: National Institutes of Health.

In an effort to maximize the optimal outcome of pregnancies and the health potential of infants born in the United States, the National Institute of Child Health and Human Development (NICHD) conducts and supports research on the health of mothers and children. A selection of the Institute's activities in the following areas are included: low birthweight, premature births, intrauterine growth, retardation, environmental hazards, nutrition, neonatal infections, diseases of childhood and infancy, and psychological facts in mother-infant separations. Research relating to children conducted by other institutes (e.g., National Cancer Institute; National Heart, Lung and Blood Institute, National Institute of Arthritis, Diabetes and Digestive and Kidney Diseases; and National Institute of Neurological and Communicative Disorders and Stroke; National Eye Institute) is also described.

National Institute of Child Health and Human Development. (1986). Mental Retardation. Washington, D.C.: National Institutes of Health.

A brief overview of National Institute of Child Health and Human Development (NICHD) role in funding and conducting research into the causes, treatment and prevention of mental retardation is described. Major findings of research being conducted by NICHD, its grantees and other institutes, (the National Institute of Allergy and Infectious Diseases; and the National Institute of Neurological and Communicative Disorders and Stroke) are discussed.

National Institute of Child Health and Human Development. (1986). Sudden infant death syndrome. Washington, D.C.: National Institute of Health.

The three primary objectives of National Institute of Child Health and Human Development's Sudden Infant Death Syndrome (SIDS) program are defined and findings of current research are described. A profile of infants at risk for developing SIDS, based on research involving interviews with mothers of over 800 infants who died of SIDS and approximately 1600 born in the same month, who did not die, is presented. While the focus of the research is discovering the etiology of SIDS, the authors also discuss one program which is exploring treatment for infants at-risk of SIDS.

Noyes, E.J. (1985). Children: A priority? Nursing Economics, 3, 136-139.

The author questions the United State's commitment to children and cites the inadequacies of current maternal and child health policies. Barriers to effective commitment to children on the federal and state levels include: a lack of federal policies, children's low priority in the federal budget and the lack of adequate data bases. The development of the latter is viewed as crucial to the development of more effective policies. An appeal is made for grassroots advocacy efforts on behalf of children, who by themselves have little impact on policy makers.

Olson, D.H. & Miller, B.C. (1983). Family studies review Yearbook. Beverly Hills, CA: Sage Publications.

This book provides important background information on basic family issues and concerns including work, stress, economics and family therapy. Specifically, sections entitled, "Family Policy", Family Stress and Coping" and "Family Economics" may be especially relevant for families having children with developmental disabilities.

Perlman, R. (Ed.) (1985). Family home care: Critical issues for services and policies. New York: The Haworth Press.

This publication tracks society's response to disabilities and focuses on contemporary policies concerning family care. Several chapters concerning issues facing families who have members with emotional disabilities are especially useful.

Pine, M. (1984). The new human genetics. How gene splicing helps researchers fight inherited disease. Washington, DC: National Institute of General Medical Sciences, Office of Research Reports.

This publication reviews highlights in genetics and current work and future directions of research. Its primary focus is a description of how genetic disorders are inherited and the processes used to detect genetic defects. Examples of disorders for which specific causes have been identified are included throughout. The publication is illustrated with many diagrams and photographs. A comprehensive glossary of related terms is provided. The publication gives the reader with an interest in genetic disorders a glimpse into current research and its implications for the diagnosis and treatment of genetic disorders.

Pineyard, B.J. (1983). Siblings of children with myelomeningocele: Examining their perceptions. Maternal-child nursing journal, pp. 61-71.

In order to gain insight into the experiences of siblings of children with myelomeningocele, the author interviewed twelve siblings from eight families. Topics discussed included their knowledge of their sibling's condition, their concerns and the impact they felt their siblings had on their own lives, friendships and school experiences. Parents were interviewed separately about their perceptions of their children's responses to questions in these areas. On the whole, the siblings appeared to be coping well. Parents' perceptions of their children's concerns were usually accurate. The greatest discrepancy was in the area of worries and concerns, many of which children kept to themselves. Recommendations for health care providers are made to enable them to monitor the effects a child with a disability has on his/her sibling(s).

Pless, B. & Perrin, J.M. (1985). Issues common to a variety of illnesses. In M. Hobbs & J.M. Perrin (Eds.), Issues in the care of children with chronic illness. San Francisco: Jossey-Bass Publishers.

Using a review of relevant literature this chapter presents differences and similarities among chronic childhood illnesses and implications for the provision of services to children and their families. The authors acknowledge the uniqueness of different illnesses and therefore the necessity for specialized medical services for these children. However, they argue that, for the sake of public policy and program development, these children and families be considered as one group due to the universal nature of many of the challenges which they face (e.g., financial burdens, emotional impact of chronicity on child). Implications and recommendations for public policy, program development and service coordination are discussed in detail. This information would be valuable for people involved in the design and implementation of programs and policies for this population.

Project Serve. (1985). New directions: Serving children with special health care needs in Massachusetts. Boston: Project Serve.

This volume reports the results of a tri-agency project directed at documenting and analyzing existing services for children with handicaps in Massachusetts. The summary of findings includes a discussion of the state family health services program, primary care providers, tertiary care facilities, consumer and family contacts, and other state agencies. Quantitative and qualitative data were gathered

regarding gaps in services or unmet needs, eligibility criteria, financing of services and linkages among systems. Detailed recommendations are made around organizational adjustments, child-centered services and family-centered services. Each recommendation lists the target populations and implementation issues.

Rosen, C.D. & Gerring, J.P. (1986). Head trauma educational reintegration. San Diego, CA: College Hill Press.

This book provides information about the multiple effects of closed head injuries upon children and adolescents and the ramifications for school performance. The potential impact of the injury upon the youngster and the ensuing effects on people who know the child are discussed in detail, together with practical suggestions for addressing the student's needs and behaviors. While reintegration of these youngsters into their homes and schools is the goal, achievement of the goal requires the availability of a range of multidisciplinary, coordinated services for the individual and his or her family. An annotated bibliography and glossary are also included.

Rosetti, L.M. (1986). High risk infants: Identification, assessment, and intervention. Boston, MA: College Hill Publication, Little, Brown and Co.

Written for professionals who work with high-risk infants and their families, this book addresses topics such as: typical and high-risk infant development, infant assessment, parental concerns, early interventions and other services. The central role of the family is stressed throughout. Major findings from the literature focus on documented differences between typical and high-risk infant development, the efficacy of early intervention programs and the need for long-term follow-up. The book provides a comprehensive overview of the research with practical suggestions relevant to the variety of professionals who work with these children and their families. Appendices include: a glossary of terms relevant to this population, case studies, a bibliography, and an annotated list of over 40 assessment tools.

Rossetti, L.M. (1986). Parental concerns in high-risk infants. In L.M. Rossetti (Ed.), High-risk infants: Identification assessment, and intervention. Boston, MA: College Hill Publications, Little Brown and Company.

The purposes of this chapter in a book about identification and assessment of and intervention with high-risk infants are 1) to discuss the circumstances which the parents of a very sick infant face, 2) to describe the potential future effects upon the family's well being, and 3) to present family intervention strategies which may be appropriate for

these families. Reviews of literature and a parent's report on topics such as the following are included: normal infant attachment, effects of early mother-infant separation, sources of parental stress related to the birth of a high-risk infant, patterns of parental adjustment, and intervention with parents. Overall, the need for a family-centered approach, both while the child is in the hospital and after discharge, is emphasized.

Russell, M.L. (1983). Alternatives. A family guide to legal and financial planning for the disabled. Evanston, IL: First Publications, Inc.

This book presents, in one clear and comprehensive volume, the basic elements of estate planning with emphasis on the special needs of families who have relatives with disabilities. The range of estate planning topics include wills, guardianship, trusts, maximizing governmental benefits for persons with disabilities, taxes, insurance, and financial planning. Because it is a comprehensive source of this specialized information, this book is a useful reference guide for professionals: lawyers, social workers, and administrators of services and organizations serving persons with disabilities.

Schilling, R.F., Gilchrist, L.D. & Schinke, S.P. (1984). Coping and social support in families of developmentally disabled children. Family Relations, 33, pp. 47-54.

Personal coping and social supports are presented as resources for parents of children with handicaps. An overview of the difficulties faced by parents is followed by a review of several studies on coping by parents. The authors describe a structured group approach to teaching parents to use personal coping and social supports.

Schopler, E. & Mesibov, G.B. (Eds.). (1984). The effects of autism on the family. New York: Plenum Press.

In response to inquiries about how they work with families, the authors, staff members at North Carolina Division for Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH), solicited the material for this book. Chapters, which were written by parents and professionals, focus primarily on key components of parent-professional relationships and the multiple roles which parents of children with autism play in relationship to their children, other family members and professionals. Personal and clinical experiences as well as relevant research findings are included. The book is particularly valuable because of the collaborative parent-professional effort it represents, reflective of TEACCH's philosophy in working with parents.

Shelton, T.L., Jeppson, E.S. & Johnson, B.H. (1987). Family-centered care for children with special health care needs. Washington, DC: Association for the Care of Children's Health.

This monograph discusses eight key elements necessary to move from agency-centered to family-centered care. The elements have been developed by parents and professionals involved in providing programs to children with special health care needs. The authors present examples of programs and policies to illustrate the complex and multifaceted nature of family centered care. In addition to several checklists for parents and planners to use in moving from agency-centered to family-centered care, the authors also include several important lists of resources and reference materials useful for parents and professionals.

Sherman, B. & Coccozza, J. (1984). Stress in families of the developmentally disabled: A literature review of factors affecting the decision to seek out-of-home placements. Family Relations, 33, 95-103.

This paper reviews the literature concerning factors associated with the stress families experience and contribute to the placements of members with disabilities out of home. Although the characteristics of the child play a major role in families' decisions to seek out-of-home placements, other situational factors include family characteristics, stress, social supports and community services. The implications for future research, clinical intervention strategies and planning community services are also discussed.

Skarnulus, E. (1979). Support, not supplant, the natural home: Serving handicapped children and adults. In S. Maybanks & M. Bryce (Eds.), Home-based services for children and families: Policy, practice, and research. Springfield, IL: Charles C. Thomas.

The author questions the "residential assumption" -- if a person has mental retardation, he/she needs residential services. He suggests in 97% of the cases more simple services are required and that it is easier to maintain -- economically and emotionally -- a person with disabilities at home than it is to reintegrate an institutionalized person back into the community. By providing a family with necessary supports, the author envisions a world where the need for residential services could be eliminated.

Snell, M.E. & Beckman-Brindley, S. (1984). Family involvement in intervention with children having severe handicaps. Journal of the Association for the Severely Handicapped, 9, 213-230.

Research examining the use of family members to intervene with children having severe handicaps is presented. In general, the evidence suggests that family members can be effective interventionists. Implications for further research as well as other critical issues including generality, measurement and cost-effectiveness of the interventions are delineated.

Sparer, E.V. (1976). The legal right to health care: Public policy and equal access. Hastings Center Report, October, 39-47.

The author raises the question of whether Americans have a right to health care and outlines the conditions which must be met for such a right to exist. Bills which have been brought before Congress and passed or not passed, and federal financing of programs which address the health care needs of specific groups of people are discussed. While not minimizing the impact of these programs, the authors contend that without specific social preconditions which lend support to them, the maximum effects of these programs cannot be achieved. The result is that some people will be without health care. Six of these social conditions and steps which need to be attained in order to make the goal of a right to good health care more realizable are discussed.

Specht, D.I. & Nagy, M. (1986). Social supports research project: Report of findings. Western Massachusetts Training Consortium, Inc.

In order to examine the current social supports of people with mental retardation who were formerly institutionalized, and the factors which impeded or fostered relationship building, interviews were conducted with clients (n=11), program administrators and program staff. A related literature review was also conducted. Findings revealed a paucity of friendships and inadequate attention by agencies to facilitating the development of friendship relationships, in a state (Massachusetts) where much effort has been devoted to community integration. Factors which support relationship building are outlined.

Starr, R.H., Districh, K.N., Fischhoff, J., Cevesne, S., et al. (1984). The contribution of handicapping conditions to child abuse. Topics in Early Childhood Education, 4(1), 55-69.

This article reviews the literature on the contributions of low birthweight, perinatal problems, congenital disorders, and mental retardation to child abuse. While existing transactional and ecological theories suggest such factors should contribute to abuse, a careful analysis of studies indicates that minor deviations in child behavior rather than major handicaps are related to the occurrence of abuse. The authors conclude that efforts to help families adjust to having a child with disabilities, while helpful in alleviating the stresses in such families, will not have a major impact on the incidence of abuse.

Stein, R.E.K. & Jessop, D.J. (1984). Does pediatric home care make a difference for children with chronic illness? Findings from the pediatric ambulatory care treatment study. Pediatrics, 73, (6), 845-853.

A longitudinal study was undertaken in order to evaluate the effectiveness of an interdisciplinary team approach in minimizing social and psychological sequelae of pediatric chronic illnesses in children and their families. Families (n=219) were randomized into a treatment group, which received pediatric home care services, and a control group, which received standard care. Interviews were conducted at time of enrollment, at 6 months, 12 months later. Scores on five major variables (satisfaction with care, child's psychological adjustment, mother's psychiatric symptoms, impact on family, and functional status measure) are compared and discussed. Significant differences between groups were found at the 6 and 12 month interviews on 3 out of 5 and 2 out of 5 variables, respectively. The findings are discussed in light of other literature and questions for further research are proposed. Given the evidence that parent's satisfaction with care may influence compliance with treatment regimens, the results have important implications for home care.

Strauss, S.S. & Munton, M. (1985). Common concerns of parents with disabled children. Pediatric Nursing, 11, 371-375.

Interviews were conducted with middle class parents of the 16 children (4 weeks - 26 months of age) who had developmental delays and were enrolled in early intervention programs, in order to increase nurses' understanding of the parents' experiences. Open-ended questions about support systems and current and future concerns were posed. Three major areas of concern were found. Other parents of children with developmental delays, program staff, religion and ministers were the most frequently cited sources of support. Three general recommendations are discussed and have relevance for health care providers and others who work with these and their families.

Stroul, B. (1986). A system of care for severely emotionally disturbed children and youth. Washington, D.C.: CASEP Technical Assistance Center, Georgetown University Child Development Center.

This monograph provides information pertaining to a project designed to provide technical assistance to states and communities in the design and implementation of systems of care for children and adolescents with severe emotional disturbances. An early phase of the project involved the solicitation of information from states and communities which were utilizing systems of care for this population. This monograph describes a conceptual model for these systems of care. Topics include: definition of the population of children and adolescents with severe emotional disturbances, systems of care philosophy, specific programs components, strategies for developing these programs, and child assessments. Several factors found to be crucial in the provision of effective services include: a continuum of community based services which may reduce the need for out-of-home placement, service coordination/case management services, and a client and family-centered approach to treatment.

Suelzle, M. & Keenan, V. (1981). Changes in family support networks over the life cycle of mentally retarded persons. American Journal of Mental Deficiency, 86(3), 267-274.

To examine variations in the use of support networks, data from a mail survey were analyzed according to four stages in the life cycle: preschool, elementary, teenage, and young adult. In general, parents of younger children use more services and support networks and are more supportive of mainstreaming; parents of older children are less supported, more isolated, and have greater need for expanded services.

Sweeney, S.M. (Undated). Family caregiving: A synthesis evaluation, new areas for research and demonstrations and policy options. Washington, DC: Office of Human Development Services, Division of Program Analysis and Evaluation.

This report presents findings from a number of research and demonstration projects and scholarly papers on the characteristics and needs of the elderly and their caregivers. The report indicates that the number of older persons over the age of 65 is growing rapidly. An even greater rate of growth is occurring in the age cohort of 85+ years. One study shows that 80% of all care is provided by an informal caregiving system. The problems with this system are the financial, physical and emotional stresses caregivers experience. In addition, women who have served as primary caregivers are now increasingly employed outside of the home. Policy development in caregiving should

recognize that the family is the central and that direct service is more useful to caregivers than direct financial aid.

Tausig, M. (1985). Factors in family decision making about placement for developmentally disabled individuals. American Journal of Mental Deficiency, 89(4), 353-361.

Variables that affect placement requests by families for their members with disabilities were examined. Results reaffirmed the importance of the degree of disability, behavior problems, and external stressors for the decision-making process but also demonstrate that previous assumptions concerning their relative importance should be reexamined. Among younger individuals with disabilities (under 21 years of age) behavior problems were most important; for older individuals (over 21), the disruption of family relations and perceived burden of care were more important. Different decision-making processes appeared to operate for younger and older persons with disabilities. These results highlight the need for improved models for explaining requests by different types of individuals and families.

Tausig, M. (1983). Matching social support needs and sources: Application to community-based service planning (draft). Akron, OH: University of Akron, Department of Sociology.

This paper describes the benefits of using natural supports to compliment those offered by the public sector, and outlines a strategy for matching family needs with appropriate sources. Family needs are divided into three categories: 1) instrumental, 2) expressive, and 3) non-routine (i.e., either instrumental or expressive needs that are unique). Likewise, sources of support are divided into three categories: 1) formal service agencies, 2) support groups external to the family (e.g., church groups, neighbors), and 3) the family unit itself. The author bases his strategy on literature showing the contrasting strengths of different forms of social network ties. Though speculative, this approach raises useful insights regarding the process family members undertake to seek help and the roles various support sources could play to assist families who provide home care.

Taylor, S.A., Racino, J., Knoll, J. & Lutfiyya, Z. (1986). The nonrestrictive environment: A resource manual on community integration for people with the most severe disabilities. Syracuse, NY: Center on Human Policy, Syracuse University.

This manual is the result of an investigation into the "state of the art" in community integration for people with severe disabilities. Beginning with a review of the basic principles of community integration, it critiques the concept of a "continuum of services." The authors argue for home-based care for children and non-group settings for adults. They use program descriptions to illustrate how services can be provided to maintain persons with disabilities in a family-based setting. This is followed by a discussion of integrated vocational settings. Finally, the manual offers guidelines and frameworks for developing community integrated services for persons with severe disabilities.

Turnbull, A.P., Summers, J.A. & Brotherson, M.J. (1986). Family life cycle: Theoretical and empirical implications and future directions for families with mentally retarded members. In J.J. Gallagher & P. Vietz (Eds.), Families of handicapped persons: Research, programs and policy issues. Baltimore, MD: Paul Brookes Publishing.

Based in "family life cycle theory," these authors present a conceptual framework for viewing family dynamics. The "family systems" model presented has four fundamental dimensions: 1) input (family structure including composition, cultural, and ideological style); 2) process (interaction involving familial cohesion, adaptability, and communication, as well as extrafamilial events such as external support); 3) output (performance within nine areas of family function); and 4) change/stress that emerges during the family life cycle. This framework portrays an interdependent, dynamic, and cyclical system where each dimension is influenced by changes in other dimensions. Though other models depicting family dynamics exist, this model offers a very useful means for conceptualizing such dynamics, suggesting that each family is unique and that a wide array of supports may be required to enhance family care.

Turnbull, A.P., Turnbull, H.R., Bronicki, G.J., Summers, J.A., Roeder-Gordon, C., Brotherson, M.J., Houghton, J., Ruben, S., Benson, H.A. & Guess, D. (1985). The wise family plans: Legal, ethical, and school-transition aspects of future planning. Lawrence, KS: University of Kansas, Future Planning Project.

The purpose of the future planning project is to assist families of people with disabilities to design life-plans which address the needs of all family members. A family-centered approach, with an emphasis on choice and self-determination, is utilized. The goals and values of the project are presented initially, followed by a series of flow charts which illustrate decision-making processes in legal (e.g., guardianship), financial and residential

program areas. Comprehensive checklists designed to identify important issues for future planning and to explore positive contributions made by children with disabilities are involved.

Tuszynski, A. & Dowd, J. (1979). Home-based services to protective service families. In S. Maybanks & M. Bryce (Eds.), Home based services for children and families: Policy, practice and research. Springfield, IL: Charles C. Thomas.

This chapter describes the Family Life Center in New Jersey which serves thirty protective service families. The program offers a therapeutic day care center providing multiple services for the children. Adults receive parent training, home management classes, and group therapy. Emphasis is placed on group sessions to develop supportive social networks and to encourage regular contact with staff. The program tries to maintain and to strengthen the family unit, offering an alternative to removing the child from the home.

Upshur, C. (1983). Developing respite care: A support service for families with disabled members. Family Relations, 32, 13-20.

Respite care is identified as an essential, temporary relief service for families of persons with developmental disabilities living at home. It helps families cope with both emergency situations and provides relief from the daily stress of caring for a family member with disabilities. Based on state site visits and surveys four major approaches to providing respite care are identified. The advantages and disadvantages of these different approaches and recommendations for developing a wide variety of respite care services suitable for different family needs are presented.

U.S. Congress, Office of Technology Assessment. (1987). Technology-dependent children: Home care -- a technical memorandum. Washington, DC: U.S. Government Printing Office.

This technical memorandum examines the problems of health care financing for technology-dependent children. The volume seeks to answer four questions: who are the technology dependent children? how many children are there? what services do they require? and to what extent does private and public insurance cover these children? A principle finding of the study is that the size of the population varies with the clinical criteria used in the definition "technology dependent." To a great extent, the cost saving potential of home care depends on the home

environment and attributes of the family. The ability of families to provide ongoing nursing care is central to lowering costs to third party payers.

U.S. Senate Committee on Labor and Human Resources. (1985). Home health care for chronically ill children: Hearings. Washington: U.S. Government Printing Office.

This volume contains the written and verbal testimonies of participants speaking before the Committee on Labor and Human Resources of the United States Senate. The hearing sought to examine the needs for pediatric home care of children with long-term illnesses and disabilities. Individuals giving testimonies represent a cross-section of parents, professional and policy makers.

Van Dyck, P.C., White, F.I. & Kaminsky, C. (1984). Creating an information base for program collaboration. Washington, D.C.: Georgetown University Child Development Center.

This workbook describes a data base which can be used by all agencies serving handicapped individuals. Information stored in the data base would include: basic demographic data, services currently being received, service provider and the functional nature of the disability. By making this type of information available across the spectrum of providers, current services can be provided more efficiently. The workbook discusses practical steps for sharing data and the necessary steps for establishing a central registry.

Walker, D.K. (1984). Care of chronically ill children in schools. Pediatric Clinics of North America, 31, 221-233.

This article identifies the major issues that schools must address in order to provide appropriate services to children with chronic illnesses. Questions frequently asked by schools when planning educational programs and daily management procedures concern physical restrictions, medications, status of physical health, diet, and emergency precautions. School-health services that are most beneficial to the children are support therapies, modified physical education, transportation, building accessibility, and counseling services. The author discusses the relationship of the pediatrician to the school and his/her need to be consultant, referral agent and educator.

Walker, D.K. (1986). Report of a national conference: School-age children with health impairments. (unpublished proceedings). January 13-15, 1986, Texas Children's Hospital, Houston Texas.

The central focus of this conference was an examination of the role of the public schools in working with children who had health impairments. The presentors at the conference examined the key issues and areas that prevent children with a wide variety of chronic illnesses from fully participating in public education. Participants at the conference examined necessary supportive services, medical procedures and policies, life planning, transitional planning and career preparation for teachers.

Warren, L. & Gordon, S. (1986). Transition practices for handicapped youngsters in early childhood settings. Waltham, MA: The Association for Retarded Citizens, Inc.

This paper discusses a study designed to examine practices for transitioning young children with handicaps from early intervention programs to local education agencies in Massachusetts. Current state and federal mandates were analyzed, programs were studied and case studies of children and families were conducted to determine the adequacy and continuity of services provided. Discrepancies in eligibility criteria among agencies, inadequate inter-agency communication, and a paucity of uniform procedures among agencies are some of the variables which appeared to contribute to delays and disruptions in services to children and their families. Recommendations designed to improve transitional practices and directions for future research are presented.

Warren, R.D. & Dickman, I.R. (1981). For this respite, much thanks ... concepts, guidelines and issues in the development of community respite care services. New York: United Cerebral Palsy Association, Inc.

This volume presents the results of a joint university-service agency project designed to demonstrate model continua of respite care and parent training services in rural and urban settings. Model programs around the country are profiled. An in-depth discussion of the issues to be considered in planning a respite care program are detailed (including start-up needs, community development, family involvement and personnel issues). Data collection instruments for the model programs are exhibited in the final section.

Watkins, E.L. & Melnick, L.R. (1985). Infant mortality, morbidity, and childhood handicapping conditions: Psychosocial factors. Chapel Hill, NC: University of North Carolina, School of Public Health, Department of Maternal and Child Health.

This publication consists of 20 articles developed from a 1985 conference on psychosocial and socioeconomic factors related to infant mortality and low birthweight. The need for a comprehensive ecological approach to the prevention, assessment and treatment of at-risk infants and their families is stressed. Suggestions for improving the outcomes for these infants and their families are presented.

Weisfeld, V.D. (Ed.). (1986). The Robert Wood Johnson Foundation special report: The rural infant care program. Princeton, NJ: Robert Wood Johnson Foundation.

This report describes ten rural health services projects designed to provide prenatal services, connect high risk women to special prenatal clinics and to assist high risk mothers and infants following discharge from the hospital. The ten projects also strengthen the involvement of health professionals in developing perinatal care services. An evaluation of this project reports that there were significant declines in infant mortality rates in targeted areas.

Wikler, L. (1984). Assessing and alleviating stress in families with handicapped children. In M.A. Slater & P. Mitchell (Eds.), Family support services: A parent/professional partnership. Stillwater, OK: National Clearinghouse of Rehabilitation Training Methods.

This paper discusses the assumptions that are basic to assessing the stresses experienced by families having a child with handicaps and the factors that predispose a family to be at high risk for stress. Three interventions are presented to reduce stress in families: linkage work (information and referral), group work, and counseling.

Wikler, L. (1983). Chronic stress of families of mentally retarded children. In Olson, D.H. & Miller, B.C. (Eds.) Family studies review yearbook: Volume 1. Beverly Hills, CA: Sage Publications.

A majority view in the literature on families of children with mental retardation is that the initial diagnosis of the condition provokes a period of disequilibrium among family members followed eventually by an adjustment to life without undue stress. This conceptual paper contests that position, and argues that there are various stresses which emerge and re-emerge over time. The author suggests that discrepancies

between expectations and the performance of the child with developmental disabilities continue periodically to bring on natural emotional reactions and a need for information. Clinicians who understand this can better serve these families and can anticipate periods of difficulty, thus possibly ameliorating some of those stresses.

Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In J.J. Gallagher & P. Vietz (Eds.), Families of handicapped persons: Research, programs and policy issues. Baltimore, MD: Paul Brookes Publishing.

This chapter provides an overview of theory and research regarding the stress felt by families who offer home care to persons with disabilities. The information presented is organized around the ABCX model of family systems. This model posits that a stressor event, A, for example having a child with disabilities interacts with the family crisis-meeting resources, B, income and support services, which interacts with the family's definition of the problem, C, to define the nature of the family crisis (e.g., family dysfunction). This author concludes by discussing the types of research that is needed regarding family care and what must be done to enhance the efforts of these families.

Zimmerman, S. (1984). The mental retardation family subsidy program: Its effects on families with a mentally handicapped child. Family Relations, 33, 105-118.

This paper presents findings from a survey of families receiving a financial subsidy to enable them to care for their child with severe mental retardation at home. Results indicate that despite the subsidy, one-half the families (n=19) eventually plan to place their child out of the home. The author suggests that the subsidy program cannot be expected to overcome strong countervailing family influences. These factors should be taken into account in the design and implementation of policies and programs for families.

IV. APPENDICES

- A. Journals and Newsletters
- B. Directories
- C. Association
- D. Bibliographies

APPENDIX A: JOURNALS AND NEWSLETTERS*

American Academy of Pediatrics. Child Care Financing Report. (Publishers address: 141 Northwest Point Boulevard, Elk Village, Illinois 60009-0927).

This quarterly newsletter provides in-depth news and analysis of public and private child health financing issues. The periodical covers a range of topics including "Eligibility Expansion of Medicaid"; "Florida Mandates Coverage of Pediatric Preventive Care Coverage"; "Risk Pools for Chronically Ill Children"; "Types of Managed Care Programs"; "Risk Pools for Chronically Ill Children."

Association for the Care of Children's Health. Children's health care. (Publisher's address: ACCH, 315 Wisconsin Avenue, N.W., Washington, D.C. 20016).

This quarterly journal publishes research studies as well as essays, speeches, and other efforts which foster psychosocial care of children and families in health care settings. In addition, the Journal includes editorials, book reviews, and other pertinent information and announcements.

Association for Persons with Severe Handicaps. (1986-1987). TASH: Newsletter. (Publisher's address: TASH, 7100 Roosevelt Way, N.E., Seattle, WA 98115).

Over the past two years, this newsletter has published numerous articles pertaining to family home care. It provides descriptions of model family support initiatives, lists and reviews relevant literature, and summarizes legislation pertaining to home care.

Halamandaris, V. (1986). Caring, 5, (11). (Publishers address: 519 C Street, N.E., Washington, D.C. 20002).

This periodical is published monthly by the National Association for Home Care. The cited issue is devoted to pediatric home care.

* Many of the organizations listed in Appendix III (Associations) also publish newsletters and journals.

Hobbs, B. (1986). News Digest. Washington, DC: National Information Center for Handicapped Children and Youth. (Publisher's address: 1555 Wilson Boulevard, Rosslyn, VA 22209).

This issue is devoted to family support services. Relevant federal and state policy issues are outlined as well as various funding options.

National Center for Clinical Infant Programs. Zero to three. (Publisher's address: 733 15th Street, N.W., Suite 912, Washington, D.C. 20005).

This bulletin of the National Center for Clinical Infant Programs describes new approaches in the delivery of a wide variety of health related services for infants, toddlers, and their families. Contributors include care providers, researchers, and policy analysts. Each issue contains reviews of relevant publications, upcoming meetings and conferences and major project awards.

National Center for Education in Maternal and Child Health. MCH exchange. (Publisher's address: 38th and R Streets, N.W., Washington, D.C. 20057).

This newsletter reviews maternal and child health initiative in major program area of the Center. The publication division of the of the Center produces additional newsletters, bibliographies, directories, proceedings, booklets, brochures, resource guides and other informational and educational materials to increase the awareness of, and access to, maternal and child health information resources.

Project ABC. Networking news. (Publisher's address: P.O. Box 7330, Station A; San Antonio, Texas 78285).

This is the official newsletter of Project Any Baby Can. The paper provides information on the care of chronically ill and handicapped children. Information on specific diseases, as well as available community resources are discussed.

APPENDIX B: DIRECTORIES

Association for the Care of Children's Health. (1987). Directory of child life programs in North America. Washington, DC: Association for the Care of Children's Health.

This directory identifies nearly 350 hospitals providing pediatric and related recreational/educational/therapeutic care. All entries are organized alphabetically by state and province. The entries include information concerning the types of programs provided, 24-hour staffing levels, educational requirements for staff, and other information for parents to use in screening health care facilities. The publication is updated every three years to ensure that the information is current and accurate.

Michigan Association of Community Mental Health Boards. (1983). Family support services: A nationwide resource guide. Lansing, MI: Michigan Association of Community Mental Health Boards.

This guide presents information on family support programs around the country, including the population served, eligibility criteria, permissible services, administrative auspices and contact persons.

National Center for Education in Maternal and Child Health. (1985). Comprehensive clinical genetic services centers: A national directory-1985. Washington, DC: National Center for Education in Maternal and Child Health.

Entries in this directory include clinical genetic services centers which provide diagnostic services, medical management, counseling, and follow-up care. All programs are located in the United States. A separate appendix lists state genetic services coordinators, newborn screening directors, and state Maternal and Child Health and Crippled Childrens Services directors.

National Center for Education in Maternal and Child Health. (1985). Reaching out: A directory of voluntary organizations in maternal and child health. Washington, DC: National Center for Education in Maternal and Child Health.

This directory includes the addresses of national and international organizations and self-help groups concerned with a wide variety of health conditions. In addition to the listing of voluntary organizations, the directory also includes a selected list of professional associations and societies.

Pediatric Research and Training Center. (1986). Proceedings of the second annual conference: Home-based services: The challenge to handicapped infants and their families: Monograph Series No. 4. Farmington, CT: Department of Pediatrics, University of Connecticut Medical School.

In presentations conducted by parents, physicians and other professionals, issues facing those people involved in the provision of home care to children with disabilities are discussed. Throughout the various presentations a number of common themes are found, including: the need for a family-centered, community-based and individualized team approach, the impact of home care on the entire family, the necessity for the development of equitable health services for all, the need to balance advocacy for special interest groups with that which acknowledges the commonalities among needs, the need to examine the long term costs of providing or not providing adequate home care. Other currently debated issues, such as the role of case manager and parent's responsibility for the care of their children with disabilities, are also raised.

National Center for Education in Maternal and Child Health. (1986). State treatment centers for metabolic disorders. Washington, DC: National Center for Education in Maternal and Child Health.

This directory of state treatment facilities for metabolic disorders was compiled to make pediatricians aware of these centers so that they may utilize the multidisciplinary services available for the diagnosis, follow-up care, treatment and study of individuals with PKU. Listings for these 117 centers, as well as directors of state newborn screening programs, Maternal and Child Health and Crippled Children's Services are provided. Each listing includes a name, address, and telephone number. The maternal PKU collaborative study, which may be of interest to physicians who have women patients of child-bearing age with PKU, is described.

U.S. Department of Health and Human Services. (1980). State laws and regulations on genetic disorders. (DHHS Publication No. (HSA) 81-5243) Rockville, MD: U.S. Department of Health and Human Services, Health Services Administration, National Clearinghouse for Human Genetic Diseases.

This volume is a compendium of the Maternal and Child Health and Crippled Children's Services in each state. The current publication is divided into two sections: Laws and Regulations and Appendices. The laws and regulations are organized under the particular state or territory which has enacted them. For each jurisdiction, an introductory

summary is given followed by sections on New Screening Statutes, Administrative Regulations, and Other Relevant Laws or Regulations. The appendices consist of a survey of newborn screening programs, Maternal and Child Health and Crippled Children's Service directors, and state legislative offices. This volume presents a good, yet brief, overview of state activities.

U.S. Department of Health and Human Services. (1985). Comprehensive clinical genetic services directory. Washington, DC: U.S. Department of Health and Human Services.

This directory offers resource information to health professionals and administrators who provide services to people who are affected by or concerned with genetic disorders. It includes the name, address and contact persons of genetics service centers in the United States which offer diagnostic services, medical management, counseling and follow-up care. Appendices contain names and addresses of state genetics service coordinators, state newborn screening directors, state Maternal and Child Health and Crippled Children's Services directors.

Yoakum, K.S. (Ed.). (1986). National directory of organizations serving parents of seriously emotionally handicapped children and youth. Families as Allies Project, Research and Training Center to Improve Services to Emotionally Handicapped Children and Their Families. Portland, OR: Portland State University

This unique directory identifies parent organizations that provide either education and information, parent training, advocacy, support groups, and/or assistance such as respite care, transportation or child care services for parents who have children with severe emotional handicaps. Organized geographically by state, each program entry identifies the specific services provided to families, the geographical area served, and the location and telephone number of the main offices.

APPENDIX C: ASSOCIATIONS

The following organizations provide information and/or services for a wide range of children's health concerns:

American Association for Respiratory Care
1720 Regal Row
Dallas, TX 75235
(214) 630-3540

American Cancer Society (ACS)
90 Park Avenue
New York, NY 10016
(212) 599-8200

American Cleft Palate Association (ACPA)
331 Salk Hall
University of Pittsburgh
Pittsburgh, PA 15261
(412) 681-9620

American Heart Association
7320 Greenville Avenue
Dallas, TX 75231
(214) 750-5300

American Lung Association
2851 Bedford Avenue
Pittsburgh, PA 15219
(412) 621-0400

Arthritis Foundations
115 E. 18th
New York, NY 10003
(212) 477-8700

Association for Children with Learning
Disabilities
4156 Library Road
Pittsburgh, PA 15234
(412) 341-1515

The Association for Persons with Severe
Handicaps (TASH)
7010 Roosevelt Way, N.E.
Seattle, WA 98115
(206) 523-8446

Association for Retarded Citizens
2501 Avenue I
Arlington, TX 76011
(817) 640-0204 or (800) 433-5255

Association for the Care of Children's
Health

3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801 or (202) 244-8924

American Foundation for the Blind
15 West 16th Street
New York, NY 10011
(212) 620-2000

Asthma and Allergy Foundation of America
1302 18th Street, N.W. # 303
Washington, D.C. 20036
(202) 293-2950

Autism Services Center (ASC)
101 Richmond Street
Huntington, WV 25702
(304) 525-8014

Candlelighters Foundation
2025 Eye Street, N.W., 1011
Washington, D.C. 20006
(202) 659-5136

Children's Hospice International
501 Slater's Lane, # 207
Alexandria, VA 22314
(703) 556-0421

Children in Hospitals, Inc.
31 Wilshire Park
Needham, MA 02192
(617) 482-2915

Clearinghouse on the Handicapped
U.S. Department of Education (OSERS)
Switzer Building # 2304
330 C Street, S.W.
Washington, D.C. 20202
(202) 732-1241

Compassionate Friends
P.O. Box 1347
Oakbrook, IL 60521

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
(703) 620-3660

Cystic Fibrosis Foundation
6000 Executive Boulevard, Suite 510
Rockville, MD 20852
(301) 881-9130

Downs Syndrome Congress
1640 W. Roosevelt Road
Chicago, IL 60608
(312) 226-0416

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
(301) 459-3700

Families of Spinal Muscular Atrophy
P.O. Box 1465
Highland Park, IL 60035
(312) 432-5551

Family Resources Coalition
230 North Michigan Avenue, Suite 1625
Chicago, IL 60601
(312) 726-4750

Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, MA 02116
(617) 482-2915

Hemophilia AIDS Project
33 South Catalina, Suite 102
Pasadena, CA 91106
(818) 793-6192

Juvenile Diabetes Foundation International
60 Madison Avenue
New York, NY 10010
(212) 889-7575 or (800) 223-1138

La Leche League International
P.O. Box 1209
Franklin Park, IL 60131-8209
(312) 455-7730 (24-hour hotline)

Leukemia Society of America
733 3rd Avenue
New York, NY 10017
(212) 573-8484

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
(914) 428-7100

Mental Health Alliance
1021 Prince Street
Alexandria, VA 22314
(703) 684-7722

Muscular Dystrophy Association of America
810 7th Avenue
New York, NY 10019
(212) 586-0808

The National Alliance for the Mentally Ill
1901 North Ft. Myer, #500
Arlington, VA 22209
(703) 524-7600

National Associations for Sickle Cell
Diseases, Inc.
3560 Wilshire Boulevard, # 1012
Los Angeles, CA 90010
(800) 421-8453

National Center for Education in Maternal
and Child Health
38th and R Streets, N.W.
Washington, D.C. 20057
(202) 625-8400

National Hemophilia Foundation
19 W. 34th Street, Suite 1204
New York, NY 1001
(212) 563-0211

National Foundation of Denistry for the
Handicapped (NFDH)
1250 Fourteenth Street, Suite 610
Denver, CO 80202
(303) 573-0264

National Society for Autistic Children
1234 Massachusetts Avenue, N.W.
Suite 1017
Washington, D.C. 20005
(202) 738-0125

National Sickle Cell Clinics Foundation
211 North Whitfield Street, Suite 170
Pittsburgh, PA 15206
(412) 441-6116

Parents of Amputee Children Together (PACT)
Kessler Institute for Rehabilitation
1199 Pleasant Valley Way
West Orange, NJ 07052
(201) 731-3600 ext. 290

Research and Training Center to
Services For Seriously Emotional
Handicapped Children and their
Regional Research Institute for H
Services
Portland State University
1912 SW 6th Avenue, Room 120
Portland OR, 97201
(503) 464-4040

Research and Training Center for
Services for Seriously Emotional
Disturbed Children
University of South Florida
13301 Bruce Downs Boulevard
Tampa, FL 33612
(813) 974-4500

Sick Kids Need Involved People (SKNIP)
National Headquarters
216 Newport Drive
Severna Park, MD 21146
(301) 647-0164

Spina Bifida Association of America
343 S. Dearborn Street, # 319
Chicago, IL 60604
(312) 663-1562

United Cerebral Palsy
10 Waterside Drive
New York, NY 10010
(212) 689-0236

APPENDIX D: BIBLIOGRAPHIES

Association for the Care of Children's Health. (1987). Books for children and teenagers about hospitalization, illness, and disabling conditions. Washington, DC: Association for the Care of Children's Health.

This directory is a cross-referenced, annotated bibliography of books dealing with illness, disability, and/or hospitalization. Each of the publications is appropriate for either preschool-aged, school-aged or adolescent-aged children. All titles are listed alphabetically by the name(s) of the author(s) and by subject. In selecting publications for inclusion in the annotated bibliography, the authors emphasized material involving sensory, orthopedic, or health impairments rather than more general health and safety issues. The brief annotations provide sufficient information for the reader to understand the main focus of the book and to gauge whether or not it would be appropriate for a particular topic.

Association for the Care of Children's Health. (1987). Child health care facilities. Washington, DC: Association for the Care of Children's Health.

This volume is one component of an Association for the Care of Children's Health project designed to enhance the quality of child health care facilities to increase their responsiveness to and support of the developmental and psychological needs of children and their families. The first half of the book is devoted almost entirely to the presentation and detailed discussion of design guidelines for all facility areas frequented by patients and their families. A brief discussion of psychological considerations is also included. The second half of the book provides an extensive literature review and annotated bibliography. Photographs and discussions of specific environmental design guidelines are found throughout.

Friedman, R.M. & Street, S. (1985). Family focused interventions: An annotated bibliography. Tampa, FL: Research and Training Center for Improved Services for Seriously Emotionally Disturbed Children; University of South Florida.

This bibliography summarizes 22 articles which describe family focused programs that attempt to maintain children with emotional disturbances in their homes. Among these articles are general resource documents as well as descriptions of specific programs.

Greenstein, R.M. & Gardiner, M.S. (undated). Reimbursement for medical genetic services: A selected bibliography. Washington, DC: National Center for Education in Maternal and Child Health.

This bibliography is one of the products of a three year grant, "Accessibility of Reimbursement for Genetic Services". It contains references in the following areas: Accessibility, Chronic Care, Consumer Issues, Cost Containment, Ethics, General Definitions, Genetic Funding, Health Insurance, Health Maintenance Organizations, International Issues, Medicare/Medicaid, New Technologies, and Quality Control.

Healy, A., Keese, P.D., & Smith, B.S. (1985). Early services for children with special needs: Transactions for family support. Iowa City IA: University Hospital School, Division of Developmental Disabilities.

This volume addresses current issues in early intervention programs for very young children who have or are at risk of disability. Three questions are addressed: 1) what is known about at-risk and disabled children and their families? 2) what are the barriers to translating this knowledge into program practice? and 3) what concrete steps can be taken to improve this transition? This book includes chapters concerning: parent-professional interactions; early intervention programs, and child development. The book also includes an extensive annotated bibliography covering child development, social support, family issues, and early intervention programs. The authors suggest that: 1) family support must become a core service and a primary goal of early intervention services; 2) the terminology used in early intervention must be clear and understandable to facilitate communication and evaluation of services, and 3) the development of interdisciplinary, coordinated services will require important changes in traditional professional agencies' concepts of territorial roles each plays.

Human Services Research Institute. (1987). Developing new family care options for Pennsylvanians: A resource guide to relevant literature and existing model programs. Cambridge: Human Services Research Institute.

This annotated bibliography includes publications and reports on families with children who have been adjudicated by the courts. The bibliography also contains an overview of four state family support program and information on cash assistance programs.

National Center for Education in Maternal and Child Health. (1985). Social aspects of genetic disorders: A selected bibliography. Washington, D.C.: National Center for Education in Maternal and Child Health.

This bibliography contains references from the professional literature and audio-visual on the social and psychological aspects of genetic disorders. Topics include: adoption, chromosomal anomalies, clergy involvement, coping, decision making, disabilities and chronic illnesses, education, ethical and legal issues, family dynamics, genetic counseling, genetic screening, and many more topics. This bibliography is intended to assist health professionals to provide genetic services more effectively.

National Center for Education in Maternal and Child Health. Sickle cell: A selective bibliography. Washington, D.C.: National Center for Education in Maternal and Child Health.

This bibliography lists educational and informational material on both sickle cell disease and trait. Sources of printed and audio-visual materials are included as well as names and addresses of comprehensive sickle cell centers, screening and education centers, and state genetic service coordinators.