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ABSTRACT

The report reviews 159 documents (1953-1982) on the role of the family in rehabilitation of persons with disabilities. The documents represent a cross section of ages as well as types and severity of disabilities and include journal articles, books, monographs, and other papers. In content, the documents fall into three major categories: psycho-social aspects (roles and concerns of family members, family reactions and dynamics); intervention with family systems (including counseling/social services and family education); and intervention by family systems (including advocacy activities and skill training). Cited in an analytical synopsis are studies dealing with family stress, counseling processes and outcomes, and change agentry. Literature is also analyzed in terms of type of research product (personal observation and data-based publications). The author concludes that there is a need for more rigorous empirical research and for research on families of older persons with disabilities. Twenty research questions are listed in areas including outcome factors of different approaches, siblings, and effective strategies. The annotated reference list following the synposis is arranged alphabetically by author's last name and provides information on title, source, and date of publication as well as a brief summary. (CL)

THE ROLE OF THE FAMILY IN REHABILITATION

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R. William English, Ph.D.

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REHABILITATION RESEARCH REVIEW

The Role of the Family in Rehabilitation

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REHABILITATION RESEARCH REVIEW

PROJECT SUMMARY

> "...Synthetic research involves reviewing the research literature available in some defined area of interest and summarizing and integrating the results into tentative conclusions regarding the current state of knowledge..."
>
> (Bolton, 1974, p.10)

The REHABILITATION RESEARCH REVIEW project originates from the National Rehabilitation Information Center's (NARIC) 1983, National Institute of Handicapped Research (NIHR) contract. To assure quality research and the maximum participation of professionals in the field of rehabilitation, NARIC invited the National Council on Rehabilitation Education (NCRE) to serve as the project's co-sponsor.

REHABILITATION RESEARCH REVIEWS were initiated to create state-of-the-art reviews on a variety of rehabilitation topics.

Each of the REVIEWS consists of two parts:

- an integrated, analytical literature synopsis, including the author's observations, conclusions, and recommendations for future research; and
- an annotated reference list, including annotated bibliographic entries.

Each REHABILITATION RESEARCH REVIEW represents the individual author's opinions and not necessarily those of NARIC, NCRE or NIHR.

Bolton, B. Introduction to Rehabilitation Research. Springfield, IL: Charles C. Thomas, 1974.

However, this type of synoptic research provides professionals with an opportunity to reflect upon the strengths and weaknesses of the research available in each subject area, and thus, offers valuable feedback to NIHR as well as to the larger rehabilitation community.

This project also stands as a model of cooperative efforts. The co-sponsorship between NARIC and NCRE strengthened the substantive value of each of the final documents. The printing contribution by The Xerox Corporation greatly increased the dissemination possibilities for the entire project. Xerox's donation of services to REHABILITATION RESEARCH REVIEWS demonstrates the Corporation's continuing dedication to active involvement in public sector projects.

These collaborative efforts are important because of the intrinsic value of the project. Each REHABILITATION RESEARCH REVIEW takes a new step in the utilization of available research. The sheer volume of research studies conducted as well as the variety of publication sources can make the use of this information a complex and time consuming process. By closing the gap between the producers and consumers of knowledge and technology, it is hoped that REHABILITATION RESEARCH REVIEWS will help to avoid duplication of research efforts and will significantly add to the possibility for innovative applications of research information.

THE NATIONAL REHABILITATION INFORMATION CENTER

The National Rehabilitation Information Center, NARIC, is a rehabilitation research library located at The Catholic University of America (CUA) and funded by The National Institute of Handicapped Research, (NIHR), of the U.S. Department of Education. Established in 1977, NARIC's goals are to:

- Facilitate dissemination of rehabilitation information;
- Promote utilization of rehabilitation research;
- Serve as an archive for NIHR and Rehabilitation Services Administration (RSA) documents; and
- Make information on assistive devices available to professionals serving disabled persons, researchers, and disabled consumers.

In sponsoring the REHABILITATION RESEARCH REVIEW, NARIC's responsibilities included identifying and selecting authors; developing author guidelines; providing each author with topical bibliographic searches of REHABDATA and other relevant databases, as well as supplying a variety of supplemental resources. NARIC staff wrote citations and annotations and supplemental materials for each document in addition to serving as editor and publisher.

NARIC will house and distribute the REHABILITATION RESEARCH REVIEW documents.

THE NATIONAL COUNCIL ON REHABILITATION EDUCATION

The National Council on Rehabilitation Education (NCRE), is a professional organization composed of over 500 educators, trainers, and staff development specialists which represents over 180 academic training programs and research projects related to the field of rehabilitation education. NCRE is dedicated to quality services for persons with disabilities, ensured by high standards of pre-professional education, continuing education for practicing rehabilitationists, and ethical standards. The organization also lobbies on behalf of enabling legislation and supports mechanisms needed to maintain quality services such as accreditation, certification, professional literature, and the like.

Participation in the REHABILITATION RESEARCH REVIEW Project provided NCRE members an opportunity to further their organizational goal of "utilization and application of rehabilitation research." NCRE authors and members of the Advisory Committee volunteered their time and expertise to the project.

Dr. Kenneth W. Reagles, NCRE Advisory Committee Chair, assisted the NARIC REHABILITATION RESEARCH REVIEW Project Director with selection of topics and authors, as well as consulting with authors regarding substantive research issues. The NCRE Advisory Committee provided a peer review of the final documents.

THE NATIONAL INSTITUTE OF HANDICAPPED RESEARCH

The National Institute of Handicapped Research (NIHR), a part of the Office of Special Education and Rehabilitation Services of the U.S. Department of Education, provides leadership and support for a national and international program of comprehensive and coordinated research regarding the rehabilitation of disabled persons. The Institute's mission also encompasses the dissemination of information concerning developments in rehabilitation procedures, methods and devices to improve the lives of persons of all ages with physical and mental disabilities, especially those who are severely disabled.

The Institute carries out its mission through a variety of programs including:

- The Research and Demonstration Project
- The Research and Training Centers
- The Rehabilitation Engineering Centers

The REHABILITATION RESEARCH REVIEW project is a component part of the Institute's goal of transforming research knowledge into comprehensive documents for dissemination and utilization. Thus, NIHR funded NARIC to develop and implement the REVIEW project. NIHR staff specialists provided a review of the documents prior to publication. Additionally, in the continuing effort for coordination and cooperation among federal agencies, staff specialists from the Rehabilitation Services Administration (RSA) also participated in reviewing the documents.

THE ROLE OF THE FAMILY IN REHABILITATION

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INTRODUCTION

The purpose of this REHABILITATION RESEARCH REVIEW is to provide an analytical synopsis and annotated reference list for the professional literature on the role of the family in rehabilitation.* By providing an extensive synthesis of the research literature on the topic of the family of persons with disabilities, it is hoped this REVIEW will contribute to improving the quality of rehabilitative services and rehabilitation education and research.

Description of Content

For this paper, a profile is provided on the focus areas and disciplines that are reflected in the literature; the focus of the

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*The author wishes to acknowledge and state his appreciation to Alice Gardner and Ann Neulicht from the University of Oregon Rehabilitation Research and Training Center in Mental Retardation, and to the staff of NARIC for their contributions in abstracting the literature for this bibliography.

content and published products is summarized; and observations and recommendations are made related to future research. The content of the documents indicated the following categories:

- Psycho-Social Aspects (including family reactions; roles of family members; concerns of family members and dynamics within families);
- Intervention with Family Systems (including counseling/social services, involvement in the child's education; family education, and models of intervention);
- Intervention by Family Systems (including advocacy activities and skill training).

A total of 159 documents are cited in the annotated reference list. Represented in this collection are 130 journal articles, 20 books or monographs, 6 chapters from books and 3 other papers.

A comprehensive approach was taken in selecting publications. This consisted of using the various computer retrieval sources available from National Rehabilitation Information Center (NARIC), identifying publications to include, and researching the secondary references from these publications for further screening. The 159 sources included are a cross-section of what the author considers to be the best material available. Attempts were made to include literature that focused on the role of the family of persons of all ages, types of disabilities, and varying severity of disability. In addition, emphasis was placed on the inclusion of "retrievable literature," such as journal articles and books.

Over time several thousand products have appeared on the topic of the family of persons with disabilities although many of these products are unpublished papers. Some of the publications that review this literature from various content perspectives are: Aspen (1981); Banta (1979); Faerstein (1981); Murphy (1982); Paul & Beckman (1981); Price-Bonham (1978); Rehabilitation Brief (1978); and Zucman (1982).

LITERATURE PROFILE

The majority of the publications that comprise the reference list are journal articles (81%), with books (13%) representing the second major type of publication. A thumbnail sketch of the emphasis that has been made in resource books and monographs on families of persons with disabilities is provided in Table 1. The reference citations for these books appear at the beginning of reference list and twenty of the books/monographs are abstracted in the reference list. Table 2 provides a similar insight into the emphasis that various professional disciplines have placed on writing about the family of disabled persons in referred periodicals.

Resource books on families of persons with disabilities appear to represent five areas of focus: (a) parent education, emphasizing how to be a responsible parent of a disabled person; (b) skill training, focusing on instructing parents and siblings in the physical and behavioral management of a disabled family member; (c) advocacy for disabled persons; (d) individual, family, and group counseling; and (e) books on specific disabilities, the large majority of which deal with families of persons who are mentally retarded.

Table 1

Resource Books on the Families of Persons with Disabilities

Focus Areas	#	%	Primary Audience Parents	Professionals
Parent Education	16	43%	5	10
Skill Training	5	14%	3	2
Advocacy	4	11%	4	0
Counseling	4	11%	0	4
Specific Disabilities	8	21%	4	4
TOTAL	37	100%	16	20

Table 2

Clusters of Journals That Have Been Published on Family

Cluster Areas	# Journals	#Articles	%Articles
Child and Adolescent Development	11	19	15%
Communication Disorders	5	13	10%
Educational Psychology	3	3	2%
Family Support Systems	3	5	4%
Physical Medicine and Rehabilitation	9	18	14%
Psychology and Psychiatry	13	15	11%
Social Work/Sociology	4	8	6%
Special Education	14	49	38%
TOTAL	62	130	100%

Although a number of books have been written on the subject, by far the largest proportion in this reference list (43%) represent the focus of parent education, which emphasizes "how to" books on parenting an exceptional child. All published books and monographs reviewed can be used by other family members or professionals, but each book is slanted more to one of these two audiences. One of two books/monographs in each focus area especially lend themselves to use by both parents and professionals. Most of the books cited (75%) have been published since 1975. About half of them appear to be geared towards a primary audience of parents and half towards professional service providers.

An examination of the various journals that have contained articles on the families of persons with disabilities (Table 2) reveals that the topic has been of concern to professionals in many related disciplines. The 130 articles included in this tabulation were published in 62 different journals and represent 8 different areas of professional service to disabled persons.

Many professional areas allied with rehabilitation -- especially special education -- have obviously chosen to publish research on the families of disabled persons. Given that special efforts were made to include studies from rehabilitation journals in this bibliography, and that no more than 14% of the citations are actually from rehabilitation journals, it is reasonable to infer that relative to other disciplines, the field of rehabilitation has chosen to pay little attention to the primary support system of its consumers.

Two other dimensions that were used to derive a profile of the

journal literature on the families of persons with disabilities were time and disability. In terms of time, the substantial majority of journal articles on the family are of recent origin. Sixty-six percent of the publications included in the reference list were published since 1978.

In terms of disability, the author believes the following about the articles cited: 47%, about half, do not place a focus on disability per se; 26% deal with mental retardation; 11% involve two or more disability groups; 11% focus on communication disorders; and 5% with other specific disability groups (Spinal bifida, spinal cord injury, cerebral palsy, and learning disabilities).

Overview of the Content and Product Focus of Family Research

Since 81% of the documents reviewed are journal articles, the summary that follows focuses on periodicals. Table 3 summarizes this information. It shows that, in the author's opinion, the research on the family of disabled persons predominately relates to three areas of content focus: (a) Psycho-Social Aspects of Disability; (b) Intervention With Family Systems; and (c) Intervention By Family Systems. Table 3 also shows that, in the author's opinion, the journal literature represents three types of research products: (a) personal observations; (b) data based research; and (c) literature reviews.

TABLE 3

Content and Products of Journal Literature on the Family

Content Area	Type of Research: Personal Observation	Data Based	Literature Review	Overall #	%
I. Psycho-Social Aspects					
A. Family Members Reactions	9	8	0	17	26%
B. Roles of Family Members	5	12	3	20	30%
C. Concerns of Family Members	4	4	1	9	14%
D. Dynamics within Families	8	7	5	20	30%
Subtotal	26	31	9	66	51%
II. Intervention with Family Systems					
A. Counseling/Social Services	14	7	0	21	44%
B. Involvement in Child's Education	8	3	0	11	23%
C. Family Education	7	2	0	9	19%
D. Models of Intervention	7	0	0	7	14%
Subtotal	36	12	0	48	37%
III. Intervention by Family Systems					
A. Advocacy Activities	4	1	0	5	31%
B. Skill Training	4	7	0	11	69%
Subtotal	8	8	0	16	12%
Total	70	51	9	130	100%
Overall Percent	54%	39%	7%		

Psycho-Social Aspects of Disabilities

The 65 journal publications on psycho-social aspects of disability tend to relate to the reactions, roles and concerns of family members, as well as interpersonal dynamics within families. All four of these dimensions are well represented in the literature, although proportionately less emphasis is placed on studying the concerns or needs of family members. An examination of the articles in this REVIEW shows that the greatest proportion of manuscripts (51%) deal with the focus area of psycho-social disability. In addition, research has been done in this area over the longest period of time and by persons from the widest spectrum of professional affiliations.

Specific journal articles reflect different themes regarding psycho-social aspects of disability. The most global theme is that one person's disability has a profound and lasting impact on nuclear family units and often on extended family systems as well. Implicit in all this research, and explicit in some, is the concept that disabled persons' families are disabled as well and often in need of assistance. Moreover, much of the research reflects the concept that the health and well-being of persons with disabilities is directly related to the well-being of their nuclear family.

The reactions of family members to a disabling condition was the primary focus of 17 articles (26%) dealing with psycho-social aspects of disability. As logic would suggest, a disability is almost always perceived negatively by family members and represents an obstacle to be coped with, integrated, and overcome. A portion of this literature

deals with adjustment of family members, initially and over a period of time (Kanner, 1953; Olshansky, 1962; and Wikler, 1981). Another major focus is research on stress. A number of studies document that a person's disability is a major life stressor for parents (Friedrich & Friedrich, 1981; Holroyd, 1974; and Tavormina, Boll, Dunn, Luscomb & Taylor, 1981). Stress appears to be greatest for mothers and for the oldest female sibling (Cleveland & Miller, 1977; Gath, 1974; and Price-Bonham & Addison, 1978), and where there is a discrepancy between expectations for a child's achievement and his/her actual performance (Meadow & Meadow, 1971; and Searle, 1978).

Research on the roles of family members is the focus of 20 documents (30%) in the accompanying bibliography. Some studies suggest that parenting roles were often modified to address the needs that the disabled child or youth might have for physical assistance, direction, monitoring, and nurturing (Berno, 1971; Meadow & Meadow, 1971; and Tavormina, 1981). In addition, it appears that parents (English & Olson, 1978; and Wikler, 1981), siblings (Klein, 1972), and grandparents (McPhee, 1982) often have to work through feelings of shame, guilt, embarrassment, anger, authoritarianism, and overprotectiveness. Insights on stress among mothers is provided by Holroyd (1979), Price-Bonham (1978) and Tavormina (1981), while stress reactions by fathers is reflected in the manuscripts by English & Olson (1978), and Tallman (1965). Studies of sibling stress reaction is shown in research by Lavigne & Ryan (1978), and Simeonsson & McHale (1981).

The "concerns/needs of family" members was the central focus of 9 of the manuscripts abstracted (14%). Six deal with the concerns of parents of mentally retarded children (Alcorn, 1974; Carr, 1959; Cunningham & Sloper, 1977; English & [illegible]n, 1978; and Murray, 1959), one with parents of a child with ce bral palsy (Knott, 1979), and 3 articles concentrated on parents of deaf or blind children (Fairchild, 1979; Large, 1982; and Leigh, 1979).

The fourth focus area within the category of psycho-social aspects of disability deals with the interpersonal dynamics within family systems when a family member is disabled. Twenty articles (30%), from the subtopic of interpersonal dynamics, dealt with two different themes. One theme is that a disability frequently contributes substantially to an altered family life style (Cohen, 1962; Doernberg, 1978; Kogan & Tyler, 1973; and Lucca & Settles, 1981). A second theme deals with stress in cases where a person's disability is described as a major ongoing stressor for families (Cohen, 1965; Doernberg, 1978; Murphy, 1982; and Taw, 1977) which can substantially contribute to failure in rehabilitation (Versluys, 1980).

Intervention with Family Stress

Forty-nine journal publications cited in the REVIEW, 37% of all journal articles included, dealt with the topic of intervention or service delivery with family systems. The largest proportion of articles within this category dealt with the provision of counseling and social services to families (43%). Proportionately less representation

is on parent involvement in the disabled child's education (25%), family education (18%), and models of intervention (14%).

One global theme cuts across the discrete areas of family intervention. This is the notion that service providers in habilitation and rehabilitation must understand, be involved in, and sometimes intervene with non-disabled family members, and occasionally even with entire family systems if they wish to maximize their effectiveness in rehabilitating disabled individuals. The reality that exists in an alarming number of instances, perhaps a majority, is that rehabilitation practitioners rarely extend their intervention efforts beyond the disabled consumer.

Journal literature on intervention with the family systems of persons with disabilities through counseling tends to cluster in three areas: (a) counseling processes with parents; (b) counseling processes with siblings; and (c) counseling outcomes. The substantial majority of articles on counseling, 9 of 14, concern counseling processes with parents. Examples are the work of Begab (1956) that addressed factors which lead parents to enter counseling; articles on the affective and content focus of parent counseling (Christensen & DeBlassie, 1980; and Matheny & Vernick 1968); and writings about general principles of counseling with parents of disabled children (Doll, 1953; Green, 1978; and Webster, 1968). Completing the reference abstracts of literature on counseling intervention are articles that dealt with principles and practices of counseling with family members (Chinitz, 1981; and Kaplan & Fox, 1968), and outcomes of counseling with family members (Baum, 1981;

Massenzio, 1979; and Weingold & Hormuth, 1953).

A second area of literature on intervention with disabled person's family system has to do with the involvement of parents in planning and evaluating the child's public education program. The 11 articles in this subarea were published between 1978 and 1982, which indicates that this is a relatively new knowledge base and one that was given impetus by the passage of Public Law 94-142.

Literature cited for this REVIEW and that deals with the family's involvement in the education of the disabled person tends to be either process or outcome oriented. Process focused literature is illustrated in articles by Dimeo & Pasquarelli (1981); Mallory (1981); Morgan (1982); Peary (1981); Turnbull (1978); and Wolf & Troup (1980). Two outcome studies that focus directly on the impact of Public Law 94-142 are by Halpern (1982) and Polifka (1981).

The third area of literature on intervention with family systems, represented by 9 articles, is that of family education. All but one of these articles are process oriented. Included is research on common feelings of parents (Behmer, 1976), assertiveness training for parents (Markel & Greenbaum, 1981), and research on practical principles and procedures for establishing and conducting family education groups (Simpson, 1982; Weingold & Hormuth, 1952). The one outcome piece of research on this topic is a study by Firth (1982) which examined the effectiveness of a parent education group experience. A central theme of literature in this area is the notion that <u>families will become stronger and more vital as members avail themselves of opportunities to</u>

gain new knowledge about disabilities and participate more in supportive experiences with other persons who are family members to a disabled individual.

The fourth and final area of journal literature on intervention with family systems deals with models of service delivery to the families of persons who are disabled. The 7 abstracts included on treatment models, all represent the personal observation approach to research. All emphasize concepts for service delivery and all consider the family, as well as the disabled member, as potential consumers of habilitative-rehabilitative services. Specific disabilities are not emphasized in most of these articles.

Two themes are emphasized in this literature on family intervention models. One theme is that service delivery to the family should be logically planned, based on a functional assessment of the family (Bray, 1980; Foster, Berger & McLean, 1981; O'Hara, Chaiklen & Mosher, 1980; and Westin & Reiss, 1979). The second is that of individualizing services to relate to the unique needs of different families. Conceptual research aimed at individualizng educational and counseling services for families is reflected in the work of Abrams & Kaslow (1977), and Adamson (1972), while a conceptualization for individualizing respite care services is provided by Cohen (1982).

Intervention by Family Systems

The third category of the literature reviewed deals with abstracts of research on the family as an agent of change with its own disabled

family member and with others. Because research on change agentry by the family is of recent origin, it is not surprising that there are proportionately fewer publications in this area than in psycho-social aspects of disability or intervention with family systems. The 16 abstracts deal with two major aspects of change: (a) advocacy activities and (b) skill training. Because both represent treatment or intervention processes aimed at change, it is reasonable that this body of literature tends not to focus on families of persons with specific disabilities.

Three of the 5 journal abstracts on advocacy are recommendation statements, mainly aimed at parents, about "how to" go about advocating for disabled persons (Massenzio, 1981; Kean, 1975; and Daniels, 1982). The other two articles on advocacy deal with continuing education. Muir, et al. (1982), describe the components of an advocacy education program and Wikler (1979) reports the results of a successful effort in using parents to teach graduate students skills for interviewing parents of disabled persons.

The second dimension to intervention by family systems represented is skill training, which is the process of training persons in the acquisition, retention, and generalization of specific behavioral skills. Skill training rates a strong endorsement based on an examination of the seven articles included in this REVIEW. Not only have mothers demonstrated competency in skill training (Hansen, et al., 1981; Morse, 1979; and Timm & Rule, 1981), but skill training represents an area where fathers and siblings can help "good old mom" contribute to

increasing the interdependence of the disabled child (Adubato, Adams & Buss, 1981; Miller & Cantwell, 1976; and Weinrott, 1974).

Types of Research Products

Besides coding the literature in terms of content focus, this author has also examined each publication in terms of the type of research or product it represents. This information is summarized in Table 3. It clearly shows that, proportionately, a majority of publications represented in this REVIEW are of a personal observation type (54%) and, as such, emphasize the qualitative, non-empirical presentation of concepts along with experiential descriptions. Many of the authors of these research contributions are practicing service providers or parent consumers.

Data-based research represents a second major type of product (39%). In recent years increasingly more publications have involved some form of data collection and analysis. While proportionately the various content areas included in the REVIEW are fairly balanced between the personal observation versus data-based research products there are exceptions. For instance, substantially more data-based publications are included that deal with the roles of family members and with skill training. In turn, proportionately more research is represented of the personal observation type that focuses on counseling intervention with families, family education, models of intervention, and parent advocacy.

The 9 literature reviews that are abstracted from periodicals, all focus on a dimension of psycho-social aspects of disability. Many of

these reviews are disability specific in that they emphasize the psychosocial aspects of family systems of persons with specific disabilities. The paucity of research reviews on aspects of interventions with and by families is a notable weakness of the state-of-the-art of research on the families of disabled persons.

OBSERVATIONS AND RECOMMENDATIONS

Observations

A review of the publications chosen for inclusion suggests a number of general observations about the literature. First, it is clear that research on the family of persons with disabilities is generally of recent origin. This observation reflects these facts: A large proportion of this literature is very recent; it emphasizes early impact and early intervention; and these publications tend to be philosophical, qualitative, and nonempirical. Secondly, far greater emphasis should be placed in future years on publishing more rigorous empirical research. Studies involving comparisons of study groups and methods of intervention with and by family systems are particularly needed. Third, a preponderance of the existing literature emphasizes the families of disabled persons who are young, generally infants or adolescents. In future research, more emphasis needs to be given to families of older persons with disabilities, including persons in young adult, adult midlife and aging life cycles. Fourth, the various professional disciplines do not appear to have placed proportionate emphasis on publishing articles in periodicals that deal with the family. Data from Table 2 suggests that educational psychology, social work and rehabilitation are disciplines that could devote more attention to the families of disabled persons. Because these disciplines -- especially rehabilitation -- deal more with older persons with disabilities, some of the unevenness in the literature would be corrected by more

publications on the family in these fields. Fifth, this author observes that there is a rich opportunity for interdisciplinary collaborations in research on the family, as well as for partnerships between professionals and family members. More imaginative, rigorous, and relevant research is likely to emerge from such endeavors.

Recommendations

Substantially more research is still needed on the family of disabled persons. Recommendations for some potential studies are suggested by the following list of 20 research questions:

1. What are the outcome effects of using family members to teach independent living skills to disabled persons?
2. What are the outcome effects of using family members as educators of both professionals and the general community?
3. How does the disability strengthen family members and family systems?
4. What kind of transition occurs when parents are replaced by different significant others (e.g., siblings) as the primary benefactor to the person with a disability?
5. What are the outcomes of different approaches, individual and group, to counseling family members?
6. What are the effects of different educational approaches with family members?
7. What are the components of an adequate support system for adults who are disabled?

8. What results occur from replications of research studies on the family?

9. How do rehabilitation needs differ for contrasting family systems?

10. What are the rehabilitation needs for families whose members are at different significant points in a life cycle?

11. How does the rehabilitation process differ with families who range along a continuum of cooperativeness and competency?

12. How does the rehabilitation process differ with families who live in rural versus urban areas?

13. What strategies have been effective in increasing rehabilitative involvement by fathers and grandfathers?

14. What strategies have been effective in helping family members to be supportive, realistic, and facilitative helpers to disabled persons?

15. What features characterize exemplary programs of intervention with families and by families of persons who are disabled?

16. What are the major concerns of siblings of persons with disabilities?

17. How do families deal with stigma by association?

18. What do parents and rehabilitation professionals consider to be the agony and the ecstasy of parent-professional interactions?

19. What are the outcomes of implementing rehabilitation plans where there have been contrasting levels of parent involvement?

20. Does continuous involvement of parents in IEP and IWRP development result in more successful rehabilitation outcomes?

38 RESOURCE BOOKS ON THE FAMILY OF PERSONS WITH DISABILITIES

General "Parent Education" (17 Books)

Fine, M. J. Handbook on parent education. New York: Academic Press, 1980.

Gallagher, J. J. Parents and families of handicapped children. San Francisco: Jossey-Bass Inc., 1980.

Heisler, V. A handicapped child in the family: A guide for parents. New York: Grune & Statton, 1972.

Howard, W. L., Dardig, J. C., & Russett, A. Working with parents of exceptional children. Columbus: Charles E. Merrill, 1979.

Karnes, M. B., & Franke, B. Family involvement. Urbana: Institute for Child Behavior and Development, 1978.

Katz, A. H. Parents of the handicapped. Springfield, IL: Charles C. Thomas, 1961.

Lukens, K., & Panter, C. Thursday's child has far to go. Englewood Cliffs, NJ: Prentice-Hall Inc. 1969.

Moore, C.B., & Morton, K.G. A reader's guide for parents of children with mental, physical and emotional disabilities. Rockville, MD: U.S. Health Services Administration, 1976.

Paul, J. L., & Beckman-Bell, P. (Eds.) Understanding and working with the parents of children with special needs. New York: Holt, Rinehart and Winston, 1981.

Perske, R. Hope for the families: New directions for parents of persons with retardation and other disabilities. Nashville: Abington, 1981.

Power, P.W. & Dell Orto, A. E. The role of the family in the rehabilitation of the physically disabled. Boston: Springer Publishing, 1981.

Seligman, M. (Ed.). The family with a handicapped child. New York: Grune & Stratton, 1983.

Spock, B., & Lerrigo, M. Caring for your disabled child. New York: The Macmillan Company, 1965.

Turnbull, A. P. & Turnbull, H. R. Parents speak out: Views form the other side of the two way mirror. Columbus: Charles E. Merrill, 1978.

Tymchuk, A. Parent and family therapy: An integrative approach to family interventions. Jamaica, NY: Spectrum Publications, 1979.

Wolfensberger, W., & Kurtz, R. A. Management of the family of the mentally retarded. Follet Educational Corporation, 1969.

Zucman, E. The family and disability. New York: The World Rehabilitation Fund, Monograph No. 14, 1982.

"Skill Training" (5 Books)

Cooper, J. O., & Edge, D.E. Parenting strategies and educational methods. Columbus: Charles E. Merrill, 1978.

Deacon, R.E., & Firebaugh, F.M. Family resource management: Principles and applications. Boston: Allyn and Bacon, 1981.

Dinkmeyer, D., & McKay, G. D. Systematic training for effective parenting: Parent's handbook. Circle Pines, MN: American Guidance Service Inc., 1976.

Lillie, D.L., & Place, P.A. Partners: A guide to working with schools for parents of children with special instructional needs. Oberview, IL: Scott, Foresman & Co, 1982.

Wolery, M.R. Parents as teachers of their handicapped children: An annotated bibliography. Seattle: University of Washington Child Development and Mental Retardation Center, 1980.

"Advocacy" (4 Books)

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DesJardins, C., et al. How to organize an effective parent advocacy group and move bureaucracies. Champaign, IL: Coordinating Council for Handicapped Children, 1978.

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Webster, E. J. Professional approaches with parents of handicapped children. Springfield, IL: Charles C. Thomas, Publishers, 1976.

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Bruininks, R. H. & Kranz, G. C. (Eds.). Family care of developmentally disabled members: Conference proceedings. Washington, DC: Rehabilitation Services Administration, 1978.

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Farber, B. Family organization and crisis: Maintenance of integration in families with a severely retarded child. Monograph No. 75. Society for Research on Child Development, 1960.

Joel, G. S. So your child has cerebral palsy. Albuquerque: University of New Mexico Press, 1975.

Kirs, S., Karnes, M. B. & Kirk, W. You and your retarded child: A manual for parents of retarded children. Palo Alto: Pacific Books, 1968.

Koch, R., & Dobson, J. C. The mentally retarded child and his family: A multidisciplinary handbook. New York: Brunner/Mazel, 1971.

Mallik, K., et al. Communication resources for the developmentally disabled: A guide for parents, paraprofessionals and professionals. Washington, DC: George Washington University Job Development Laboratory, 1977.

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ANNOTATED REFERENCE LIST

THE ROLE OF THE FAMILY IN REHABILITATION

ANNOTATED REFERENCE LIST

PSYCHO-SOCIAL ASPECTS

Family Members Reactions

Booth, T. A. From normal baby to handicapped child: Unravelling the idea of subnormality in families of mentally handicapped children. Sociology, 1978, 12(2), 203-221.

Analysis of data from case histories of 46 families with severely disabled children. Interviews record gradual process by which the status of children diagnosed as severely disabled changes from normal to disabled. Outlines the social aspect accompanying clinical education and diagnosis.

Birenbaum, A. On managing a courtesy stigma. Journal of Health and Social Behavior, 1970, 11, 196-206.

To manage a courtesy stigma parents should recognize its situational variability which allows emulation of conventional behavior. Examines the adaptations of mothers of mentally retarded children through their relationships with family, friends and other parents of retarded children.

Cook, J. J. Dimensional analysis of child-rearing attitudes of parents of handicapped children. American Journal of Mental Deficiency, November 1963, 68, 354-361.

Presents results of an analysis attempting to delineate attitudes of mothers of selected groups of disabled children using a model defined by two attitudinal dimensions: authoritarian family ideology and conventionality-anxiety.

English, R. W., & Olson, K. K. Parenting handicapped children: Earliest experiences. Journal of Special Educators, 1978, 15(1), 10-17. (NARIC Call No. 03151)

Manuscript based on edited verbatim responses of parents to questions about their earliest experiences with their disabled child. The parent group consisted of two men and three women chosen

from a larger parenting group formed through their child's involvement in an on-campus early intervention preschool program. Disabilities of the children included Down's syndrome, cerebral palsy, learning disability, and epilepsy.

Friedrich, W. M., & Friedrich, W. L. Psychosocial assets of parents of handicapped and nonhandicapped children. American Journal of Mental Deficiency, 1981, 85(5), 551-553.

Measurement of stress and stress-mediating variables in parents of 34 disabled children for comparison to a control sample of parents of nondisabled children.

Gerber, G. L. Conflicts in values and attitudes between parents of symptomatic and normal children. Psychological Reports, 1976, 38(1), 91-98.

Analysis of conflicts between parents of normal, disturbed, and learning disabled children with regard to values and attitudes of acceptance or rejection of children.

Hanchett, J. It's a family affair. Mainstream, 1982, 7(5), 24; 28. (NARIC Call No. J0785)

Discussion of approaches to promote adjustment to life with a disabled family member.

Holroyd, J. The questionnaire on resources and stress: An instrument to measure family response to a handicapped member. Journal of Community Psychology, 1974, 2, 92-94.

Describes a multidimensional, objective, self-administered test for measurement of degree and variety of response to a physically or mentally disabled family member.

Kanner, L. Parents' feelings about retarded children. American Journal of Mental Deficiency, 1953, 57, 41-49.

Results of interviews with parents of Down's syndrome infants shortly after diagnosis.

Olshansky, S. Chronic sorrow: A response to having a mentally defective child. Social Casework, 1962, 43, 190-193.

Theorizes that chronic sorrow, a form of periodic grief, is a natural phenomenon that affects most parents of mentally retarded persons.

Parks, R. M. Parental reactions to the birth of a handicapped child. Health & Social Work, 1977, 2(3), 51-66.

Exploration of ways in which hospital social workers can help parents deal with the crisis reaction, grief, and mourning therapy attending the birth of a disabled child. Includes table identifying stages in grief process.

Peck, J. R., & Stephens, W. B. A study of the relationship between the attitudes and behavior of parents and that of their mentally defective child. American Journal of Mental Deficiency, 1960, 64, 839-844.

Investigates the relationship between attitudes and behavior of parents toward their mentally retarded child and attitudes and behavior of the child. Case study material includes social history; school, training, physical, and psychological data; Fels Parent and Child Behavior Scales, and a rating scale for child-concept.

Sarason, S. Psychological problems in mental deficiency. New York: Harper and Brothers, 1963©, 402 p.

Focuses on the influence of family reaction to mentally defective child on the child's behavior. Study uses Fels Parent Behavior Scales.

Searle, S. J. Stages of parent reaction. Exceptional Parent, April 1978©, 27-29.

Paper arguing that various stresses emerge periodically over time in families of developmentally disabled children where discrepancies between expectations and performance of the child provoke this chronic cycle.

Tavormina, J. B., Boll, T. J., Dunn, N. J., Luscomb, R. L., & Taylor, J. R. Psychosocial effects on parents of raising a physically handicapped child. Journal of Abnormal Child Psychology, 1981, 9(1), 121-131.

Assessment of coping strategies employed by 133 mothers and 93

fathers of children with diabetes, asthma, cystic fibrosis, and hearing impairment. Includes evaluation of psychosocial effects on parents of raising a physically disabled child.

Voysey, M. Impression management by parents with disabled children. Journal of Health and Social Behavior, 1972, 13, 80-89.

Analysis of problems parents of disabled children face in encounters with others outside the immediate family and the strategies parents adopt to manage these problems.

Walsbren, S. E. Parents' reactions after the birth of a developmentally disabled child. American Journal of Mental Deficiency, 1980, 84(4), 345-351.

Comparison of 30 families of a developmentally disabled child less than 1.5 years old with 30 families of a nondisabled child. Half of the families live in California and half Denmark.

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Paul, J. L., & Beckman-Bell, P. Parent perspectives. In J. L. Paul (Ed.), Understanding and working with parents of children with special needs. New York: Holt, Rinehart and Winston, 1981©, 229 p.

Tew, B. J., Payne, E. H., & Lawrence, K. M. Must a family with a handicapped child be a handicapped family. Developmental Medicine and Child Neurology, 1974, 16(Supp. 32), 95-98.

Roles of Family Members

Arkava, M. L., & Mueller, D. M. Components of foster care for handicapped children. Child Welfare, 1978, 57(6), 339-345.

Description of a survey developed to match foster parents with disabled children. Addresses specific tasks and demands of this type of foster care.

Banta, E. M. Siblings of deaf-blind children. Volta Review, 1979, 81(5), 363-369.

Brief review of literature on effects of the deaf-blind child on the family and siblings.

Berns, J. H. Grandparents of handicapped children. Social Work, 1980, 25(3), 238-239.

Discussion of grandparents' reactions to the birth of a disabled child. Suggests ways grandparents can help the child develop and overcome resentment, embarrassment, and overprotective reactions they may experience.

Breslau, N., Weitzman, M., & Messenger, K. Psychologic functioning of siblings of disabled children. Pediatrics, 1981, 67(3), 344-353.

Study of families of pediatric patients with cystic fibrosis, cerebral palsy, myelodysplasia, and multiple handicaps to discover relationship between sibling disability and psychological functioning of normal siblings.

Buck, F. M., & Hohmann, G. W. Personality, behavior, values, and family relations of children of fathers with spinal chord injury. Archives of Physical Medicine and Rehabilitation, 1981©, 62, 432-438.

Investigates relationships between spinal cord injury in fathers and subsequent adjustment patterns of children.

Cleveland, D. W., & Miller, N. Attitudes and life commitments of older siblings of mentally retarded adults: An exploratory study. Mental Retardation, 1977, 15(3), 38-41.

Study to determine if life commitments of normal adult siblings had been influenced by having a mentally retarded sibling.

Cumm'ngs, S. T. The impact of the child's deficiency on the father: A study of mentally retarded and chronically ill children. American Journal of Orthopsychiatry, 1976©, 46(2), 246-255.

Study examining how a disabled child affects the psychological functioning of the father.

Gath, A. Sibling reactions to mental handicap: A comparison of the brothers and sisters of mongol children. Journal of Child Psychology and Psychiatry, 1974, 15, 187-198.

Investigation of sibling reaction to presence of a Down's syndrome child in the home. Parents and teachers completed behavioral rating scales on 89 sisters and 85 brothers of 104 Down's syndrome children.

Klein, S. Brother to sister, sister to brother. Exceptional Parent, 1972©, 2(1), 10-15.

Edited transcript of a 2-hour interview with four college students discussing experiences as siblings of a disabled person. Disabilities of siblings included physical impairment, hearing loss, brain damage, autism, and severe mental retardation.

Lavigne, J. V., & Ryan, M. Psychologic adjustment of siblings of children with chronic illness. Pediatrics, 1979, 63, 616.

Results of a comprehensive study of families of pediatric patients with cystic fibrosis, cerebral palsy, myeldysplasia, and multiple disabilities being treated at two Cleveland teaching hospitals.

McPhee, N. A very special magic: A grandparent's delight. Exceptional Parent, 1982 ©, 12(3), 13-16.

A grandmother's story of gradual acceptance of her severely disabled grandson from initial anger and hostility to recognition of the child as a person.

Meadow, K. P., & Meadow, L. Changing role perceptions for parents of handicapped children. Exceptional Children, September 1971©, 21-27.

An aid to professionals helping parents of a disabled child. Focuses on understanding the socialization process parents must undergo in terms of both technical and emotional aspects of the parental role.

Murphy, A. T. Members of the family: Sisters and brothers of handicapped children. Volta Review, 1979, 81(5), 352-362.

Review of literature on siblings of disabled children. Emphasis

on inadequate attention paid to the role of siblings in the family process.

Price-Bonham, S., & Addison, S. Families and mentally retarded children: Emphasis on the father. Family Coordinator, July 1978, 27, 221-230.

Review of literature published from 1960-1978 which focused on mentally retarded children and their fathers. Addresses problems and challenges including finances, emotional tension, professional services, and long-term care.

San Martino, M., & Newman, M. Siblings of retarded children: A population at risk. Child Psychiatry and Human Development, 1974, 4(3), 168-172.

Discussion of siblings of retarded children as a population frequently seen at child psychiatric clinics and likely to have emotional problems.

Simeonsson, R. J., & McHale, S. M. Review: Research on handicapped children: Sibling relationships. Child: Care, Health, and Development, 1981, 7(3), 153-171.

Review of literature addressing bidirectional effects in sibling relationships involving disabled children.

Tallman, I. Spousal role differentiation and the socialization of severely retarded children. Journal of Marriage and the Family, 1965, 27, 37-42.

Aspects of Parson-Bale's theory of socialization were used as conceptual framework for hypotheses about the role of parents of severely retarded children. Data supports prediction that fathers would be less skillful than mothers in coping with a retarded child.

Trevino, F. Siblings of handicapped children: Identifying those at risk. Social Casework, October 1979, 80, 488-493.

Emphasis on importance of including the entire family in the diagnostic process and of considering the effects of a disabled child on a normal sibling.

Wikler, L., Wasow, M., & Hatfield, E. Looking for strengths in families of developmentally disabled children. Social Work, 1981.

A discussion of the clinical implications of parents of developmentally disabled children who reported that this parenting experience had made them stronger. The authors suggest that more clinical emphasis should be placed on the strengths rather than the negative aspects of the family life.

Concerns of Family Members

Alcorn, D. Parental views on sexual development and education of the trainable mentally retarded. Journal of Special Education, 1974, 8(2), 119-130.

Survey conducted among parent members of a state association for the retarded to explore certain aspects of sexuality in trainable mentally retarded individuals and attitudes of parents toward sex education and management of the retarded individuals.

Carr, L. B. Problems confronting parents of children with handicaps. Exceptional Children, February 1959, 25, 251-255.

Guidance for the parents of disabled children in developing and maintaining desirable foundations for their child's personality and in making necessary adjustments in their own personalities.

Cunningham, C. C., & Sloper, T. Parents of Down's syndrome babies: Their early needs. Child: Care, Health and Development, 1977, 3, 325-347.

Results of detailed interviews with parents of Down's syndrome infants soon after diagnosis. Study investigates extent to which proposed recommendations were practiced.

Fairchild, B. Parental concerns. Journal of Rehabilitation of the Deaf, 1979, 12(4), 84-90.

Text of a speech given by a hearing impaired child, who served as Acting Director of the International Association of Parents of the Deaf (IAPD). Emphasis on typical concerns of parents with hearing-impaired or deaf children.

Hersh, A., Carlson, R. W., & Lossino, D. A. Normalized interaction with

families of the mentally retarded--To introduce attitude and behavior change in students in a professional discipline. Mental Retardation, 1977, 15(1), 32-33.

Investigation of effects on students of social work of supplemental experience with families having a retarded member.

Justice, R. S., O'Conner, G., & Warren, N. Problems reported by parents of mentally retarded children: Who helps. American Journal of Mental Deficiency, 1971, 75(6), 685-691.

Findings based on interviews of parents of 171 community-labeled mentally retardated persons regarding problems with the children and the resources used to deal with them. Perceived availability and effectiveness of personal, public, and private resources examined.

Knott, G. P. Attitudes and needs of parents of cerebral palsied children. Rehabilitation Literature, 1979e, 40(7), 190-196.

Major premise of this literature review is that parents of children with cerebral palsy have multiple needs. Findings indicate professionals should consider parents and children in a holistic manner.

Large, T. Effects of attitudes upon the blind: A reexamination. Journal of Rehabilitation, 1982e, 48(2), 33-34; 45 (NARIC Call No. J1162.)

Study of 16 successful blind people to identify effects attitudes of other people have on rehabilitation and adjustment of blind people. Includes case studies and bibliography.

Leigh, I. W. The support a parent needs from the audiologist and speech pathologist. Hearing Rehabilitation Quarterly, 1979, 4(1), 9.

A deaf professional who is the parent of both a hearing and a deaf child shares views on attitudes of professionals toward families with hearing-impaired children.

Murray, Mrs. M. A. Needs of parents of mentally retarded children. American Journal of Mental Deficiency, 1959, 63, 1078-1088.

A parent of a retarded child and president of Virginia Association for Retarded Children discusses special considerations, problems,

and experiences which influence life functioning of families with retarded children.

Dynamics within Families

Birenbaum, A. The mentally retarded child in the home and the family cycle. Journal of Health and Social Behavior, 1971, 12, 55-65.

Emulating traditional parenting is one method to aid in managing a child with mental retardation. The mothers role performance may be skewed, but routine domestic life is possible as long as normal-appearing activity is available.

Bray, G. P. Reactive patterns in families of the severely disabled. Rehabilitation Counseling Bulletin, 1977©, 20(3), 236-239.

Stages of client adjustment to severe disability are related to client's family adjustment process. Implications for counseling and intervention are addressed.

Cohen, P. C. The impact of the handicapped child on the family. Social Casework, 1962, 43(3), 137-142.

Observations based on experiences of the Family Service of the Cincinnati Area in leading family life education groups for parents of disabled children and providing direct casework services services to families who seek help in raising disabled children.

Doernberg, N. L. Some negative effects of family integration of health and educational services for young handicapped children. Rehabilitation Literature, 1978 ©, 39(4), 107-110.

Identification of additional stresses that treatment of disabled children places on families. Recommendations for more sensitivity among service professionals to pressures and disruption of family support systems and more restructuring of service delivery patterns to minimize these effects.

Dunlap, W. R., & Hollinsworth, J. S. How does a handicapped child affect the family: Implications for practitioners. Family Coordinator, 1977, 26(3), 286-293.

Study of 404 families with a developmentally disabled child to identify problems and stresses created by such children. Includes

families' perceptions of supportive services needed to meet demands of disabled children.

Faerstein, L. M. Stress and coping in families of learning disabled children: A literature review. Journal of Learning Disabilities, 1981©, 14(7), 420-423.

Review of literature on adaptive and maladaptive coping reactions experienced by parents of disabled children.

Farber, B., & Ryckman, D. B. Effects of severely mentally retarded children on family relationships. Family Relations, 1965, 2, 1-17.

Review of research and informal written observations on problems emerging with the presence of a severely mentally retarded child in the family. Summarizes literature on family problems and coping strategies.

Gabel, H., & Kotsch, L. S. Extended families and young handicapped children. Topics in Early Childhood Special Education, 1981©, 1(3), 29-35.

Explores the functional connections between young disabled children and their extended families, especially grandparents. Discusses intervention programs that include extended family components such as the Family, Infant, Toddler Project at Vanderbilt University.

Greenberg, R. Psychiatric aspects of physical disability: Impact on the family. Adolescent Psychiatry, 1979, 7, 281-288.

Analysis of characteristic disturbances of interactions and relationships in families with a disabled adolescent member.

Kogan K. L., & Tyler, N. Mother-child interaction in young physically handicapped children. American Journal of Mental Deficiency, 1973, 77(5), 492-497.

Report on initial phase of an ongoing longitudinal program of direct observation of social interaction patterns between 10 preschool-age physically disabled children and their mothers in play and therapy.

Lucca, J. A., & Settles, B. H. Effects of children's disabilities on parental time-use. Physical Therapy, 1981©, 61(2), 196-201.

Using an interview technique to collect data, researcher's studied the amount of time mothers of disabled children spent in primary physical care of family members and in self-care. Analysis of data from 59 Delaware families revealed, among other things, significant differences in the amount of personal care time available to the primary care giver and the disability classification of the child.

Murphy, A. T. In support of families, Volta Review, 1979, 81(5), 378-384.

Examination of support services and sources available to families of disabled children.

Murphy, A. T. The families of handicapped children: Context for disability. Volta Review, 1979, 81(5), 265-278.

Discussion of family as the context for a child's disability. Aspects of the family of the hearing-impaired child are explored such as the roles of the father and siblings and relationship of mental health to hearing impairment.

Murphy, M. A. The family with a handicapped child: A review of the literature. Journal of Development and Behavioral Pediatrics, 1982, 3(2), 73-82.

Review of literature treating the impact of a disabled child on the family system.

Schell, G. C. The young handicapped child: A family perspective. Topics in Early Childhood Special Education, 1981©, 1(3), 21-27.

Parent of Down's syndrome child discusses three factors particularly influential in parental adjustment: severity of handicap, disability support systems in the family, and external support systems.

Schild, S. The family of the retarded child. In R. Koch and J. C. Dobson (Eds.). The mentally retarded child and his family: A multidisciplinary handbook. New York: Brunner/Mazel, 1971©, 431-442, 504 p.

The chapter examines parental reactions to the identification of mental retardation in the family; the strains on family roles and relationships, and the problems confronting families having a retarded member.

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

Analysis of data from a mail survey questionnaire completed by 330 parents of mentally retarded children. Results indicate how parents' use of personal and professional support networks varies over the life cycle of mentally retarded children.

Tew, B. J., Laurence, K. M., Payne, H., & Rawnsley, K. Marital stability following the birth of a child with spina bifida. British Journal of Psychiatry, 1977, 131, 79-82.

Investigation of the effects of a disabled child's birth on marital relationships. Sample of 142 families of children with neural tube malformation and 56 families of surviving spina bifida children.

University of Florida Rehabilitation Research Institute. The role of the family in rehabilitation. Rehab Brief, 1978, 1(4). (NARIC Call No. 02834)

Reports on research indicating the families of rehabilitation clients may assist in treatment and reinforce client rehabilitative behavior.

Versiys, H. P. Physical rehabilitation and family dynamics. Rehabilitation Literature, 1980, 41(3-4), 58-65.

Examination of relationship between failure in rehabilitation and disordered family dynamics, family alienation, or family collapse under overwhelming stress.

Wikler, L. Chronic stresses of families of mentally retarded children. Family Relations, April 1981, 30, 281-288.

Overview of stresses in families of mentally retarded children. Discussion of chronic stress theory and implications.

Zisserman, L. The modern family and rehabilitation of the handicapped: A macrosociological view. American Journal of Occupational Therapy, 1981e, 35(1), 13-20.

Examination of structural and functional changes in modern families which render them ill-equipped to care for chronically disabled members.

Zucman, E. The family and disability. World Rehabilitation Fund, 1982, 120 p.

Critical analysis of principal currents of foreign thought during the past 10 years on such topics as parental behaviors and child development, effects of disability on family life, and aids to parents of disabled children.

INTERVENTION WITH FAMILY SYSTEMS

Counseling/Social Services

Baruth, L., & Burggraf, M. Counseling parents of exceptional children. Guilford, CN: Special Learning Corp., 1979©, 211 p.

This book is a collection of readings on counseling parents of exceptional children. Part I consists of 11 papers looking at historical and theoretical aspects. Part II contains 26 papers addressing specific exceptionalities including learning disability, mental retardatiton, behavioral disability, speech or sensory disability and orthopedic disability.

Baum, V. Counseling families of deaf children. Journal of Rehabilitation for the Deaf, 1981, 15(1), 16-19.

Suggests framework for counseling including strategies and areas of counselor awareness useful in counseling families with deaf members.

Becker, S. Counseling the families of deaf children: A mental health worker speaks out. Journal of Rehabilitation of the Deaf, 1981, 15(1), 10-15.

Presentation of a variety of approaches to education and upbringing of deaf children and to practical counseling for families of the deaf. Aimed at the audience of inexperienced counselors and parents.

Begab, M. J. Factors in counseling parents of retarded children. American Journal of Mental Deficiency, 1956, 60, 515-524.

Exploration of factors which influence counseling of parents of retarded children, the understanding of which is vital to rehabilitation or adjustment of the retarded child and/or the parents.

Buscaglia, L. The disabled and their parents: A counseling challenge. Thorofare, NJ: Charles B. Slack, Inc., 1975 ©.

Author challenges doctors, psychologists, counselors, educators, physical and occupational therapists, social workers, and psychiatrists to be more cognizant of the need for competent, realistic guidance experienced by disabled persons and their families. Includes bibliography and reading list.

Chinitz, S. P. A sibling group for brothers and sisters of handicapped children. Children Today, 1981, 10(6), 21-23.

Description of a therapeutic group of 7-to-14 year old siblings of disabled children meeting for 8 weeks at the Bronx Center of United Cerebral Palsy.

Christensen, B., & Deblassie, R. R. Counseling with parents of handicapped adolescents. Adolescence, 1980, 15(58), 397-407.

Examination of problems faced by parents of disabled adolescents and role of counseling in helping the parents cope.

Doll, E. A. Counseling parents of severely mentally retarded children. Journal of Clinical Psychology, 1953©, 9, 114-117.

Classic article on counseling parents of mentally retarded children describes typical questions parents ask as well as different professional strategies and attitudes for intervention and care.

Forman, M. A., & Hetznecker, W. The physician and the handicapped child: Dilemmas of care. Journal of the American Medical Association, 1982©, 274(24), 3325-3326.

Commentary of two physicians describing certain "dilemmas of care" faced by the doctor who diagnoses a disabled child, including social and transactional situations which affect the initial and ongoing treatment of child and family.

Green, R. R. Counseling techniques for working with the family of the hearing impaired child. Hearing Rehabilitation Quarterly, 1978, 3(4), 17-20.

Guidelines for counselors who work with parents of hearing-impaired children.

Kaplan, F., & Fox, E. Siblings of the retardate: An adolescent group experience. Community Mental Health Journal, 1968, 4(6), 499-508.

Description of the first phase of a study of adolescent siblings of retarded children. Discussion includes project development, functioning, and technical problems, as well as issues raised in group meetings.

Markel, G., & Greenbaum, J. Assertiveness training for parents of disabled children. Exceptional Parent, 1981, 11(4), 17-22.

Discussion of parental assertivenss as an aid in educational planning for disabled children.

Massenzio, S. The effects of a supportive group experience with mothers of children with severe special needs. American Archives of Rehabilitation Therapy, 1979, 27(1), 1-3.

Study of effects of a support group experience on mothers of severely retarded children in decreasing mothers' loneliness and increasing acceptance of retarded children.

Matheny, A. P., & Vernick, J. Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived. Journal of Pediatrics, 1968, 74, 953-959.

Examination of the effects of an informational educational approach for providing help to parents of retarded children.

Miller, L. G. Toward a greater understanding of the parents of the mentally retarded. Journal of Pediatrics, 1968, 73(5), 699-705.

Recommendations for doctors dealing with diagnosis and family counseling related to mentally disabled children.

Norton, F. H. Counseling parents of the mentally retarded child. School Counselor, 1976, 23(3), 200-205.

Discusses the role of the counselor in understanding parental reactions to mental retardation and in helping families live successfully with their mentally retarded child.

Opirhory, G., & Peters, G. A. Counseling intervention strategies for families with the less than perfect newborn. Personnel & Guidance Journal, 1982©, 60(8), 451-455.

Recommendations for counselors in - or outside hospitals who work with families of children born with birth defects.

Raech, H. A parent discusses initial counseling. Mental Retardation, 1966, 4(2), 25-26.

Comments of a parent of a mentally retarded child on the importance of skillful professional handling of initial counseling.

Rubin, A. L., & Rubin, R. L. The effects of physician counseling technique on parent reactions to mental retardation diagnosis. Child Psychiatry and Human Development, 1980, 10(4), 213-221.

Study of the effects of physician counseling techniques on parent reactions to diagnosis of mental retardation. Interviews with 26 mothers of mentally retarded children helped identify circumstances and counseling techniques that parents considered most influential.

Sweeney, A. Genetic counseling in families with hearing impairment. Journal of Rehabilitation of the Deaf, 1978, 12(1), 1-11.

This article was written to enlighten professionals working with deaf children about Mendelian laws of inheritance and the principles of genetic counseling. It presents a brief history of early research into deafness and heredity, modes of inheritance, well known syndromes and aspects of genetic counseling.

Tavormina, J. B. Relative effectiveness of behavioral and reflective group counseling with parents of mentally retarded children. Journal of Consulting and Clinical Psychology, 1975©, 43(1), 22-31.

Comparison of the effectiveness of behavioral and reflective group counseling for parents of mentally retarded children. Focus on teaching parents how to apply principles of learning theory to child-rearing problems.

Webster, E. J. Counseling with parents of handicapped children: Guidelines for improving communication. New York: Grune and Stratton, 1977 ©.

A variety of counseling approaches and methodologies for training counseling students or improving counseling practice.

Webster, E. J. Parent counseling by speech pathologists and audiologists. Journal of Speech and Hearing Disorders, 1966©, 31(4).

An approach to counseling parents of children with communication disorders is presented with guidelines for implementation by groups of parents.

Webster, E. J. Procedures for group parent counseling in speech pathology and audiology. Journal of Speech and Hearing Disorders, 1968©, 33(2), 127-131.

Suggestions for clinical use of group discussion and role-playing with parents of persons with speech and hearing disabilities.

Weingold, J. T. Parents' groups and the problem of mental retardation. American Journal of Mental Deficiency, January 1952, 56, 484-492.

Discussion of the phenomenon of parent group formation to share experience and cope with their mentally retarded children. Issues, obstacles, and goals are examined.

Weingold, J. T., & Hormuth, R. P. Group guidance of parents of mentally retarded children. Journal of Clinical Psychology, 1953©, 9, 118-124.

Discusses need for group guidance of parents of mentally retarded children. Child and family are seen as part of the community in which attitudes of acceptance may lead to success in life achievement.

Wolfensberger, W., & Kurtz, R. Management of the family of the mentally retarded. Chicago: Follet Educational Corporation, 1969©.

Comprehensive compilation of 120 articles written by professionals who work with families and individuals affected by mental retardation. Intended to improve management skills of those working with families of retarded individuals, to orient students or workers to pertinent insights into successful management techniques, and to provide a sense of history and continuity through this presentation of literature.

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Involvement in Child'S Education

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