THINKING ABOUT HOME AND FAMILY SUPPORT

A Guide to the Literature

With Selected Readings

prepared for

The Governor's Council for the Handicapped and Gifted Fairbanks, Alaska

by

John O'Brien

Responsive Systems Associates 1447 Peachtree Street, NE, Suite 811 Atlanta, Georgia, 30309

CONTENTS

A GUIDE TO THE LITERATURE

How can we describe the ways different environmental contexts affect people's development?

How can public policy support home and family life?

How do neighborhoods and churches relate to home and family support?

How are social networks related to home and family support?

How can professionals relate constructively to natural helpers?

What should the relationship be between professionals and people with handicaps and their families?

How can we learn about home and family supports from the experience of people with handicaps and their families?

Which informal home and family support initiatives can we learn from?

Which model service systems can we learn from?

Local Systems

Guides for family members

Gui dance

Respite

Early Intervention

Which state-level home and family support service policies can we learn from?

READINGS

Eric Trist. The Search Conference Concept.

David Sibbet. Graphic Formats

David Morley and Rafael Ramirez. Food for the Future of Mexico: An Action Learning Perspective.

CDF. Child Watch: Looking Out for America's Children

John McKnight. Survival of the Family

John McKnight. Politicizing Health Care

Eric Trist. New Directions of Hope

Gerben DeJong. Independent Living

Gunnar Dybwad. Re-Discoveery of the Family

Nicola Shaefer. Parent Partnership with Professionals

Robert Lifchez & Barbara Winslow. How to Research

Andy Baxter. The Newfoundland Strategy.

The Parent Study Group. An Example of Involvement.

Marsha Forest & Judy Snow. The Joshua Committee.

INTRODUCTION

This is a companion to Planning Together, which is a handbook for people who want to plan improvements in home and family support.

The Guide to the Literature is organized by a set of questions. Like the planning process described in Planning Together, the guide begins by calling attention to the larger environmental context that shapes efforts to improve home and family support. Each question is followed by a brief description of some helpful resources and a set of references.

Following the literature guide are copies of some of the resources referenced here and several from Planning Together Readings are identified in the guide with an "*".

Home and family support is a very broad area. This guide makes no pretense of comprehensiveness. Comments and suggestions for inclusion are welcome.

How Can We Describe the Ways Different Environmental Contexts Affect People's Development?

Inventors of effective family supports need vocabulary to describe the complicated set relationships between the multiple contexts in which people and their families grow and develop. Urie Bronfenbrenner has recast developmental psychology by considering the mutual influences of growing people and the immediate environments in which they live as they are affected by larger social contexts. Using the image of a set of Russian dolls, one nested inside the next, he describes four levels of environments and reviews what's known about their effects on each other and on human development. Bronfenbrenner's ideas stimulate thinking about how and where supports can be effective. His language is difficult -partly in response to the complexity of what he is trying to describe; partly in response to the press of academic environments. He is presently directing a longitudinal, cross-cultural study to explore the application of his theory.

Urie Bronfenbrenner. Toward an Experimental Ecology of Human Development. American Psychologist. 32: 513-532. (1977)

Urie Bronfenbrenner. The Ecology of Human Development: Experiments by Nature and Design. Cambridge: Harvard University Press. 1979.

How Can Public Policy Support Home and Family Life?

People of every political persuasion have strong views on the proper relationship between the practices of government and family life. Simple declarations of belief ("government should stay out of family life" or "government should be responsible for insuring the quality of family life") ignore the complex interdependencies that make up present day family life.

Using the 1980 White House Conference on Families as a point of departure, John Dempsey sketches the field of family public policy at the US federal level. He describes the relationships of issues and interests that form an important context for services that affect the way families with handicapped members are supported. Mary Blehar reviews the initiatives sponsored by the National Institute of Mental Health to assess the "family impact" of many different federal programs.

Thinking About Home & Family Support/ 2

Kenneth Kenniston summarizes the work of the Carnegie Commission on Children. His discussion of "Services Families Need" demonstrates the strong potential linkages between families with handicapped members and many other community interests. These conclusions complement the more technical work of the National Research Council.

The Children's Defense Fund (CDF) produces a series of powerful studies documenting the real life effects of large scale programs. Their reports are strong advocacy statments which link everyday family experience with big numbers from state and federal plans and budgets. The content of their reports is well worth attention, but advocates may learn even more from their methods of work and presentation formats. Many of their techniques for monitoring the effects of federal and state programs on local people are described in Child Watch, * the handbook for a joint project between CDF and the Association of Junior Leagues. A local Child Watch Project could be an important way to widen the network of people concerned about home and family support.

Mary Blehar. Families and Public Policy. In Eunice Corfman, ed. Families Today. Volume II. NIMH Science Monographs 1. US Government Printing Office, 1980.

Children's Defense Fund. Child Watch: Looking Out for America's Children. Washington: CDF, 1982.

CDF. EPSDT: Does it Spell Health Care for Poor Children? Washington: CDF. 1980.

CDF. Children Without Homes. Washington: CDF, 1981

John Dempsey. The Family and Public Policy: The Issue of the 1980's. Baltimore: Paul H. Brookes, 1981.

Kenneth Kenniston. All Our Children. New York: Harcourt, Brace, Jovanovich, 1977.

National Research Council. Toward a National Policy for Children and Families. Washington: The National Academy of Sciences. 1976.

How Do Neighborhoods and Churches Relate to Home and Family Support?

Neighborhoods, church congregations, and other people sized groups have a powerful effect on everyone's quality of life. Peter Berger and John Neuhaus define "mediating structures" as the institutions that stand between an individual in private life and the large institution of public life. They advocate a policy focus on empowering the family, neighborhoods, and voluntary associations as the source of meaning and value in people's lives. Lowell Levin and Ellen Idler apply these ideas to health care, noting that lay people should properly be seen as the major providers of health care, not its consumers. Since families still provide the majority of care for people with handicaps, there are important applications of Levin and Idler's ideas to home and family support.

John McKnight speaks eloquently of the realtionship between the neighborhood, the family, and care. "Politicizing Health Care" # describes the multiple values created by a neighborhood based approach to a set of social problems separated by professional logic. "Survival of the Family" * identifies the erosive effects of common bureaucratic practice.

Harry Boyte provides examples of citizen action to empower local, neighborhood, and workplace groups. Concern about meaningful support for home and family life cuts across the political spectrum in important ways. Groups on the right, like the American Enterprise Institute which sponsored Berger and Neuhaus, and groups on the left, like Boyte's Citizen Heritage Center, differ on large scale causes and cures but display striking similarities in their proposals for family support. This bredth of concern could form the basis for a broad, and somehwhat unlikely action network.

Ellen Nelson examines the church congregation as a source of support to people with handicaps and their families. She describes three ways churches assist: as providers of fellowship and socially integrative expereinces, as direct service providers, and as mediating structures focused on advocacy. Robert and Martha Perske have written a beautiful orientation to the needs of people with developmental special needs which has proven especially useful to congregations and voluntary associations.

In "New Directions of Hope", * Eric Trist describes the kinds of structures communities need to develop and renew their competence to support people.

Peter Berger and R.J. Neuhaus. To Empower People: The Role of Mediating Structures in Public Policy. Washington: The American Enterprise Institute, 1977.

Harry Boyte. The Backyard Revolution: Understanding the New Citizen Movement. Philadelphia: Temple University Press, 1980.

Lowell Levin and Ellen Idler. The Hidden Health Care System: Mediating Structures and Medicine. Cambridge: Ballinger, 1981.

John Mc Knight. Politicizing Health Care. Social Policy, Summer 1978.

John Mc Knight. Survival of the Family. Institutions Etc. December, 1982.

Ellen Nelson. The Local Church as a Resource for People with Mental Retardation Living in the Community. Ph.D. Dissertation. The Heller School, Brandeis University, 1983.

Robert and Martha Perske. New Life in the Neighborhood: How Persons with Retardation or Other Disabilities Can Help Make a Good Community Better. Nashville: Abingdon, 1980.

Eric Trist. New Directions of Hope. Regional Studies. 13: 439-451. (1979)

How are Social Networks Related to Home and Family Support?

The notion of social networks has organized much discussion, some research and a little bit of human service practice. The organizing image is of each person linked in multiple ways to others in a net of relationships that influence the quality of our lives and our ability to achieve our purposes.

Seymour Sarason explores social networks as a response to the resource crisis. Drawing on personal experience and on case studies of network efforts as well as a review of social science literature, he uses the concept of social network, with its informal exchanges, to reframe the chronically troublesome issues of shortage of professional resources, fragmentation and coordination of services, and agency reform. He links his ideas about social networks to the theme of psychological sense of community:

ſ

ſ

ſ

Thinking About Home & Family Support/ 5

"[Not] until people accepted the fact of limited resources —not until they saw that to achieve their goals would require them to exchange resources in barter style with others who had some of the resources they needed—that they stood a chance of experiencing a more satisfying sense of community. It was not only that people needed each other in a psychological sense, but they also needed each other to achieve their goals at work.

Sarason describes the roles and tasks and the stages of development of devised social networks: people trying on purpose to make a network.

Benjamin Gottlieb has edited a collection of papers summarizing several current lines of social science inquiry on the nature of naturally occuring networks and the ways network relationships affect physical and mental health.

Much of the work on application of social network ideas in mental health practice flows from the work of Gerald Caplan. Robert Curtis describes some of the practical implications of social network theory for service design.

Phillip Seed explored the question "Who helps people with mental handicaps in rural, remote areas of northern Scotland?" Through field study, Seed describes the kinds and amounts of support people offer their handicapped neighbors. He then identifies policy issues from the point of view of preserving and extending available natural supports. The methodology in this small book could be useful in many settings.

Gerald Caplan. Support Systems in Community Mental Health: Lectures on Conceptual Development. New York: Behavioral Publications, 1974.

Robert Curtis. The Future Use of Social Networks in Mental Health. Boston: Social Matrix Research. 1979.

Benjamin Gottleib, editor. Social Networks and Social Support. Studies in Community Mental Health, Number 4. Beverly Hills: Sage, 1981.

Seymour Sarason, et al. Human Services and Resource Networks. San Francisco: Jossey Bass, 1977.

Thinking About Home & Family Support/ 6

Seymour Sarason and Elizabeth Lorentz. The Challenge of the Resource Exchange Network. San Francisco: Jossey Bass, 1979.

Philip Seed. Mental Handicap: Who Helps in Rural and Remote Communities? Kent: Costello Educational, 1980.

How Can Professionals Relate Constructively to Natural Helpers?

For agencies and their workers, home and family support is always a shared enterprise. Narrowly, it is shared by the the person and family supported. But it also offers important opportunities to assist other people who surround a household to improve their competence and confidence in offering assistance.

Alice Pancoast and Diane Collins provide a detailed description of their assumptions and practices for assisting natural helpers. They describe ways to locate people who are central to natural helping networks and provide sound advice on the sorts of professional attitudes and activities that will help and those that will hurt. Building on this work, Charles Froland, Diane Pancoast and their associates studied thirty agencies with innovative approaches to supporting informal helping networks. This careful study offers important distinctions among types of natural help, strategies for supporting different types of helping networks, and different ways for profesionals to approach helping networks.

Eva Salber has studied natural patterns of health care, most recently among people in rural and urban areas of North Carolina. Based on her investigations she has developed a process for identifying and assisting the people others turn to for lay health advice.

The World Health Organization has committed itself to developing a strategy for developing countries based on informing and training community leaders, natural helpers and family members. Einar Helander and his associates are field testing a set of guides for policy makers, community leaders, agency workers, and family members that make home and family support the major focus of national effort on behalf of people with handicaps.

Alice Collins and Diane Pancoast. Natural Helping Networks. Washington: NASW, 1976.

Charles Froland, et at. Helping Networks and Human Services. Beverly Hills: Sage, 1981.

Thinking About Home & Family Support/ 7

Elnar Helander, et al. Training the Disabled in the Community. An Experimental Manual on Rehabilitation and Disability Prevention for Developing Countries. Geneva: World Health Organization. 1980.

Eva Salber. Where does Primary Care Begin? The Health Facilitator as a Central Figure in Primary Care. Israeli Journal of Medical Sciences. 17: 2, 100-111. (1981) See also Tom Ferguson. Taking Care of Each Other. Medical Self-Care #19: 16-21. (1982)

What Should the Relationship Be Between Professionals and People with Handicaps and Their Families?

The most common answer to this question has cast the person who relies on services into a subordinate role as client or patient. Clients receive. They many be given opportunities to express preferences and opinions. but these expressions are evaluated by service providers. Who are presumed to know best. This traditional answer is powerfully questioned by the independent living movement among people with physical disabilities. This movement has developed around the themes of consumer choice and control of supports and other resources. Those who provide care and assistance are in fact and in name employees of the person assisted. People should be supported to live in their own homes and to choose whatever relationship to the world of work fits their interests. The notion of choice replaces assessment as the definer of service. Funds flow to people with handicaps who them becomne empowered consumers of needed services.

Gerben DeJong describes this movement as redefining the basic ideas of service and support and calling for a new orientation of service policy and practice. In "Independent Living: From Social Movmemnt to Analytic Paradigm," * he traces the correlations of this shift to broad social and cultural trends.

Jean Cole describes the differences between independent living as a service type within the old view of rehabilitaion and independent living as an alternative way to understand and respond to people who rely on services.

Michael Winter and his collaborators at the Berkley Center for Independent Living describe the development of a set of supports for people and families in their own homes which fits the themes of the independent living movement. This pioneering organization continues to struggle, change, and grow. Its current problems in

Thinking About Home & Family Support/ 8

organizational design and mutual regulation with service bureaucracies are an important source of new learning.

Nancy Crewe and her associates take stock of the effects and implications of the independent living movements on service systems.

The independent living movement sets a new context for understanding the relationship of services to families whose young children are handicapped and services to people whose handicaps makes it very difficult for them to make judgments for themselves.

Most such service programs have an implicit idea of the proper role for people who receive services and their families. Wolf Wolfensberger describes a number of the basic assumptions services make about home and family life and offers a normalization-based approach to family guidance, education, and support.

In "The Re-Discovery of the Family," # Gunnar Dybwad points out the centrality of voluntary action by the parents of people with handicaps in the development of present attitudes, policies and services. He analyzes the effects of professionalizing services on families and outlines principles for a renewed emphasis on home and family life as the focus of service.

Nicola Shaefer, * herself the parent of daughter with severe handicaps, makes a strong case for full partnership between parents and professionals. She notes that partnership, as opposed to clienthood, constitutes a critical support to family life in itself. She describes her experiences in sharing with other parents to develop parental strength for the conflicts and responsibilities of full partnership.

As Peter and Helle Mittler note, parental involvement is one of the "good ideas" embodied in many programs. They discuss the stages in the evolution of partnership between services and parents and offer useful self-evaluation questions for professionals.

Ann and Rutherford Turnbull, who are both professionals and parents of a son with developmental special needs, offer an important critique of professionally initiated parent involvement mechanisms. They demonstrate that bureaucratic services can easily translate the opportunity for parent involvement into a requirement that can itself cause strain for some families. The "uncooperative family" can be the creation of one sided involvement strategies. As a remedy they suggest that programs recognize and support different levels of involvement from full and equal decision making to no participation. These suggestions, combined with the

Thinking About Home & Family Support/ 9

parent-to-parent initiatives described by Nicola Shaefer and the positive service practices described by the Mittlers provide a good climate for partnership.

Jean Cole. What's New About Independent Living? Archives of Physical Medicine and Rehabilitation. 60: 458-462. (1979)

Nancy Crewe, et al. Independent Living For Physically Disabled People. San Francisco: Jossey Bass, 1983.

Gerben DeJong. Independent Living: From Social Movement to Analytic Paradigm. Archives of Physical Medicine and Rehabilitation. 60: 435-446. (1979)

Gunnar Dybwad, The Re-Discovery of the Family. Mental Retardation. 32: 1. 18-30. (1982)

Peter and Helle Mittler. Partnership With Parents. Stratford-upon-Avon: National Council for Special Education, 1982.

Nicola Shaefer. A Better Life for People Who Have Severe Multiple Handicaps: Parent Partnership with Professionals. Mental Retardation. 31:5, 3-9. (1981)

Ann and Rutherford Turnbull. Parent Involvement in the Education of Handicapped Children: A Critique. Mental Retardation (AAMD). 20:3 115-122. (1982)

Michael Winter, et al. Independent Living: The Right to Choose. In Myron Eisenberg, et al. eds. Disabled People as Second Class Citizens. Series on Rehabilitation, Volume II. New York: Springer, 1982.

Wolf Wolfensberger. Essays on Normalization-Based Guidance, Education, and Supports for Fmailies of Handicapped People. Toronto: NIMR, 1983.

Thinking About Home & Family Support/ 10

How Can We Learn About Home and Family Support From the Experience of People With Handicaps And Their Families?

The most important source of information for planning improvements in home and family support is the experience of the people supported.

Raymond Lifchez and Barbara Winslow are architects who studied the daily lives of more than 200 people with severe physical disabilities who live independently in Berkeley, California. They profile seven people in depth to develop an appreciation of the variety designers must account for in their plans, describe the formal and informal networks that provide support, and provide an interesting photographic catalogue of the ways people have invented to adapt their physical and social environments to their disabilities. They discuss the linkage between people's experience and the planning process in a chapter on "How to Research." Their work is an exemplar for service planners.

People with handicaps and their families differ in many important ways. Typical planning and service practices tend to standardize people in ways that may render services ineffective. Anselm Strauss uses the notion of "career" to organize his discussion of the life experience of people disabled by chronic diseases. He illustrates the problems service provides create when they ignore the way people and their families experience life at home.

Rosalyn Darling also used the organizing idea of "career" to study the ways 25 families responded to the birth of an infant with a severe handicap. Thinking about a personal and family career with a handicap helps focus attention of the way peoples situations change with time.

Ann Shearer draws on interviews with many different people with handicaps to describe the experiences of living with a handicap and the kinds of assistance people need.

The stories of particular people and their families are a rich source for understanding the variety of ways people experience life with a handicap and the wide range of formal and informal supports that people develop for themselves. It doesn't make sense to generalize —people who write books about their experience are likely to be as unique in their perceptions of their needs as the rest of us. But reading these stories can sensitize the planner and serve as a preparation for the critical task: visiting families and meeting people in one's own community and listening to their stories for lessons.

Thinking About Home & Family Support/ 11

Robert Bogdan and Stephen Taylor assisted two people who lived much of their lives in a state school for the retarded to record their autobiographies. Both people have lived in community settings with varying degrees of structure and support. Their ideas abou what creates problems and what helps people with mental retardation negotiate community life is worth serious study.

Nicola Shaefer tells the story of family life with Catherine, who has been severely multiply handicapped since birth. Her family's story demonstrates tremendous inventiveness in family learning and adaption.

Lotte Moise describes growing up with her daughter and provides insight into the history of family involvement in developing services. She speaks clearly of the dilemmas in Barbara's developing independence and of the family's experience around Barbara moving into a group residence.

Maureen Lynch writes as the sister of a person who is handicapped. Family circumstances and service system problems led to her living for a year with her sister Mary Fran.

Ann and Rutherford Turnbull invited parents who also have service professional roles to describe their experiences and perspectives.

> Robert Bogdan and Steven Taylor. Inside Out: Two First Person Accounts of What it Means to be Labelled "Mentally Retarded." Buffalo: University of Toronto Press.

> Rosalyn Darling. Families Against Society: A Study of Reactions to Children with Birth Defects. Beverly Hills: Sage, 1979.

> Raymond Lifchez and Barbara Winslow. Design for Independent Living: The Environment and Physically Disabled People. Berkely! University of California Press, 1979.

Maureen Lynch. Mary Fran and Mo. New York: St. Martin's Press, 1979.

Lotte Moise. As Up We Grew with Barbara. Minneapolis: Dillon Press, 1980.

Nicola Shaefer. Does She Know She's There? (Second Edition). Toronto: Harper and Row, 1983.

Thinking About Home & Family Support/ 12

Ann Shearer. Disability: Whose Handicap? Oxford: Blackwell. 1981.

Anselm Strauss. Chronic Illness and the Quality of Life. St. Louis: Mosby. 1975.

Ann and Rutherford Turnbull. Parents Speak Out: Views from the Other Side of the Two-Way Mirror. Columbus: Merrill, 1978.

Which Informal Home and Family Support Initiatives Can We Learn From?

Some of the most far reaching developments in home and family support are occuring at the edges of the formal service system.

In several places, the distinctions between mutual support, service and political action to reform the service system are blurred. People with handicaps and family members find working together for change a major support in itself. Douglas Biklen describes the effects of this type of organizing. Andy Baxter provides a case study of its effects in the remote areas of Newfoundland and Labrador.

Sally Puff describes an effective approach for parents of severely handicapped, institutionalized children to organize other parents around the value base provided by the principle of normalization.

Toronto's Parent Study Group* is an extended, action learning network which exemplifies the power of support through mutual, person focused action.

Marsha Forest and Judy Snow describe "The Joshua Committee" a group of people committed to meeting the needs of one person with a severe physical disability.

Andy Baxter. Helping Communities to Help Themselves: The Newfoundland Strategy. Mental Retardation. 32:2. 13-19.

Douglas Biklen. Community Organizing: Theory and Practice. Englewood Cliffs: Prentice Hall, 1983.

Marsha Forest and Judy Snow. The Joshua Committee. (reproduced here)

The Parent Study Group: An Example of Involvement. (reproduced here)

Thinking About Home & Family Support/ 13

Sally Puff. They Care Enough: Parent Participation Training Project. Seattle: The Troubleshooters, 1982.

Which Model Service Systems Can We Learn From?

Local Systems

Nearly every discussion of comprehensive services makes the point that home and family support services are important. But relatively little has been written about systems of organized support services outside the independent living movement described above. This unfortunately makes it hard to understand the interaction among different formal and informal supports. Ann Shearer provides a good description of the way a range of home and family supports for young children have developed near Liverpool in England.

Most of what has been written falls into four categories: guides for family members, guidance, early intervention, and respite.

Ann Shearer. A Community Service for Mentally Handicapped Children: Bernardo's Chorley Project. Liverpool! Bernardo Social Work Papers #4. 1978.

Guides for Family Members

There are a number of excellent guides and resource books for people with disabilities and their families. Here is a sampler. Robert and Martha Perske provide strong and gentle guidance to parents of children with disabilities. Nancie Finnie has written an exemplary guide to assisting young children with physical disabilities at Home. Nancy Mace and Peter Rabins, provide information and practical guidance for familes with older members who have Alzheimer's Disease. Gloria Hale has edited an encyclopedia of aides and adaptions for people with physical disabilities.

Nancie Finnie. Handling the Young Cerebral Palsied Child at Home (Second edition). New York: Dutton, 1975.

Gloria Hale. The Source Book for the Disabled. New York: Bantam Books, 1981.
Nancy Mace and Peter Rabins. The 36 Hour Day: A

Thinking About Home & Family Support/ 14

Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life. Baltimore, Johns Hopkins, 1981.

Robert and Martha Perske. Hope for the Families: New Directions for Parents of Persons with Retardation or other Disabilities. Nashville: Abingdon, 1981.

Gui dance

Wolf Wolfensberger provides a frameowrk for relating to families with handicapped members and provides direct advice to parents. The theory underlying this approach to family guidance is further described by Frank Menolascino.

More experienced parents can provide unmatched support and guidance to familes in the early stages of adjustment to having a handicapped member. Fran Porter describes the design and implementation of a pilot parents program. So does the Canadian Association for the Mentally Retarded (CAMR).

CAMR. Pilot Parents: An Organizer's Handbook. Toronto: NIMR, 1976.

Frank Menolascino. Understanding Parents: A Crisis Model for Helping Them Cope More Effectively. In Frank Menolascino and Paul Pearson, eds. Beyond the Limits! Innovations in Services for the Severely and Profoundly Retarded. Seattle: Straub, 1974.

Fran Porter. Pilot Parents: A Design for Developing A Program for Parents of Handicapped Children. Omaha: Greater Omaha Association for Retarded Citizens, 1977.

Wolf Wolfensberger. Essays on Normalization-Based Guidance, Education, and Supports for Fmailies of Handicapped People. Toronto: NIMR, 1983. Respite

. [

Much has been written about respite programs. Indeed it may be that "respite" has become a sort of substitute concept for home and family support. If so, it would be unfortunate since many respite schemes are facility based and justify themselves in terms of "relieving" parents, perhaps of an almost unbearable burden. This unduly limits options.

The California Institute for Human Services assisted the California State Council on Developmental Disabilities with a planning process that included a survey of providers and consumers, a conference reflecting the state of the art, and a comprehensive plan for change.

United Cerebral Palsy supported the development and study of several model respite programs.

Washington's Developmental Disabilities Planning Council sponsored the development of an adult education course to prepare in home respite workers for people with substantial handicaps. Eugene Edgar, et al. describe the curriculum and instructional process.

Maureen Oswin has made an in-depth observational study of facility based respite care in England. She identifies a number of disturbing unintended consequences of this approach to family relief. Children, families, and direct care staff all experience significant problems. Parents much prefer in-home respite or the option of hiring a neighbor or family member to provide temporary care in her home.

California Institute on Human Services. The Future of Respite Services in California. Sacramento: California DD Council, 1981.

California Institute on Human Services. Respite Services for Californians with Developmental Special Needs: Recommendations for Change. Sacramento, 1982.

Eugene Edgar, et al. In Home Respite Care: Student Manual. Seattle: University of Washington, 1978.

Maureen Oswin. The Short-Term Residential Care of Mentally Handicapped Children. In Brian Cooper, ed. Assessing the Handicaps and Needs of Mentally Retarded Children. London: Academic Press, 1981.

United Cerebral Palsy Association. For This Respite, Much Thanks... Concepts, Guidelines and Issues in the Development of Community Respite Care Services. New York: UCP, 1981

Early Intervention

The first in-home service for many families with young handicapped children is usually some form of eraly intervention program. Early intervention is aimed at improving the competency of a young child. In-home early intervention most often aims to improve parental ability to teach or exercise their children, though sometimes in-home early intervention workers simply provide direct service to a child.

Robert Wiegerink and Joan Bartel describe a policy framework for early intervention. INTER-ACT provides a complementary guide for planning large scale service initiatives. Both of these documents mention in-home services as one component of a comprehensive approach to early intervention.

There are many, many in-home early intervention programs. Susan Weber and her associates describe the application of the Portage Guide to Home Teaching in rural areas. Carl Dunst and Regina Rheingrover identify and review 49 studies of the effectiveness of early intervention. By analyzing the evaluation designs, they raise provocative questions about the confidence one should place in findings of program effectiveness.

Carl Dunst and Regina Rheingrover. An Analysis of the Efficacy of Infant Intervention Programs with Organically Handicapped Children. Evaluation and Program Planning. 41287-323. (1981)

INTER-ACT. Early Intervention for Children with Special Needs and Their Families. Monmouth: WESTAR, 1981.

Susan Weber, et al. The Portage Guide to Home Teaching. Portage: Cooperative Educational Service Agency, 1975.

Ronald Wiegerink and Joan Bartel. Early Childhood Services in the 80's. DD Themes and Issues #15-26. Chapel Hill: Frank Porter Graham Child Development Center, 1981.

Thinking About Home & Family Support/ 17

Which State-Level Home and Family Support Service Policies Can We Learn From?

Several states have been exploring policy options in home and family support. Elizabeth Kraniak provides a reasonably current review of these initiatives.

Wade Hitzing describes a policy framework for family support services to meet the needs of people with severe behavior problems. He also discusses Ohio's H.B. 836, a bill under consideration to provide a framework for family supports.

Robert Bruniniks and Gordon Kranz describe issues in family support policy, including the issue of cash subsidy to families.

As part of its effort to control utilization of nursing homes, Wisconsin's Department of Health and Social Services has implemented th Community Options Project inselected counties. This project provides for preadmission planning to determine whether a person said to need nursing home care could be supported to remain at home or in a community residential setting. Funds are available to design personalized supports, and there is a strong emphasis on the involvement of families and natural helping networks.

Robert Bruniniks and Gordon Kranz. Family Care of Developmentally Disabled Members. Minneapolis: University of Minnesota, 1979.

Wade Hitzing. Family Support Services: Meeting the Needs of Persons with Severe Behavior Problems. Columbus: Ohio Society for Autistic Citizens, 1982.

Elizabeth Kraniak. Family Support Programs: A Review. Madison: Wisconsin Bureau of Developmental Disabilities, 1982.

Division of Policy and Budget. The Community Options Program: An Evaluation of Early Implementation Experience. Madison: Wisconsin Department of Health and Social Services, 1983.

Thinking About Home & Family Support/ 18