LIBERTY BAPTIST THEOLOGICAL SEMINARY

MINISTRY TO FAMILIES OF HANDICAPPED CHILDREN

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By

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LIBERTY BAPTIST THEOLOGICAL SEMINARY

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ABSTRACT

MINISTRY TO FAMILIES OF HANDICAPPED CHILDREN

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Public attention has been drawn to the presence and needs of handicapped members of society. Little attention, however, has been given by the institutions of society, beginning with organized religion, to the families of the handicapped, the caregivers, and their special needs. This project is directed to the clergy and consists of two parts. The first is a seminar for clergy, to inform and sensitize them to said families. The second is a model forum with which the clergy will be equipped, in turn, to inform, sensitize, and prompt congregational members toward appropriate outreach in this specialized ministry.

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INTRODUCTION

Remarking on public social policy and its impact on the families of handicapped children, Moroney said:

> Over the past 25 years, little emphasis has been given to the development of those services that attempt to support the family as opposed to services that focus on individuals or services that substitute for the family.[1]

This is, in brief, the rationale for this project. As in secular society the families of the handicapped have been by-passed in receiving the services they need, so also in organized religion. The typical local congregation gives little attention to the handicapped and virtually none to their families. The handicapped themselves constitute at least a tenth of the population of society. Add families to their population and one can immediately visualize a highly significant segment of society which is largely overlooked in the church's outreach.

As a personal reflection, the thrust of the thesis grows out of the writer's own experience. For much of his childhood, he lived in a "handicapped family" (the term to be defined below). He lived with the blind, the deaf, the wheelchair-bound, some of whom were relatives and some of whom were residents in his parents' nursing home. As an adult, handicapping came even closer when one of the writer's children was diagnosed as

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[1] Robert M. Moroney, "Public Social Policy: Impact on Families with Handicapped Children," in Understanding and Working with Parents of Children with Special Needs, ed. James L. Paul (New York: Holt, Rinehart and Winston, 1981), 192.

hearing impaired. The writer experienced the range of reactions from shock and denial to acceptance, typical at such times.

While in internship with a Lutheran seminary, the writer was assigned to ministry with the handicapped. Following ordination, most of his work was with either the handicapped or the disadvantaged, a coincidence of an importance brought out in the body of the text and in the seminar. During the late 1950's and early 1960's, he was involved in the racial integration of the church. During the 1970's, he served the handicapped in the metropolitan area of Chicago, furthering their being mainstreamed in congregations of the region. Besides the goal of mainstreaming, his emphasis in the church-at-large was to minister to the needs of the total family of the handicapped. For a period of time in the 1980's, he left full-time ministry and was engaged as a QMRP (qualified mental retardation professional). In early 1993, the writer was called to serve in the Lynchburg, Virginia community where opportunities have presented themselves to be involved, and to engage his members in ministry to the handicapped and to their families.

The project is designed to inform and alert the decision makers of local churches, especially the clergy, to the magnitude of the handicapped population and the even greater size of their families. The writer wishes to let them know of those families' existence in the community and of their needs in coping with their burdens, and to suggest services which can be rendered in behalf of the families.

The approach is in a seminar format. The presentation is divided into four segments: the impact of having a handicapped child, biblical references to the handicapped, the question of suffering, and ways in which the local congregation can minister to families of the handicapped. The writer recruited parents of the handicapped, various professionals working with the handicapped, and pastors to serve as a test group. They were asked to critique the presentation for its validity, its relevance, and its potential for helping churches engage in effective ministry to both the handicapped and their families. The seminar was then "field tested," as it were, by a presentation to the monthly conference of Lutheran pastors in central Virginia.

Review of the Literature

The project faces two principal problems relating to literature. Although significant works were written prior to 1975, notably by persons like Farber, the passage of the education bill for the handicapped (PL 94-142) drastically changed the family situation and the literature. The state institutions for the handicapped were largely emptied and parents and siblings were challenged to live with and care for handicapped members. The second problem is that little has been published relating to organized religion and ministry to "the handicapped family." Insights for pastoral counseling are therefore largely dependent upon extrapolation from secular sources.

In the interest of further exploration, the writer includes a list of several works for "Suggested Reading" following major divisions in the body of the thesis. They are drawn from these areas: general information on handicaps, special education, practical handbooks for parents and non-technical participants, family life, counseling, and pastoral care. The lists are not exhaustive. Additional publications, however, are included in the bibliography.

Practical Application of the Project

The local church which is aware of the opportunity for ministry to families of the handicapped faces the same challenges secular agencies face in the community, as indicated above. The members need knowledge of the problem and the need. They need to share a value system which responds to the needs of the handicapped family. They need some form of resources in order to operate a program. They need commitment to the program. They need to be prepared for failure, should initial efforts be inappropriate, with the determination to reexamine and try again.

The practical application of the project is twofold: a seminar for clergy and an ensuing forum for their lay members. The seminar text covers four areas vital for clergy to know: the impact of having a handicapped child, what the Bible says about the handicapped, analysis of why crises enter our lives, and what the church can do in ministry to these families. It includes a booklist for further research by the pastors. The forum provides a background on the categories of handicaps and insights on family life as the non-handicapped relate to the handicapped member. It suggests ways in which the local congregation can engage in practical ministries. It includes a glossary of terms and a list of agencies and organizations through which further assistance and information are available on and for the handicapped and their families on the community, state and national levels.

Limitations of the Project and Thesis

The project and thesis do not consist of a survey. There are no identifiable populations to be compared, as would normally be the case in an empirical research project.

The topic refers to the handicapped, but more specifically to their families, not to the handicapped themselves. The objective is twofold: to contribute to making clergy aware of the families and to sensitizing them and, through them, their church members, to the families' needs for ministry.

Previous research has referred to topics of a spiritual nature. A distinction, however, has not always clearly been made between religion as a personal experience and organized religion. The project tries to avoid drawing false conclusions from the wrong item.

Contacts by local congregations with the handicapped are usually with adults. This project and thesis deal with families. In most instances, the handicapped to which we refer are children rather than adults, and children who reside with their families. Some handicapped church members may be institutionalized. This material does not cover such special forms of ministry, although pastors need to be sensitive to the inner turmoil of those parents, as well, whose children are so placed.

Because this focuses on the families, no effort is made to suggest materials for religious instruction of the handicapped. Each denomination has its own resources for such specialized teaching.

As was mentioned in the overview of literature, relatively little has been written on ministry to the families of the handicapped. Much has been written about the parents, siblings, and even the extended family, all of which is vital for pastoral care and understanding, but very little of substance has been written on the spiritual aspects of the parents' circumstances. Much has been written about each handicap, and about the care, education, and employment of the handicapped, but application of the information to pastoral care is mostly by inference.

Perhaps the most significant development in society's dealing with the handicapped and their families came about through legislation--P.L. 94-142, passed in 1975. With that, all the handicapped children were guaranteed education appropriate for their needs. The law compelled the education establishment to deliberately involve the parents as part of planning for their children's special education. In many ways, it was truly revolutionary. It also changed what had been taught and accepted in the care of the handicapped and their families prior to 1975. Many good works written before that date will indeed continue to be of great value, but, for the most part, the writer has looked at those writings published after 1975.

The families of the handicapped are faced with crises. That calls for a meaningful form of pastoral counseling, but, unless the pastors called upon are trained in counseling, there is little more that they can do than to be supportive and to furnish practical information useful to the families at such times. This project and thesis, therefore, do not suggest ways in which in-depth counseling ought to be carried out.

This work does not suggest that it contains all the steps needed in establishing an effective ministry to families of the handicapped. It will hopefully lead to informing and sensitizing clergy about the needs experienced by such families, and will outline programs for that purpose and for advocacy in the congregations. Each congregation is unique. The pastor who is moved to draw his people into such ministry will necessarily tailor it to their collective temperament and to their resources.

The emphases contained in this work are directed toward an impact on the clergy, but they are not intended to produce clerical experts in the field. Rather, they look toward the future and urge the pastors to engage their people in such ways that, after the pastors may leave their positions, the work among families of the handicapped will go on.

CHAPTER 1

BACKGROUND TO THE PROJECT

Statement of the Problem

In 1982, it was reported that yearly 3.4 million children are born in the United States, of whom a third had an impairment or disabling condition.[2] At about that time, the National Advisory Committee on the Handicapped reported 12 percent of the child population to be handicapped.[3] As for etiology, every fifth handicapped child inherits defects from the parents, an equal portion suffer prenatal environmental effects, and the majority suffer from an interaction of heredity and environment,[4] of whom only 1 percent are institutionalized.[5] Lists of disabilities vary. Within this paper, handicapping conditions are those defined by and listed in the 1990 P.L. 101-476, Individuals with Disabilities Education Act (IDEA): autism, deafness, deaf-blindness, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, serious

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[2] Robert L. Marion, "The Mentally Retarded Child in the Family," in The Handbook of Family School Intervention: A Systems Perspective, ed. Marvin J. Fine and Cindy Carlson (Boston: Allyn and Bacon, 1992), 134.

[3] Colleen J. Mandell and Edward Fiscus, Understanding Exceptional People (New York: West, 1981), 5.

[4] Bonnie Wheeler, Challenged Parenting: A Practical Handbook for Parents of Children with Handicaps (Ventura, CA: Regal Books), 27.

[5] Moroney, "Public," 193.

emotional disturbance, specific learning disability, speech or language impairment, traumatic brain injury, visual impairment including blindness. "Other health impairment" is limited strength, vitality or alertness due to chronic or acute problems, such as a heart condition, etc. Since 1991, ADD (attention deficit disorder) has been included in this classification. "Serious emotional disturbance" would seem to best describe the hyperactive child (ADHD), but the Department of Education places him in the "other health impairment" category.[6]

The American system is unique; in two-thirds of the world, no special medical or educational facilities are available for the disabled.[7] The focus of this paper, however, is on the families of the handicapped. Advocacy in behalf of the disabled child's interests have met with significant success; services for the parents have been slow in developing.[8] Little emphasis has been given to serve the needs of the total family of the handicapped child.[9]

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[6] NICHCY, "Disabilities Which Qualify Children and Youth for Special Education Services Under the Individuals with Disabilities Education Act (IDEA)," News Digest 14 (October 1993).

[7] Leo Buscaglia, The Disabled and Their Parents: A Counseling Challenge (Thorofare, NJ: Charles B. Slack, 1975), 171.

[8] James L. Paul and Patricia B. Porter, "Parents of Handicapped Children," in Understanding and Working with Parents of Children with Special Needs, ed. James L. Paul (New York: Holt, Rinehart and Winston, 1981), 19.

[9] Moroney, "Public," 192.

Families of the Handicapped

The phases through which parents of newly-identified handicapped children go have been likened to those of patients facing the reality of their terminal illness. The first, or primary, is the experience of shock, denial, grief, and depression. The secondary phase includes ambivalence, guilt, anger, and shame and embarrassment. The tertiary phase involves efforts at bargaining, adaptation and reorganization, and acceptance and adjustment.[10]

Parents may understand their child's handicap intellectually, but seldom are they able to accept it emotionally.[11] Furthermore, parental grief referred to above is dissimilar to that suffered, for example, at the death of a loved one. Rather, it is chronic, recurring periodically throughout the years of caregiving--parents never stop grieving.[12] Kew has said that they have been labelled "the handicapped family."[13] To be sure, some families weather the problems well; other families suffer in every segment of family life--the state of the parents' marital life, the place of the siblings, the relation of the extended family.[14]

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[10] Richard M. Gargiulo, Working with Parents of Exceptional Children (Boston: Houghton Mifflin, 1985), 22-30.

[11] Harold D. Love, Parental Attitudes toward Exceptional Children (New York: Charles C. Thomas, 1970), 37.

[12] Barbara Hillyer Davis, "Disability and Grief," Social Casework 68 (June 1987): 352-357; Marianne Spain Kratochvil and Sally Anne Devereux, "Counseling Needs of Parents of Handicapped Children," Social Casework 69 (September 1988): 420-426.

[13] Stephen Kew, Handicap and Family Crisis: A Study of the Siblings of Handicapped Children (New York: Pitman, 1975), 157.

[14] Rosalyn Benjamin Darling, "The Economic and Psychosocial Consequences of Disability: Family-Society Relationships," in Childhood Disability and Family Systems, ed.

(continued...)

Kew also said that it is no exaggeration to say of "the handicapped family" that its very foundation as a social unit is threatened.[15] That condition has been described in several ways. It is isolated,[16] it is highly vulnerable,[17] and it fights the two enemies of fatigue and loneliness.[18] When these families openly reflect on the disabilities of their children, they are heard to talk about four things: their family, their own unhappiness, professionals, and the road to recovery.[19] Many special-needs children are raised by single parents, usually mothers. The needs of these women, struggling alone, are especially burdensome, striving to satisfy respite, security, and social needs.[20]

Although services for parents and other members of "the handicapped family" have been slow in developing, even those offered have not always been welcomed as readily as

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[14] (...continued)
Michael Ferrari and Marvin B. Sussman (New York: Haworth Press, 1987), 53; Bernard Farber, writing in 1959, laid the foundation for the study of the handicapped family: "Effects of a Severely Mentally Retarded Child on Family Integration," Monographs of the Society for Research in Child Development, No. 71 (1959).

[15] Kew, Handicap, 54.

[16] Dorothy Jeffree and Sally Cheseldine, "Working with Parents of Adolescents: The Work of the Path Project," in Parents, Professionals and Mentally Handicapped People, ed. Peter Mittler and Helen McConachie (Cambridge, MA: Brookline Books, 1983), 181.

[17] Jeffree and Cheseldine, "Working with Parents," 109.

[18] Jeffree and Cheseldine, "Working with Parents," 144.

[19] Helen Featherstone, A Difference in the Family: Living with a Disabled Child (New York: Penguin Books, 1980), 10.

[20] Penny L. Deiner, "Systems of Care for Disabled Children and Family Members: New Paradigms and Alternatives," in Childhood Disability and Family Systems, ed. Michael Ferrari and Marvin B. Sussman (New York: Haworth Press, 1987), 208-209.

might be expected. Interestingly, even the personalities of the parents may be dominant factors in the selection of the kind of treatment their children will receive, programs selected to be in congruence with their own needs.[21] Groups formed for the parents' benefit are an example. Mori observed:

> Frequently, professionals are disappointed in parent participation in formalized groups. Parents may resist participation because they are not yet ready to listen to others' problems, because they feel their needs are already being met by the professional, or because they do not realize the benefits that sharing may afford.[22]

Research on families of the handicapped is by no means complete. Studies are still needed on the role of the father[23] and on the impact of the handicapped member of his or her siblings.[24]

Professionals

It was noted above that one of the frequent topics of conversation by parents of the handicapped is about professionals. The delivery of professional services in included in legislation about the handicapped. Thirteen, listed as follows, may be required by students with disabilities in order to benefit from special education. They include the fields of audiology, occupational therapy, physical therapy, psychological services, medical services

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[21] Alan O. Ross, The Exceptional Child in the Family: Helping Parents of Exceptional Children (New York: Grune and Stratton, 1964), 66.

[22] Allen A. Mori, Families of Children with Special Needs: Early Intervention Techniques for the Practitioner (Rockville, MD: Aspen Systems Corporation, 1983), 217.

[23] Helen McConachie, "Fathers, Mothers, Siblings: How Do They See Themselves?" in Parents, Professionals and Mentally Handicapped People, ed. Peter Mittler and Helen McConachie (Cambridge, MA: Brookline Books, 1983), 128-129.

[24] Kew, Handicap, 9.

for diagnostic or evaluation purposes only, school health services, transportation services, counseling services, speech-language pathology, social work services, parent counseling and training, recreation therapy, and early identification and assessment of disabilities in children.[25]

The relationship of parents and professionals is, of course, extremely vital and important. The very ability to cope and become mobilized to meet the many challenges is often determined by the revelation of the child's problem, combined with the quality of support and guidance available at that time.[26] The severity of the crisis, unfortunately, is in inverse order to the search for help by the parents--the more "crisis-laden" the child and the family, the less likely help will be found.[27]

Ross has noted that felt needs for professional assistance vary. The needs of the child vary with time, and the needs of parents vary, as well. The types of assistance are diverse--some need information and advice, a few want supportive counseling, and yet a few need personal psychotherapy. Ross also observed that the milder the disability, the greater the difficulty on the part of parents to accept the problem.[28] The goals in

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[25] NICHCY, "Related Services for School-Aged Children with 13 Disabilities," News Digest 1 (1991) 1-19.

[26] Albert T. Murphy, "Parent Counseling and Exceptionality: From Creative Insecurity toward Increased Humanness," in Professional Approaches with Parents of Handicapped Children, ed. Elizabeth J. Webster (Springfield, IL: Charles C. Thomas, 1976), 32.

[27] Milton Seligman, Strategies for Helping Parents of Exceptional Children: A Guide for Teachers (New York: The Free Press, 1979), 75.

[28] Ross, Exceptional, 72, 82, 126.

counseling, then, are to first see the child as a child, and the disability second. Counseling attempts to develop the parent's potential together rather than apart.[29]

Stewart offers the following description of counseling:

> Counseling is a helping relationship between a knowledgeable professional and parents of an exceptional child, working toward a better understanding of their unique concerns, problems, or feelings. It is a learning process focusing upon the stimulation and encouragement of personal growth by which parents are assisted in acquiring, developing, and utilizing the skills and attitudes necessary for a satisfactory resolution to their problem or concern. Parents are helped toward becoming fully functioning individuals who are assets to their child and value harmonious living as members of a well-adjusted family unit.[30]

The recurring lament expressed by parents is the fragmented service received from the professionals; no one lends overall guidance to the variety of programs engaged. Often, that responsibility is relegated to that "someone else."[31] Articulate parents have chided professionals for their manner, and would encourage the professionals to be more humble and to show parents respect. Professionals are urged to learn practical helps for parents and to recognize that a partnership with parents is essential. They ought especially to understand that the handicapped child needs personal relationships outside the family.[32] These words are fitting advice for physicians, teachers, and social workers, as well as counselors.

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[29] Buscaglia, Disabled, 277-278.

[30] Jack C. Stewart, Counseling Parents of Exceptional Children (Columbus, OH: Charles E. Merrill, 1978), 22-23.

[31] Gary Best, Individuals with Physical Disabilities: An Introduction for Educators (St. Louis: C. V. Mosby, 1978), 75.

[32] A. P. Turnbull, "From Professional to Parent: A Startling Experience," in Parents Speak Out: Then and Now, ed. H. R. Turnbull III and A. P. Turnbull (Columbus, OH: Charles E. Merrill, 1985), 131-135.

Organized Religion and the Handicapped

As noted above, 12 percent of the children in the United States have handicapping conditions. On an average, however, a local church has only one or two handicapped members.[33] Suggested reasons for this vary. It may be that attitudes which prevail in society, inspite of its advances, are still prejudicial. Only recently has the notion been modified that parents are to blame for their children's handicaps.[34] It has also been suggested that the handicapped suffer prejudice similar to that which is racially-based.[35] Parents who sense such attitudes in church members are understandably less inclined to be active in church.

The problem is more complex than bias. The spiritual reactions of parents of the handicapped to the crisis have tended to fall into one of the following three categories. Some simply accept it as the will of God and some believe it is a punishment from God.

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[33] J. R. Ball, "Pastoral Help for Families of Handicapped Children," in Understanding and Working with Parents of Children with Special Needs, ed. James L. Paul (New York: Holt, Rinehart and Winston, 1983) 135.

[34] Paul, Understanding, 6.

[35] John Gliedman and William Roth, The Unexpected Minority: Handicapped Children in America (New York: Harcourt Brace Jovannovich, 1986), 22; Frank Warren and Sandra Hopfengardner Warren, "The role of Parents in Creating and Maintaining Quality Family Support Services," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes, 1989), 60; Seymour R. Sarason and John Doris, Educational Handicap, Public Policy, and Social History: A Broadened Perspective on Mental Retardation (New York: The Free Press, 1979), 357.

Some react with anger at a divine force which would do such a thing.[36] A study of Roman Catholic mothers revealed that many of that faith accepted the handicap of their children better than those whose church bodies encouraged a searching self-examination to explain circumstances and events.[37] Another study made a distinction between religious beliefs and formal ties to religion--the subjects found help in their personal faith, but little from the organized religious bodies to which they belonged.[38]

Religious parents have been found to experience a greater struggle than the non-religious, also risking a cut-off from the sustaining power of religious faith needed in times of crisis.[39] "Tension is a prime characteristic of families with children who have an impairment," according to Ikeler, who went on to classify the half-dozen forms their stress takes. There are the bereaved, the stigmatized and isolated, the self-stigmatized, guilt-laden, and weak, the "stuck-together-family," the stress of a myriad of practical issues, and the theodic crisis.[40]

The theodic category, Ikeler said, can be a key factor in the psychological health of the disabled family. A principal role to be played by the pastor of the spiritually intense

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[36] Raymond Schmitt, "Religious Views of Parents of Retarded Children," Journal of Religion and Health 17 (1978), 80-87.

[37] G. H. Zuk, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," American Journal of Mental Deficiency 64 (1959): 145.

[38] Rachel R. Fewell, "Supports from Religious Organizations and Personal Beliefs," in Families of Handicapped Children: Needs and Supports Across the Life Span, ed. Rachel R. Fewell and Patricia F. Vadasy (Austin: PRO-ED, 1986), 297-316.

[39] Featherstone, Difference, 34.

[40] Bernard Ikeler, Parenting Your Disabled Child (Philadelphia: Westminster, 1986), 234, 240.

family is to provide satisfactory answers to the question "Why?"--why bad things happen to good people.[41] As has been observed, the American culture persists in maintaining the myth that everything has a happy ending; the birth of a handicapped child challenges that notion, often to the confusion and frustration of the parents.[42] Religion can play an important role for parents in such circumstances. Even social workers in secular agencies have begun to give serious consideration to the place of spiritual values in the resolution of the crises of life.[43]

Church Programs and the Handicapped

What can the local congregation and the pastor of the church do in response to the needs of "the handicapped family"? It has been said that parents want the church to be in contact with them at the time of the birth of their children--in a time of crisis, they may need counseling and they may need information on services in the community available to them and their handicapped children.[44] Hartbauer says, "The pastor's role is largely one of listening."[45] Ferguson and Heifetz would add, "For all families, a pastoral willingness to

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[41] Vera Steiner and Dan Steiner, "Developing Personhood," in Celebrating Differences, ed. Aldred H. Neufeldt (Newton, KS: Faith and Life, 1984), 72.

[42] Mori, Families, 24.

[43] Edward R. Canda, "Spirituality, Religious Diversity, and Social Work Practice," Social Casework 69 (1988): 238-247; M. Vincentia Joseph, "Religion and Social Work Practice," Social Casework 69 (1988): 443-452.

[44] Ball, "Pastoral," 145; Philip M. Ferguson and Louis J. Heifetz, "An Absence of Offering: Parents of Retarded Children and Their Experiences with the Clergy," Pastor Psychology 32 (Fall, 1983): 49-57.

[45] Roy E. Hartbauer, "Understanding the Pastor's Role in Ministering to the

(continued...)

share their suffering was perceived as crucial, whether they had received it or not."[46] Yet, many parents never think of contacting a pastor.[47]

The church has nonetheless been referred to as the organization best suited for the advocacy needed by the handicapped and their families, for the reordering of the whole interrelationship of handicapped children, their families, and society at large.[48] To engage in meaningful ministry in this specialized area, churches, like secular agencies, must weigh risks and costs involved. Participants need to share four qualities: knowledge, shared values, resources, commitment, and the readiness to fail and try again.[49]

As an organization, the local church sensitive to the presence and needs of the handicapped and their families will provide ways in which the handicapped can participate in worship, religious education, and parish fellowship. This paper is concerned about the non-handicapped family members. Most obvious to those familiar with the problems of family life with the handicapped is the need for respite. The local church can provide this,

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[45](...continued)
Handicapped," in Pastoral Care of the Handicapped, ed. Roy E. Hartbauer (Berrien Springs, MI: Andrews University, 1983), 6.

[46] Ferguson and Heifetz, "Absence," 52.

[47] Sigurd D. Peterson, "The Pastoral Care of Parents of Mentally Retarded Persons," Pastoral Psychology 13 (September, 1962): 37-44.

[48] Gloria Durka, "A Neglected Ministry: Special-needs Children and Their Families," in Family Ministry, ed. Gloria Durka and Joanmarie Smith (Oak Grove, MN: Winston Press, 1980), 92.

[49] David Rostetter and James L. Hamilton, "Risk Factors Beyond the Child and Family," in Finding and Educating High-risk and Handicapped Infants, ed. Craig T. Ramey and Pascal L. Trohanis (Baltimore: University Park Press, 1982), 244-247.

oftentimes in cooperation with secular agencies.[50] Groups for parents can also be organized to share experiences, gain information, get relief from loneliness, gain a true and balanced perspective, realize strength in numbers, be comforted.[51]

The central figure in any form of church activity is the pastor. Most, however, are no more aware of the presence and needs of the handicapped in the community than are their members. The one or two families with handicapped members, it is safe to say, are atypical of the "handicapped families." Most are not in church. Pastors who are in positions of advocacy tend to have the personal experience of being in "handicapped families" themselves, their own or those in which they were raised.[52] Without the insights that come from training or experience, it is important that pastors examine themselves and be clear about their own value judgments relating to the handicapped and their families before offering life-shaping and long-term counsel.[53]

The practical application of this work, therefore, is to provide not only information about the problems with which parents of the handicapped must cope, the services which are already provided in society for their benefit, but also practical programs and materials with which church leaders can address the needs in the local church.

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[50] Bill Gaventa, "Respite Care: An Opportunity for the Religious Community," Exceptional Parent 20 (1990): 22-26.

[51] Wheeler, Challenged, 69.

[52] Dorothy Garst Murray, "A Parent Speaks to Pastors on Mental Retardation," Pastoral Psychology 13 (September, 1962): 23-30.

[53] Donald C. Houts, "Pastoral Management of Predictable Birth Anomalies," Journal of Religion and Health 13 (1974): 107-113.

CHAPTER 2

MAJOR HANDICAPS PARENTS ENCOUNTER

"Handicapped" or "Disabled"?

For the most part, the terms, "handicapped" and "disabled," are used interchangeably in the text. One must be sensitive, however, to the fine distinction which can be, and often is, made. A disability is a condition, whatever its origin, which is not normal. When that condition, or disability, interferes with normal concourse in life's activities, it becomes a handicap. To say that either disability or handicap is "relative" or "in the mind" is to ignore reality. Disabilities exist in the population which distinguish the victims from the majority and prevent normal activity either alone or with others. The writer uses them synonymously because where there is a handicap there is a disability as its cause. Where there is a disability it potentially becomes a handicap in one or another aspect of life.

Select Categories of Handicaps

Hartbauer provides a broad division of three groups for us: skeleto-muscular anomalies, sensory deprivation, and mental-emotional problems. The skeleto-muscular group is most easily identified. The person's structure would be abnormal, his or her functioning or paralysis would be abnormal, or parts of the body may be lost by surgery, accident, or from congenital factors. An observable physical impairment would be cerebral palsy. Deafness and blindness are sensory deprivations. Hartbauer uses mental and emotional problems as his third group, manifested by disorientation or an inability to cope with life. The third group is broad, but this writer would use it for those several mental disorders parents and clergy may frequently encounter. Such disorders include learning disorders (LD), attention deficit disorder/ attention deficit hyperactive disorder (ADD/ADHD), and then mental retardation (MR).[54]

DSM-IV Definitions

With the exception of hearing impairment, the other handicaps to be considered in this paper are included in the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association,[55] with the exception of hearing impairment. Mental disorders may accompany, or even be an outgrowth of, hearing impairment, but the handicap itself does not originate as a mental disorder.

Learning Disorder

Approximately 5 percent of the public school population in the United States is identified as having LD, between 60 and 80 percent of whom of male. Symptoms manifest themselves in difficulties with mathematics, reading, and writing. Identification of LD must consider other possible influences, such as the child's ethnic or cultural background. With the passage of time, the child with LD will probably reveal demoralization, a low

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[54] Roy E. Hartbauer, "Preface," in Pastoral Care of the Handicapped, ed. Roy E. Hartbauer (Berrien Springs, MI: Andrews University Press, 1983), xi-xv.

[55] Diagnostic and Statistical Manual of Mental Disorders, 4th ed. 4th ed. (Washington, D.C.: American Psychiatric Association, 1994).

self-esteem, and deficits in his or her social skills. The school drop-out rate is 40 percent, 1.5 times the average. LD may also be found in children with ADHD, and also in children with Conduct Disorder, Oppositional Defiant Disorder, Major Depressive Disorder, or Dysthymic Disorder. The origin of LD is difficult to trace, but it has been found in those suffering from lead poisoning, fetal alcohol Syndrome, or with the fragile X syndrome.[56]

Attention-Deficit/Hyperactivity Disorder

ADHD children reveal their disorder at home or in school, and usually before the age of 7. The prevalence of the disorder is estimated to be from 3 to 5 percent of the school-age population. The essential features are persistent inattention and/or hyperactivity-impulsivity that exceed the same behavior in the normal population. Hyperactivity shows itself by fidgetiness, impulsivity, by impatience. The nature of the disorder is such that a variety of types are grouped under the label of ADHD. Not only is the child's academic performance impaired, but his or her social skills are inappropriate, as well. The DSM says, of the family,

> Family relationships are often characterized by resentment and antagonism, especially because variability in the individual's symptomatic status often leads parents to believe that all the troublesome behavior is willful.[57]

Fathers and mothers react to their ADHD children differently. Often, the mother carries the burden because she spends more time with the child. The father has fewer difficulties

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[56] DSM-IV, 47-51.

[57] DSM-IV. 81.

because he escapes the need for constant parental supervision. As Barkley said, "It is not uncommon to see problems in the marital relationship develop out of these discrepancies in child behavior toward each parent."[58] Similar to children with LD, ADHD children may have Oppositional Defiant Disorder or Conduct Disorder. They also struggle with mood swings, anxiety, and problems with learning and communication. It is therefore not surprising that a significant percentage of ADHD children fall into antisocial, even criminal, behavior as adults.[59]

Mental Retardation

Approximately one percent of the population is mentally retarded, although the percentage estimate varies with definitions used. To be diagnosed as MR, the onset must occur before the age of 18. If the condition is mild, it may escape diagnosis until later in the child's life. Other more severe forms, such as Down's syndrome, would be discovered at an early age. Borderline MR is generally in the IQ range of 71-84. Some mild conditions canbe improved and even overcome through appropriate training and favorable environmental opportunities. The code commonly used for the degree of MR is as follows:

Mild Mental Retardation: IQ level 50-55 to approximately 70
Moderate Mental Retardation: IQ level 35-40 to 50-55
Severe Mental Retardation: IQ level 20-25 to 35-40
Profound Mental Retardation: IQ level below 20 or 25[60]

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[58] Russell A. Barkley, Attention-Deficit Hyperactivity Disorder: A Handbook for Diagnosis and Treatment (New York: The Guilford Press, 1990), 141.

[59] Barkley, Attention-Deficit, 124-125.

[60] DSM-IV, 78-94.

Persons in the last three categories require outside care, whereas those in the mild classification can, with help, engage in community living.[61]

Hearing Impairedness

Causes of deafness at birth may be genetic (inherited) or because of maternal disease, such as rubella. Generally, 50 to 60 percent of all deafness is attributed to genetic factors, carried by a recessive gene. Although parents tend to resist the notion that their child's deafness is of genetic origin, there is compensation, however small, that a child with such an etiology tends to perform better in academic pursuits, to have a slightly higher IQ than deaf children generally have, and to be free of other defects suffered by children who are deaf from nongenetic causes. In today's American society, a significant portion of the adult deaf population were victims of the 1963-1965 rubella epidemic. The percentage of deaf rubella babies, which is usually about 10 percent, jumped to between 40 and 80 percent during the epidemic. Two other causes of deafness have been identified. One is premature birth, 17 percent of deaf school-age children falling into that category. The second is blood type incompatibility between the child and its mother (especially with complications of the Rh factor). Later diseases causing deafness in children are meningitis (accounting for a tenth of deafness in children) and encephalitis. As for categories of deafness, they are measured in decibel units (dB). Although there is considerable variability, 10 to 25 dB loss is normal. With 25 to 40 dB loss, the deafness is only slight, becoming mild-to-moderate with 40 to 55 dB. The latter understands conversational speech within a short range of a few feet. Moderately severe deafness occurs with the loss

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[61] DSM-IV, 39-46.

of 55 to 77 dB, and severe loss at 70 to 90 dB makes normal conversation impossible. Profound loss is over 90 dB. Communication, however, and subsequent learning, will vary with the individual child. A gifted child with profound loss may function as nearly hearing, while another with substantial hearing may not be able to process the communication sufficiently to function beyond that associated with profound deafness and its limitation.[62]

Handicaps Evoke Varying Parental Reactions

Mild handicaps are often the most difficult for the parents to accept. They always hold out hope for a cure or a remedial change. Moderate handicaps are often the most taxing on individuals in the family and on the family as a unit. Severe handicaps evoke differing reponses from the parents. Those who are aware of the severity may be factual and seek objective information. If awareness is only partial, the parents may cling to fearful hope for change. Those parents who know the least may deny the reality of the situation and even try to place the blame on others.[63]

Parents and Learning Disorder

Kronick observed that few parents of LD children comprehend the disability, a disorganization of processing, planning, and execution of events, and few are clear about its treatment.[64] LD tends to be a greater disappointment for fathers than for

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[62] Eugene Mindel and McCay Vernon, They Grow in Silence: The Deaf Child and His Family (Silver Spring, MD: National Association of the Deaf, 1977), 25-38.

[63] Stewart, Counseling, 89-120; Alan O. Ross, Exceptional, 124.

[64] Doreen Kronick, Social Development of Learning Disabled Persons (Washington, D.C.: Jossey-Bass Publishers, 1981), 196.

mothers--children are extensions of fathers. Their egos are fed when pushing their children into intellectual pursuits. Even in the task of reading, fathers of LD children have demonstrated directive, domineering, and intrusive behavior. Mothers, on the other hand, are more supportive.[65]

Parents and Mental Retardation

Of the children born in the United States each year, a third have some impairment or disability. Each week, about 2,100 infants are born who are, or will become, mentally retarded.[66] The incidence is not so low that most of the population is not aware of it. Yet, social distance develops between the community and families with MR children. As Marion described,

> Their loneliness will be manifested not only within the family circle but also without. Visiting patterns are visibly affected since not only do parents make less visits outside the home but fewer friends visit homes of parents with mentally retarded children.[67]

That author encouraged therapists to in-turn encourage such families to maintain outside contacts, especially with support groups. Love observed, however, that the greatest obstacle to parenting a mentally retarded child is "the psychological threat to the parent," who feels he or she is a failure.[68]

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[65] Kronick, <u>Social Development</u>, 41-45.

[66] Marion, "Mentally," 134.

[67] Marion, "Mentally," 141.

[68] Love, Harold D., <u>Parental</u>, 41.

Parents and Hearing Impairment

A difference has been noted in the manner in which parents react to having a retarded child or having one with sensory loss, deafness or blindness. Generally, society can give empathy when a child is without hearing or sight, but not when he or she is mentally defective. This is somewhat ironic because retardation has been subjected to the most extensive study, according to Ross.[69] Nonetheless, Love maintains that parents of the deaf wrestle with acceptance and hope the child is simply slow in developing.[70] The key factor in this relationship, of course, is the matter of communication. The parents hold intense anger at the awkwardness of the circumstances, and the bewildered deaf child lives with a sense of being less than acceptable. Mindel and Vernon add that "love and anger are easily communicated without words." Seldom do the parents rise above the frustration of limited communication and of unfulfilled hopes. They project the following results:

> If the parents fail to resolve their feelings of grief, anger, guilt and helplessness, they will be forced to remain arrested in the earliest stages of their psychological reactions to the child's deafness.[71]

There is almost never a final stage of realistic acceptance.

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[69] Alan O. Ross, The Exceptional Child in the Family: Helping Parents of Exceptional Children (New York: Grune and Stratton, Inc., 1964), 100.

[70] Love, Parental, 129.

[71] Mindel and Vernon, They Grow, 22.

Overview

Mori produced a book for the professional working with families of children with special needs which suggested early intervention techniques.[72] As one considers the four categories of disabilities and the introduction of the disabled child into the family, his advice about the needs of the parents are significant for supportive professionals, as well, such as the clergy and other church helpers.

About the learning-disabled, Mori said,

> Parents of a learning-disabled child are often confused and frustrated by the inconsistencies they see in their child's behaviors . . . This constant state of uncertainty is stressful for all concerned.[73]

Parental actions toward ADHD children are described in this way:

> Mothers of hyperactive children exerted significantly greater effort to control and structure the behavior of their children than did mothers of nonhyperactive children.[74]

Mental retardation, Mori noted, confronts the parents with three crises, which occur at scattered points during the child's development. The first is the novelty shock, followed by a value crisis. Then the reality crisis occurs.

> The professionals must be aware of the crisis the parent is experiencing . . . [I]n novelty shock [he or she] needs information and emotional support . . . [In the] value crisis . . . ongoing, intensive counseling . . . [In the] reality crisis . . . practical assistance to solve day-to-day problems.[75]

Parents of children who are physically or sensorily impaired (such as the deaf) need encouragement to allow freedom of movement, as much as the disability will allow.

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[72] Mori, Families.

[73] Mori, Families, 109.

[74] Mori, Families, 28.

[75] Mori, Families, 146.

> Some parents prevent their physically or sensorily impaired children from engaging in the same number and quality of social interactions as nonhandicapped children.[76]

Supportive church leaders can greatly assist parents as they strive for greater flexibility.

Recommended Reading

One of the best and most comprehensive collections of articles on families of the handicapped, referred to as caregivers, is edited by George H. S. Singer and Larry K. Irvin (1989), Support for Caregiving Families: Enabling Positive Adaptation to Disability.[77] The contents range from information on roles filled in families to such matters as cash assistance and trusts. A work which is easier to use and apply is Allen A. Mori's Families of Children with Special Needs: Early Intervention Techniques for the Practitioner, written in 1983.[78] JackStewart's Counseling Parents of Exceptional Children (1978) is a good introduction to counseling and relationship with parents.[79] It has good descriptions of the various levels of disabilities and reactions to them. A very good book on disabilities and the people involved is by Colleen J. Mandell and Edward Fiscus (1981), Understanding Exceptional People.[80] It is not only an overview of disabilities but also a look at what goes on inside the handicapped person in dealing with his problem. A work of similar contents and value, published in 1982, was edited by Arthur L. Presnsky and Helen Stein Palkes, Care of the

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[76] Mori, Families, 107.

[77] George H. Singer and Larry K. Irvin, eds., Support for Caregiving Families: Enabling Positive Adaptation to Disability (Baltimore: Paul H. Brookes, 1989).

[78] Mori, Families.

[79] Stewart, Counseling.

[80] Mandell and Fiscus, Understanding.

Neurologically Handicapped Child: A Book for Parents and Professional.[81] Because it is important to hear from the parents themselves, H. R. Turnbull III and Ann P. Turnbull furnish this in their 1985 collection, Parents Speak Out: Then and Now.[82] The parents describe their circumstances when their children are diagnosed as handicapped and returns to hear their stories and thoughts at later times. A very good collection of articles dealing with various handicapping conditions, the families of the handicapped, and teachers who must work with them, is Childhood Disorders: Preschool and Early Elementary Years, edited in 1984 by Joseph N. Murray and Caven S. McLoughlin.[83] An earlier work on the family which still has value in spite of changes made by legislation is Ray H. Barsch's 1968 book, The Parent of the Handicapped Child: The Study of Child-Rearing Practices.[84]

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[81] Arthur L. Prensky and Helen Stein Palkes, eds., Care of the Neurologically Handicapped Child: A Book for Parents and Professionals (New York: Oxford University Press, 1982).

[82] H. Rutherford Turnbull III and Ann P. Turnbull, eds., Parents Speak Out: Then and Now (Columbus, OH: Charles E. Merrill, 1985).

[83] Joseph N. Murray and Caven S. McLoughlin, eds., Childhood Disorders: Preschool and Early Elementary Years (Springfield, IL: Charles C. Thomas, 1984).

[84] Ray H. Barsch, The Parent of the Handicapped Child: The Study of Child-Reading Practices (Springfield, IL: Charles C. Thomas, 1968).

CHAPTER 3

THE SHOCK AND IMPACT OF DIAGNOSIS

Early Stages of Awareness

Parallel with the commonly recognized stages of death and dying, the stages of awareness for parents of newly-identified handicapped children are parallel. The lists are several, but parents are observed to engage in denial, anger, guilt, despair, and finally acceptance.[85] Another list of reactions are shock, refusal, guilt, bitterness, envy, rejection, and adjustment.[86] Yet another is a failure to believe the diagnosis, followed by self-blame, then anger and/or self-pity, and finally integration.[87] As will be explained below, parents find it easier to adjust, offering acceptance and cooperation, if the handicap is diagnosed as severe rather than mild or moderate; parental expectations of the less severely afflicted tend to be too high and not realistic.[88] Whatever the series, the situation is one of mourning.

Such reactions are instant. The impact of the information, as it sinks in, brings about other forms of inner wrestling. For some, it is a loss of self-esteem, a sense of shame and ambivalence, depression, rising to a notion of self-sacrifice and even defensiveness.

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[85] Bonnie Wheeler, Challenged, 20, 22.

[86] Harold D. Love, Parental, 27-36.

[87] Joseph N. Murray, "Handicapped Children and Their Effect on the Family," in Childhood Disorders: Preschool and Early Elementary Years, ed. Joseph N. Murray and Caven S. McLoughlin (Springfield, IL: Charles C. Thomas, 1984), 16.

[88] Alan O. Ross, Exceptional, 124.

Conflict, however, underlies a sense of disillusionment, fed by unrealistic expectations. Parents have an overwhelming sense of aloneness and vulnerability. They feel inequity at what they are suffering and that they have become insignificant. Their orientation is to the past, rather than the future, and, with that, a loss of the sense of immortality.[89] Parents have been found to differ significantly in their depth of feelings with the several stages. Fathers, for example, find it hardest to deal with the stage of denial, while guilt is the burden of the mothers.[90]

Causes of Disabilities/Handicaps

What causes disabilities? An accident, for example, or a factor in the environment such as the substance abuse by the mother, give plausible explanations for some. The factor more difficult to explain and accept is that of heredity. Each, heredity and environment, accounts for a fifth of the disabilities so diagnosed at birth. The remaining percentage is an interaction of both.[91] Furthermore, how is the abnormal condition to be labeled, a disability or a handicap? There is no clear distinction provided to put the conditions in contrast, whether biologically or socially produced, and often they are used as terms interchangably.[92]

It is possible, however, to classify the conditions--they may be orthopedic disabilities or health impairments. The first impacts the skeletal and muscular capacity to maintain

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[89] Philip Roos, "Parents of Mentally Retarded Children," in Parents Speak Out: Then and Now, ed. H. R. Turnbull, III, and A. P. Turnbull (Columbus, OH: Charles E. Merrill, 1985), 249-252.

[90] Wheeler, Challenged, 22.

[91] Wheeler, Challenged, 27.

[92] Gliedman & Roth, Unexpected, 9.

oneself in a straight or normal condition. Health impairments, on the other hand, are not visually obvious. They do, nonetheless, restrict physical well-being, health, and the victim's physiological functioning.[93] As will be shown below, these conditions vary in their severity. Some are so mild as to escape notice, while others may be so severe they even impact continually on their immediate surroundings. In terms of inner turmoil, parents tend to carry a burden of guilt, and the reader may be able to empathize with their feeling, for congential defects, birth injuries and chronic diseases.[94]

Handicapped Children Population

In 1970, Gliedman and Roth estimated that 11.4 percent of the population up to age 21 was handicapped.[95] By 1976, approximately 8 million children in the United States were so classified, which was 12 percent of the child population.[96] It is difficult to arrive at exact totals for the handicapped. A recent Louis Harris Survey studied disabled of working age, 16-64. Of their sampling, 28 percent had no disability until after the age of

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[93] Best, Individuals, 46.

[94] Ross, Exceptional, 123.

[95] Gliedman and Roth, Unexpected, 6-7.

[96] Mandell and Fiscus, Understanding, 5. The National Advisory Committee on the Handicapped 1976 estimates 8 million (12% of child population) were in special education, ages 3-21, during the 1978-1979 school year, based on state agencies' reports to the U.S. Office of Education (published August 3, 1979):

mentally retarded	915,635	1.83%
deaf/hard of hearing	85,562	.16%
speech impaired	1,214,994	2.42%
visually impaired	32,576	.06%
emotionally disturbed	301,258	.60%
orthopedically impaired and other health impaired	177,100	.35%
learning disabled	1,154,430	2.30%

55.[97] Gliedman and Roth had encountered the same problem in their study of 1980.[98] To give a complete picture, however, references to the disabled and handicapped ought to include the elderly and chronically ill, as well as children.[99]

Parental Perception and Projected Outcomes

How the parents perceive the handicaps of their children is understandably influenced by its severity and the nature of the handicap. Blindness and cerebral palsy, for example, are obvious and cannot be ignored. Deafness cannot be detected visually, nor can learning disabilities. If the disability is so gross, that is, so obvious that it cannot be denied, parents can no longer engage in the fantasy that it is not real or that it will eventually go away. When the condition is relatively mild, parents have been known to go shopping for the doctor who will reassure them of the children's growth to normalcy and the parents tend to continue in the stage of denial. The sad fact has been observed that parents are poorly informed about the nature of their children's defects and its implications.[100]

How the handicapped child will fare is largely dependent upon the ability of the parents to understand the condition and the services needed. It has been noted that many

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[97] National Organization on Disability/Louis Harris Associates, "Remarks by Humphrey Taylor," July 21, 1994, NOD/Harris Survey of Americans with Disabilities (Washington, D.C.: National Organization on Disability), 2.

[98] Gliedman and Roth, Unexpected, 6-7.

[99] George H. S. Singer and Larry K. Irvin, "Family Caregiving, Stress, and Support," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes Publihsing Company, 1989), 3.

[100] Ross, Exceptional, 47, 74.

fine programs have been created by professionals for handicapped children only to have their value lost because the emotional needs of the parents had not first been dealt with satisfactorily.[101] Furthermore, the American value system may oftentimes block the immediate application of special services. Judeo-Christian thought inculcates the notion that challenges can be met and overcome through suffering, or through self-knowledge, or through simple acceptance combined with faith, or through a combination of all said positions.[102]

The handicapped member of a family cannot long be ignored nor the condition overlooked. The very distance which develops between the family of the manifestly handicapped and others, even family and friends, continues to widen over time.[103] The parent, e.g. of a retarded child, with a high level of awareness, will use the word "retarded" without hesitation, will recognize the limitation involved, and will ask professionals for information. With partial awareness, the parent may refer to symptoms, experience the struggle of hope and fear, and worry about coping. The parent with minimal awareness denies the abnormality, blames others for the child's symptoms, and believes proper treatment will bring the child to normalcy.[104]

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[101] Eugene D. Mindel and McCay Vernon, <u>They Grow in Silence: The Deaf Child and His Family</u> (Silver Spring, MD: National Association of the Deaf, 1971), 23.

[102] Singer and Irvin, "Caregiving," 13.

[103] Robert Marion, "Mentally," 141.

[104] Jack C. Stewart, <u>Counseling</u>, 89-90.

A course must be set for the future of the family, but the decisions involved depend on three areas of consideration. They depend on the family's projections, roles, and placement variables.

First, does the family project that the handicapped member will enter a regular school? Will he or she be independent and will he or she survive when the parents are gone?

Next, considering the family as a unit, are there extremes within that unit? Are the mother and child too closely knit? Is the marital bond of the parents affected? Does the family place an extraordinary value upon being independent?

As for the future placement of the handicapped member, assuming the move is necessary, parents must consider whether or not the needs will be better met elsewhere, whether continued presence of the handicapped member is a hardship, and whether remaining would subject him to further isolation and limited communication.[105]

Recommended Reading

On family life, the pre-1975 authority perhaps most widely referred to is Alan Ross in, e.g., The Exceptional Child in the Family: Helping Parents of Exceptional Children (1964).[106] An expert also often quoted is Bernard Farber and his 1959 monographs, "Effects of a Severely Mentally Retarded Child on Family Integration."[107] He is best remembered for observing the negative impact on the marriage of the parents. For parents,

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[105] Elouise Jackson, "Environments of High-Risk and Handicapped Infants," in Finding and Educating High-Risk and Handicapped Infants, ed. Craig T. Ramey and Pascal L. Trohanis (Baltimore: University Park Press, 1982), 61-62.

[106] Ross, Alan, Exceptional.

[107] Farber, "Effects."

David Melton's 1984 Promises to Keep[108] is a handbook on LD, brain-injured children, et al. He makes good comments on the importance of both parents in the child's life. About parents is Harold D. Love's 1970 book, Parental Attitudes toward Exceptional Children,[109] offering good insights into parental reactions and attitudes. A very good collection of articles was edited by E. Philip Trapp and Philip Himselstein, Readings on the Exceptional Child: Research and Theory (1972).[110] It includes sociological evaluations of the families and the impact of the retarded child on such families. It is of vital importance that the pastor consider all members of the handicapped person's family--the siblings (and even extended family members) as well as parents. Stephen Kew devoted his 1975 book to that subject, Handicap and Family Crisis: A Study of the Siblings of Handicapped Children.[111] Currently, there is a great interest in the family as a system. Michael Ferrari and Marvin B. Sussman brought together articles under that general topic in Childhood Disability and Family Systems (1987).[112] Helen Featherstone touched on major aspects of family life with the disabled in her 1980 book, A Difference in the Family: Living with a Disabled Child.[113] Her words are frequently referred to elsewhere. A very good evaluation

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[108] David Melton, Promises to Keep (New York: Franklin Watts, 1984).

[109] Love, Parental.

[110] E. Philip Trapp and Philip Himelstein, eds., Readings on the Exceptional Child: Research and Theory, 2nd ed. (New York: Appleton-Century-Crofts, 1972).

[111] Kew, Handicap.

[112] Michael Ferrari and Marvin B. Sussman (eds.), Childhood Disability and Family Systems (New York: Haworth Press, 1987).

[113] Featherstone, Difference.

of that problem is contained in John Gliedman and William Roth's 1980 The Unexpected Minority: Handicapped Children in America.[114]

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[114] Gliedman and Roth, Unexpected.

CHAPTER 4

WHAT SCRIPTURE TEACHES ABOUT THE HANDICAPPED

Scripture, viewed here as the inspired and infallible word of God, gives considerable attention to the disadvantaged. Related subtopics will be considered in this section which treat disability and disadvantage in similar terms. A recent Harris Survey of the disadvantaged allows a basis for this. Harris reports that Americans with disabilities have much lower incomes, are undereducated, are underemployed, and are prevented because of disabilities from socializing in ways accepted by others as normal social involvement.[115]

The writer hastens to say that this is not an exhaustive study of all Scripture says and teaches about the handicapped (and related matters). That which follows, in its several parts, are the salient points revealed by the Holy Spirit in His inspired Word. The Scripture passages quoted below are from the New International Version.

The Condition of Being Handicapped Is Placed on a Level with the Disadvantaged

> Leviticus 19:14-15: "Do not curse the deaf or put a stumbling block in front of the blind, but fear your God. I am the Lord. Do not pervert justice; do not show partiality to the poor or favoritism to the great, but judge your neighbor fairly."
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> Acts 3:1-2: One day Peter and John were going up to the temple at the time of prayer . . . Now a man crippled from birth was being carried to the temple gate called Beautiful, where he was put every day to beg from those going into the temple courts.

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[115] Taylor, Preface remarks, 1994 N.O.D./Harris Survey, 23.

God's Old Testament injunctions against injustice to the poor and defenseless is often combined with reference to the handicapped, as in Leviticus 19, above. Poverty and disability have been inseparable in the global view of social conditions over the centuries. The cripple at the temple gate in Jerusalem, to whom Peter and John responded (Acts 3), was placed there for economic reasons: he begged for contributions to keep himself alive.

In Scripture, God Repeatedly Shows His Concern for the Less Fortunate

> Isaiah 58:6-7: "Is not this the kind of fasting I have chosen: to loose the chains of injustice and untie the cords of the yoke, to set the oppressed free and break every yoke? Is it not to share your food with the hungry and to provide the poor wanderer with shelter--when you see the naked, to clothe him . . . "

> James 1:27: Religion that God our Father accepts as pure and faultless is this: to look after orphans and widows in their distress . . .

The Children of Israel practiced self-denial in fasting, but they were chided by God through Isaiah (ch. 58). They went through the motions without understanding true worship and without comprehending that one honors God by caring for the less fortunate. The orphans and widows to whom James referred (ch. 1) were needy, no doubt suffering physically as well as materially. Old and New Testaments testify to God's concern for the disadvantaged and disabled and for His people, that they reflect that same concern in their charitable works.

God Pronounces Guidelines Which Protect the Disadvantaged

> Proverbs 31:8-9: "Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy."

> Philippians 2:3-5: . . . in humility consider others better than yourselves. Each of you should look not only to your own interests, but also to the interests of others. Your attitude should be the same as that of Christ Jesus . . .

Today, the advice of King Lemuel's mother is paraphrased as being "a voice for the voiceless" (Proverbs 31). Throughout his two books, Solomon also urges God's people to help those who cannot help themselves. The words of Paul in Philippians 2:5 remind Christians of their Model in the Lord Jesus. In the words that follow (2:6-11), one reads that the King assumed the human nature of His subjects for their salvation. That humble and giving attitude is to be manifested among His subjects, which runs counter to sinful man's inclination and can be attained only by the power of the Holy Spirit working within him.

God Also Gives Pronouncement to His Advantaged People to Assume Responsibility for the Care of the Disadvantaged

> Deuteronomy 15:4, 7-8: . . . there should be no poor among you . . . If there is a poor man . . . be openhanded and freely lend him whatever he needs.
>
> Matthew 19:21-22: "If you want to be perfect, go, sell your possessions and give to the poor . . . " . . . he had great wealth . . . (Luke 12:33)

When Jesus quoted Deuteronomy 15:11 in the house of Simon the Leper (Matthew 26:11), "There will always be poor people," He was not sanctioning such a miserable condition. It was simply a matter of fact. That section, in fact, enjoined the Israelites to do all they could to either help avoid a fellow Israelite's plight in poverty or to at least alleviate it. A rich young man who had asked Jesus how to be saved (Matthew 19) could not bring himself to associate his material blessings and God's compassion with the needs of those not so fortunate.

The Messiah of the Old Testament Identified with the Disadvantaged and the Christ of the New Testament Focused Much of His Ministry on the Disabled and Disadvantaged

> Isaiah 42:1,18-19: "Here is My Servant . . . Hear, you deaf; look, you blind, and see! Who is blind but My Servant, and deaf like the Messenger I send? Who is blind like the One committed to Me, blind like the Servant of the Lord?"
>
> Matthew 11:4-5: Jesus replied, "Go back and report to John what you hear and see: The blind receive sight, the lame walk, those who have leprosy are cured, the deaf hear, the dead are raised, and the good news is preached to the poor."

Isaiah's descriptions of the Suffering Servant makes His concern for the handicapped and vulnerable very obvious (Isaiah 42, et al.). Some interpreters see the descriptions as referring to the perfect Kingdom of heaven which is yet to come in which there will be no suffering or disability. Taken with the actual ministry of the Messiah in Jesus of Nazareth, it would seem apparent that the handicapped were objects of special concern to Him in His earthly ministry, as well. This was a testimony to the disciples of John the Baptist (Matthew 11), which identified Jesus as the Messiah described by Isaiah.

The Savior's Model Extended to God's People in Both the Old and New Testaments by the Holy Spirit

> Isaiah 11:2,4: The Spirit of the Lord will rest on Him . . . with righteousness He will judge the needy, with justice He will give decisions for the poor of the earth.
>
> 1 Corinthians 12:7,27-28: Now to each one the manifestation of the Spirit is given for the common good . . . And in the church God has appointed . . . those able to help others . . .

To live in Jesus, St. John said (1 John 2:6), one must walk as He did. Jesus also cautioned His disciples (Matthew 10:24) that the student is not above his teacher, but hopes to be like his teacher. To reach out in compassion and ministry to those less fortunate, whether they are disadvantaged or disabled, or both, is to walk in the footsteps of Jesus our Lord and Model. For His ministry, Jesus was empowered by the Holy Spirit. That same empowerment is available to the believers.

Disadvantaged and Disabling Conditions are Not Punishments from God, but Part of His Plan for His People

> Deuteronomy 8:2-3,16: Remember how the Lord your God . . . humbled you, causing you to hunger and then feeding you . . . to teach you that man does not live on bread alone but on every word that comes from the mouth of the Lord . . . to test you so that in the end it might go well with you.

> John 9:1-3: As He went along, He saw a man blind from birth. His disciples asked Him, "Rabbi, who sinned, this man or his parents, that he was born blind?" "Neither this man nor his parents sinned," said Jesus, "but this happened so that the work of God might be displayed in his life."

The Christian knows from revelation that God does not punish His children. Indeed, because the iniquity of the whole world was laid on His Son, whatever adversity believers endure must be viewed as testing and chastisement from their loving, heavenly Father. In this life, therefore, there is no punishment in an apocalyptic sense. Suffering in this world is a reminder of its temporal nature and that believers are dependent upon the mercy of God. When Jesus was asked about the cause of a blind man's condition, who was culpable, He said neither the blind man nor his parents were to blame (John 9). God would use the situation for His own purposes, and all such things do, indeed, work together for the good of His children.

Ministry by God's People to the Disadvantaged is Ministry to God Himself

> Genesis 12:1-3: The Lord had said to Abram, "Leave your country . . . and go to the land I will show you . . . I will bless those who bless you, and whoever curses you I will curse; and all people on earth will be blessed through you."

> Matthew 25:37-40: "Then the righteous will answer Him, 'Lord, when did we see You hungry and feed You, or thirsty and give You something to drink? When did we

> see You a stranger and invite You in, or needing clothes and clothe You? When did we see You sick or in prison and go to visit You?' The King will reply, 'I tell you the truth, whatever you did for one of the least of these brothers of mine, you did nor Me.'"

We do not see God, but we are in service to Him, manifested in particular in service to those who need our assistance. "All people on earth," God told Abraham, "will be blessed through you," that blessing being effective because of Abraham's covenant with God (Genesis 12). They saw God through him. Those who receive ministry from Jesus' followers see Jesus, as it were, for the followers' ministry is as to Him. (Matthew 25) In this context, ministry by Christians to the handicapped is ministry as to Jesus Christ.

This chapter touches on a few of the portions of Scripture which connect the believer's life in faith with objects of their ministry done in love for the Lord. It gives some relationship between the place of suffering in this finite existence with the infinite glory awaiting of God's faithful. In the next chapter, consideration will be given to the puzzle of "Why?" Why does God allow suffering to beset His own?

CHAPTER 5

THE QUESTION OF SUFFERING

In 1975, George W. Paterson wrote a book for parents and others in helping professions entitled, Helping Your Handicapped Child. In his approach to the question of suffering (for most parents of handicapped children ask "Why?"), he proposed a matrix on suffering's origin. The two directions were the source (did God originate suffering or not?) and effect (is suffering beneficial or not?). The nature of the four perspectives of suffering were punishment, redemption, providence, and absurdity.[116]

To represent the four quadrants of the matrix this writer has chosen a school of thought (pantheism in the New Age, basing comments on the work by Clark and Geisler) and three noted persons (Martin Luther, C. S. Lewis, and Harold Kushner). No single thought system or personage represents every aspect contained in each quadrant. Paterson cautions that no family of the handicapped experiences only the one quadrant, but they may overlap from time to time. The experience, in fact, may shift from one perspective to another under varying circumstances.

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[116] George W. Paterson, Helping Your Handicapped Child (Minneapolis: Augsburg Publishing House, 1975).

God as the Source of Suffering -- the Key Word: Punishment

In this, with God as its source, suffering is a harmful experience. It is, in fact, an expression of God's wrath and judgment against sinful and/or fallible man. Helpless to stand against it, the only response on the part of man is patient submission.

Pantheism, itself, cannot be called a system of thought. Over the centuries of varied expressions reflective of divergent cultures and times, it defies efforts at systematization. It nonetheless continues to appear in the history of thought, relentlessly emerging from the mystical side of man's imagination and his sinful nature to explain the mysteries of life's ambiguities. Nonetheless, for the purposes of this paper, basic elements and emphases place it as neatly as other philosophies, into the first quadrant of the matrix.

We look at the Eastern notion of pantheism because it underlies the New Age, which has received extensive notoriety in recent years in Western society. Basic to pantheism is the teaching about karma, defined in this way:

> "karma": the law of merit and demerit, which teaches that every person receives in this life the rewards or punishments for previous lives; the law of moral cause and effect.[117]

As Clark and Geisler examine whether pantheism can adequately explain pain and suffering in the creation's experience, they highlight the fact that, in so doing, one is forced to deal with the question of evil and to attempt to solve that encounter. In its history, pantheism has developed several options, ranging from a matter of great significance to a matter of illusion.

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[117] David K. Clark and Norman L. Geisler, Apologetics in the New Age: A Christian Critique of Pantheism (Grand Rapids, MI: Baker Book House, 1990), 239.

Briefly, pantheistic thought may travel this succession of options. First, God Himself is or contains evil. Second, not a god but two gods vie with each other, one good and one evil--dualism. Third, Clark and Geisler tell us, liberal Christians and some evolutionists see evil as an inherent part of the finitude of nature. The fourth option is theistic determinism. Holding God as sovereign over all, therefore the Creator of evil as well as good, may be illustrated by Islam and by extreme forms of Calvinism. A fifth view teaches that God created free creatures with the capacity of free will to choose evil. The last view, and the one generally chosen by pantheists, holds that evil may be an illusion or in some way simply unreal.[118]

Making the connection between long-standing pantheism and parallel thoughts given prominence in contemporary New Age, Clark and Geisler say,

> The New Age view of evil follows the dual answer found in pantheism. On the one hand, suffering is cause by karma, the cosmiclaw of justice where virtue is rewarded and vice is punished . . . On the other hand, evil is not ultimately real . . . [119]

Attempting to come to grips with the problem of good and evil, pantheism has maintained that we are ourselves responsible for pain. The reward or punishment received in this life is for actions in previous lives. To be saved, however, and to ascend toward God, depends on adherence to ethical self-discipline. Yet, since all distinctions collapse in the oneness of God, one must eventually transcend the illusory nature of good and evil. Hence, there are

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[118] Clark and Geisler, Apologetics, 204-205.

[119] Clark and Geisler, Apologetics, 131.

no moral truisms. Hence there is no pain and sorrow. One suffers only because it is believed that pain is inflicted.[120]

God as the Source of Suffering -- the Key Word: Redemption

In this view, God is the source of suffering but suffering is intended for a benefit and a blessing. It actually expresses God's love, to which the sinner responds with acceptance, with cooperation, and with gratitude. While it does not redeem the sinner's soul, it is part of the plan of God leading through the misery of this life to the glory and bliss of heaven. It is redemptive.

Like St. Paul, Martin Luther endured the "burden of the churches" at the time of the Reformation. He was caught up in the political, economic, social, and ecclesiastical upheavals of his time and was frequently the object of persecution. He also suffered physically, a condition which he attributed to his early years of severe self-denial and enforced sedentary condition of the monastery. He developed what one biographer, Ewald Plass, entitled Luther's "sickroom philosophy." As in everything else, Luther held that sickness is in the hands of the Lord. He also felt that, in the actual affliction, God used the devil as an instrument. Plass quoted Luther as saying:

> . . . all sadness or sickness comes from the devil, not from God. But God ordains it and permits it to happen . . . again, whatever pertains to life is God's grace and benefaction.[121]

Sickness and disease, to Luther, were not natural phenomena alone, explained on materialistic grounds.

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[120] Clark and Geisler, Apologetics, 128-131.

[121] Ewald M. Plass, This Is Luther: A Character Study (St. Louis, MO: Concordia Publishing House, 1948), 182.

In Lutheran Cyclopedia, under "Providence," the will and ways of God are described.[122] (In footnote 122, the article is given sans the Scripture quotations.) According to Lutheran teaching, definite laws were implanted by God into His creatures and thus express His providence. Both God and the means are operative, however, so that His providence is therefore exercised through secondary means. Divine providence is operative only so long as God works through the secondary causes, a fact beyond full human understanding.

The cyclopedia goes on to explain that the providence of God does not take away either the liberty or the responsibility of man. Man is not an automaton, and God is

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[122] "Lutheran Cyclopedia, s.v. "Providence" (St. Louis, MO: Concordia Publishing House, 1954), 859. [The following quotation omits Scripture references.]

> Divine providence is that activity of God whereby He uninterruptedly upholds, governs, and directs the world which He has made. Divine providence extends over the entire creation. It provides for the continued existence of all individual creatures, directs their actions, and controls their destinies. This includes lifeless creation, plant life, animal life, the world of men and all that concerns men, heaven, hell, in fact, everything.
>
> Divine providence normally expresses itself in definite laws which represent inner urges and drives implanted by God in His creatures. These laws proclaim the benignity of the Creator.
>
> Divine providence is ordinarily exercised through secondary causes, which, however, are operative only so long as God works through them. Scripture teaches that both God and the means are operative, a fact which cannot be completely explained by the human mind.
>
> Divine providence deprives men neither of their liberty nor of their responsibility; it neither reduces men to automata nor makes God responsible for sin. Thus while God is operative in me and acts through men also when their deeds are evil, He is not the author of sin.
>
> From the viewpoint of God all is predetermined and immutably fixed, yet from the human viewpoint things happen contingently, events can be modified and depend on circumstances and decision which men make and for which they are responsible.
>
> The ultimate goals of divine providence are (1) the temporal and eternal welfare of men, particularly the salvation of the elect; (2) the spreading of the Gospel; (3) the promotion of the glory of God.

operative in man and acts through him even when he sins, but He is not the author of sin. Furthermore, the cyclopedia states:

> From the viewpoint of God all is predetermined and immutably fixed . . . yet from the human viewpoint things happen contingently, events can be modified and depend on circumstances and decisions which men make and for which they are responsible . . .[123]

In Lutheranism, divine providence is taught to have three ultimate goals: the welfare of man, especially his eternal salvation, the spreading of the Gospel, and the glory of God.

Thus, in his "sickroom philosophy," Luther looks through the burden of sickness and pain to the agony of Christ on the cross. That agony was more than any man could endure. Furthermore, man's suffering is a stepping stone to God when used properly, for it draws us closer to Him and His Word of grace.[124] In his "The Fourteen of Consolation: For Such as Labor and Are Heavy Laden," written in 1520, Luther says Christ "consecrated and hallowed all sufferings, even death itself," by His most holy touch. Thus, the Christian is hard and ungrateful who does not long for sufferings.[125]

To put such extreme language into perspective, one does well to consider Luther's words in his treatise on good works, also written in 1520:

> This is real strength, to trust in God when to all our senses and reason He appears to be angry; and to have greater confidence in Him than we feel.[126]

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[123] "Providence," 859.

[124] Plass, Luther, 184.

[125] Martin Luther, "The Fourteen of Consolation: For Such as Labor and Are Heavy Laden" (1520), in Works of Martin Luther (The Philadelphia Edition), Vol. I (Philadelphia: Muhlenberg Press, 1943), 138.

[126] Martin Luther, "A Treatise on Good Works" (1520), in Works of Martin Luther (The Philadelphia Edition), Vol. I(Philadelphia: Muhlenberg Press, 1943), 192.

Later, Luther adds:

> God sends us suffering and trouble that He may teach us to have patience and peace; He bids us die that He may make us live, until a man, thoroughly trained, becomes so peaceful and quiet that he is not disturbed, whether it go well or ill with him, whether he die or live, be honored or dishonored. There God Himself dwells alone, and there are no works of men.[127]

Because, on the way to heaven, the believer is disciplined by suffering, it is for his benefit and blessing. It is actually an expression of God's love, to which the believer responds with acceptance, cooperation, and gratitude.

God is Not the Source of Suffering -- the Key Word: Providence

Earlier in this century, C. S. Lewis wrote on "the problem of pain," as his book was entitled. To Lewis, attaching the word "love" to human suffering is to trivialize love. It would then make man the center. He is neither the center of things, nor does God exist for man. Man, in fact, does not exist for his own sake. The purpose of man is that he be the object of God's love (to which, of course, man responds with love). Man is to be one with whom God is "well pleased."[128] There are only three alternatives to existence, according to Lewis. The two are extremes: to be God or to be miserable. The remaining alternative is to "be like God and to share His goodness in creaturely response," which, obviously, is recommended by Lewis.[129]

Two doctrines are central to Lewis' argument on the problem of pain. The one he rejects: the doctrine of total depravity. The other explains the presence of evil; man's free

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[127] Luther, "Works," 247.

[128] C. S. Lewis, The Problem of Pain (New York: MacMillan Publishing Company, 1962), 47-48.

[129] Lewis, Pain, 54.

will. Regarding the former, Lewis states that logic dictates that if we are caught in total depravity, we would not know it. To the contrary, experience shows that there is goodness in human nature.[130] Nonetheless, God "made all things good and for the sake of their goodness." One of those good things is the free will of rational creatures. That, of itself, included the possibility of evil. And so it came to be.[131]

To overcome the problem of pain, Lewis suggests three operations, and those operations are themselves painful. The first is to surrender one's will. That process is painful. The second operation is that, burdened with pain, one's illusion is shattered that what we have is our own. Good or bad, we have no such ownership. The final operation of suffering to choose is full and total surrender to God. That surrender demands pain. God does not directly cause pain, but, under His providential guidance, it can be beneficial. He turns the evil that besets man into good, and man ought to respond with faith, with patience, and with hope.[132]

God is Not the Source of Suffering -- the Key Word: Absurdity

Paterson's fourth quadrant is the absurd. As an illustration of the absurdity of suffering under almighty God, the writer draws upon Harold Kushner's analysis of why bad things happen to good people, which is the title of his well-known book. In this segment, God most assuredly is not the cause of suffering, which is harmful. Suffering originates in nature, or in human error, or, if one believes in Satan, in demonic forces. To such

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[130] Lewis, Pain, 68.

[131] Lewis, Pain, 69.

[132] Lewis, Pain, 91-99.

conditions, suffering man can respond either with determined resistance or with courage endurance.

Kushner sets up and rejects the various conventional explanations given to explain suffering and the compliance of God therein. He rejects the notion that human pain ultimately contributes to something of value. He rejects the notion that God has a grand plan and that, somehow, the pain of the present fits into it in a wonderful way to be revealed and understood at some future point in time. He rejects the notion that, in the midst of hopelessness, miracles can be expected. He rejects the explanation that the person suffering is guilty of some failing or action and that God is punishing him. Ultimately, and most important for his argument, Kushner rejects the notion that for every event or experience there is a logical explanation.

Key phrases from Kushner's writing are, "misfortunes do not come from God at all . . . there are some things God does not control." He also says, "Some things happen for no reason, . . . there is randomness in the universe . . . Laws of nature do not make exceptions for nice people . . . God does not cause it and cannot stop it."[133] One reason bad things happen to good people "is that our being human leaves us free to hurt each other, and God can't stop us without taking away the freedom that makes us human."[134]

Having established that God is not the cause of suffering, indeed, that He cannot avert it from our lives, Kushner goes on to offer his view of the ways of man and the ways of God. Significantly, he approaches the subject as an evolutionist. In fact, he says the

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[133] Harold S. Kushner, When Bad Things Happen to Good People (New York: Avon Books, 1981), 44-46, 58.

[134] Kushner, Bad Things, 81.

Genesis account of creation strongly suggests that, when God said, "Let us make man in our image," it was another way of saying man evolved from the animal kingdom.[135] Turning to the suffering of today, the author says that it is when we acknowledge that there are some things God does not control, at that point we can see the many good things that become possible and can avoid the pain of expecting unrealistic developments which never take place.[136]

Kushner does not suggest ignoring the things that make man sad and angry. Those same things, he says, sadden and anger God. Terrible occurrences such as murder and robbery "represent that aspect of reality which stands independent of His will."[137] What ought angry man do? He writes:

> The goal, if we can achieve it, would be to be angry at the situation, rather than at ourselves, or at those who might have prevented it or are close to us trying to help us, or at God who let it happen.[138]

God does not cause pain, but we can turn to Him for help in overcoming it. The evil events do not have any good reason for happening, but, Kushner asserts, we can give them a meaning, thus redeeming tragedies from their senselessness. The question to be asked when faced with suffering is not why it happened but rather what, now that it has happened, can one do about it.[139]

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[135] Kushner, Bad Things, 72.

[136] Kushner, Bad Things, 44-45.

[137] Kushner, Bad Things, 55.

[138] Kushner, Bad Things, 108.

[139] Kushner, Bad Things, 136.

Kushner would focus our attention away from God and to our fellowmen. Prayer, for example, "when it is offered in the right way, redeems people from isolation." In a religious service, one does not find God but, rather, a congregation of people with whom to share the vital things of life.[140] Using the example of a family with a handicapped child, Kushner says that God did not send the disability but He is, nonetheless, the answer for those who suffer under those circumstances: "He gives us the strength to cope with the problem."[141] In this lies the practical good of religion.

The ideas contained in Kushner's thesis prompts the question of the value of God in one's life. He neither kills nor cures. What difference can He make? It is Kushner's observation that God inspires some people, such as doctors, nurses, and social workers, to help other people who have been hurt by life.[142] He offers something of a summary statement in the following:

> Religion alone can affirm the afflicted person's sense of self-worth. Science can describe what has happened to a person; only religion can call it a tragedy. Only the voice of religion, when it frees itself from the need to defend and justify God for all that happens, can say to the afflicted person, "You are a good person, and you deserve better. Let me come and sit with you so that you will know that you are not alone."[143]

Kushner typifies the absurd--God does not cause suffering, which is harmful, but He also is helpless to do anything about it except to give encouragement through people. Suffering

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[140] Kushner, Bad Things, 121.

[141] Kushner, Bad Things, 127.

[142] Kushner, Bad Things, 136.

[143] Kushner, Bad Things, 143.

originates, then, in nature, human error, or even demonic forces (if one believes in demons). One can resist ("What can I do about it?") or simply resign with courageous endurance.

Christian Responses to the Question "Why?"

Wheeler offers a set of guidelines for parents of handicapped children when they begin questioning the will and wisdom of God in their lives:

1. While I can question I must not demand answers and accountability from God.
2. I must be willing to wait (maybe until heaven) for my answers.
3. I must not let my unanswered questions cause bitterness and come between me and the Lord.
4. I must remember and apply the Serenity Prayer to my questioning: "God grant me the courage to change the things I can [my attitude]; the patience to accept the things I cannot change [my child's diagnosis, waiting for answers]; and the wisdom to know the difference."[144]

Meanwhile, as Christian parents exercise the virtue of patience and the gift of childlike faith, the following observations put forth by David Miller are reminders for stalwarts and enlightening for new believers.

Similar to the Lutheran cyclopedia statement ("From the viewpoint of God all is predetermined and immutably fixed, yet . . . events can be modified . . . "),[145] Miller has written,

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[144] Bonnie Wheeler, Challenged Parenting: A Practical Handbook for Parents of Children with Handicaps (Ventura, CA: Regal Books, 1983), 33.

[145] "Providence," 859.

> God chooses us to meet the needs of our children, and not the reverse. Parents are selected to receive, on loan, children who are created by God and who need someone to raise them.[146]

This thesis says that God was very specific in selecting the right parents for the needs of particular children. Miller says, "God trusts those to whom He gives the greatest challenges."[147]

Nonetheless, the question is repeated: Why me? Why are there problem children? God entrusts difficult children to good parents for necessary care and upbringing.[148] Miller says there is no answer to the existence of problem children. Drawing upon Matthew 18:7, he does voice a warning:

> Down-syndrome babies are born into the world because there is sin in the world. Non-compliant boys and girls populate our families because there is sin in the world. Hyperactive, learning-disabled, psychotic, sociopathic, and self-destructive children live in this world because there is sin in the world.
>
> But you and I had better not be that one who becomes a tool of sin and injures children in some way. It is our task to do our best . . . [149]

On that premise of sin in the world, Luther turned attention to Jesus Christ who,

> by His most holy touch, consecrated and hallowed all sufferings, even death itself, hath blessed the curse, glorified the shame, and enriched poverty, so that death has been made a door to life, curse a fount of blessing, and shame the mother of glory.[150]

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[146] David R. Miller, Tough Kids (Elgin, IL: David C. Cook Publishing Company, 1993), 14.

[147] Miller, Kids, 16.

[148] Miller, Kids, 17.

[149] Miller, Kids, 18.

[150] Luther, "Fourteen," 138.

Miller says, in fact, that "challenging children are a compliment from God!"[151] Whatever the nature of the parental responsibility dealing with special needs, it reflects God's trust in the parents, not His punishment for inherited sin or for past transgressions. As Miller says, "God would never require a child to be sacrificed to mental retardation or deafness to atone for the sins of parents."[152]

Paraphrasing St. Paul's words (1 Corinthians 4:2) on that expected of Christian stewards, what is required of parents of children with special needs except that they be found faithful?

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[151] Miller, Kids, 28.

[152] Miller, Kids, 27.

CHAPTER 6

THE CHURCH AND THE HANDICAPPED FAMILY

As has been emphasized above, the population of the handicapped and those related to the handicapped is significant in size. The church ought not to be as unaware of them and their special needs. We receive assurances that seminaries are now including information about the handicapped in the training curriculum. We would urge that the seminarians also be prepared for the role they, as pastors, will play when their church members become parents of handicapped children.

As the spiritual counselor and guide, the pastor will try to assist the handicapped church members with their conditions and will assist with the social, economic, emotional, and occupational effects of the handicaps. He will try to mitigate the negative impact of the handicap on interpersonal relations within the family. Most especially, he will be asked to answer the question "Why?" Hartbauer says,

> They call upon you [the pastor] because they feel <u>you</u> have all the answers, <u>you</u> can explain God and His ways, <u>you</u> can "call on God" because <u>you</u> are considered a representative of God.[153]

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[153] Hartbauer, "Understanding," 1-2.

The family wants the pastor as a source of strength, one to give sincere answers to their questions, one on whom they can lean, and someone to both listen to them and accept them as they are. They also need someone they can blame, albeit in a misplaced manner.[154]

The Expectations of the Pastor

The need for support such as a pastor can give begins with the crisis itself, as soon as there is an awareness of something gone wrong. The telling is crucial, for the family members are extremely sensitive at that time. Thomas observed,

> Whether parents are told skillfully or clumsily, early or late, whether they are tough or tender, this period calls for intensive support, not only in practical day-to-day child care but also in working through the emotions aroused. The connection between initial reaction and subsequent attitudes is rather uncertain.[155]

The pastor ought to be properly informed, and then assist in the next step in the flow of that information to the family itself.

Most families in American society are not deeply involved in church life and do not have meaningful relations with their clergy. This narrows the possibility of pastoral care being given to parents in the early, critical hours, days, and weeks when a child is diagnosed as having a handicap. Although spiritual support is beneficial, most such families manage to do without it and find ways to adjust on their own or through other means of information and support.

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[154] Hartbauer, "Understanding," 1-2.

[155] David Thomas, The Social Psychology of Childhood Disability (New York: Schocken Books, 1978), 111.

Hanson, Ellis, and Deppe observed that, under normal circumstances, the handicapped families "negotiate the adaptations" within several months.[156] Some, of course, need more time, depending on the complexity and severity of the handicap. Their adjustment period may, in fact, last for years or for the life of the child. Pastors and their churches must be alert to the births or later diagnoses of handicapped children in their spiritual care. They ought to address the need quickly or they risk losing the families and the opportunities at hand.

To be sure, with the bewildering array of new obligations thrust upon the family of a handicapped child, confusion can be expected to be profound. As Gallagher, Beckman, and Cross facetiously put it:

> Families seem to need a one-stop supermarket set of services that would help them to adapt to the multitude of problems that surround them.[157]

No such supermarket exists, but the local pastor and church can render assistance of inestimable value by being informed of available services, of existing programs for the handicapped and their families, and by helping the family through the maze.

The handicapped family ought to be a significant and important object of ministry for the pastor. As the leaders among God's people are admonished by Scripture to be a voice for the voiceless (Proverbs 31:8), so also pastors can be sensitive to the stigma the

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[156] Marci J. Hanson, Lynne Ellis, and Janet Deppe, "Support for Families During Infancy," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes, 1989), 207.

[157] James J. Gallagher, Paula Beckman, and Arthur H. Cross, "Families of Handicapped Children: Sources of Stress and Its Amelioration," Exception Children, 50:10-19.

handicapped family member inadvertently puts upon the others in his or her home. Thomas has described it in this way:

> Parents of visibly handicapped children, though themselves not stigmatized, marry a courtesy stigma and occupy an ambiguous social position . . . [seen in] their association with the stigmatized during encounters with normals . . . [158]

Thomas said those who are stigmatized by normals include friends or relatives of publicly identified radicals, homosexuals, criminals and mental patients. Parents of the handicapped are also stigmatized.[159]

Those who have had experience ministering to members of minority groups or to those who are disadvantaged will recognize the following dilemma. Pastors and churches, together with other service-oriented agencies in the community, may offer well-organized and well-funded programs designed to focus on the special needs of individuals or families, only to be rejected. Slentz, Walker and Bricker have explained that rejection may occur when that which was offered originated from value systems, personal or cultural, divergent from those of the people being served. Those disadvantaged and minority groups may place great emphasis upon individualistic and/or family-oriented solutions to life problems. In addition, families experiencing poverty and/or dysfunction tend not to welcome workers from an outside agency (or church). The pastor and church members must let the disadvantaged know they are not being judged, but, rather, the church is attempting to facilitate service as needed.[160] Furthermore, the church, in its social service outreach, ought

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[158] Thomas, Psychology, 121.

[159] Thomas, Psychology, 121.

[160] Kristine L. Slentz, Barbara Walker, and Diane Bricker, "Supporting Parents Involvement in Early Intervention," in In Support for Caregiving Families: Enabling (continued...)

to try to be sensitive to the particular interests and concerns, as well as needs, of the persons addressed and to do so directly, to individuals and their families, not as an impersonal program-implementation.[161] The personal touch has been underscored by Krauss and Giele, who observed that past services have been largely targeted to individuals, not to the families and the social systems from which individuals comes.[162]

The first step pastors and their church members can take to minister effectively to handicapped families is with their hearts--with compassion, understanding, and patience. The next section deals with the practical implementation of those attitudes, and suggests that the variety of approaches fit under the families' foremost need: respite.

Practical Ministerial and Congregational Helps

Better than elaborate programs for the handicapped and their families is the compassion of church members. Handicapped families are particularly vulnerable to stress. It is not out of place to be aware of the statistics on suicide and divorce when the stress becomes too severe.[163] In all likelihood, neither the pastor nor his church members are trained in dealing with the threat of suicide or even with divorce in its later stages. They

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[160](...continued)
Positive Adaption to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes, 1989), 223.

[161] Slentz, Walker, & Bricker, "Supporting," 223.

[162] Martha Krauss and Janet Z. Giele, "Services to Families During Three Stages of a Handicapped Person's Life," in Childhood Disability and Family Systems, ed. Michael Ferrari and Marvin B. Sussman (New York: The Haworth Press, 1987), 225-226.

[163] Gallagher, Beckman, and Cross, "Families," 11.

can, however, be instrumental in the early stages of stress by providing an environment which is both preventative and one which is conducive to intervention.

A home in which stress is exceptionally high is that of the single parent, usually the handicapped child's mother. The needs of single mothers of retarded children have been studied which revealed that the mothers' priorities were, in order of importance, respite, financial help, and personal and social outlets. The study of single mothers with normal children is very helpful because of the contrast it offers. The priorities of single mothers with normal children were in opposite order: social/personal outlets, financial help, and then respite. Single mothers of retarded children are extremely isolated socially, struggling without formal or informal networks.[164]

Morton described the complaints of parents of the handicapped in terms that are repeated many times over. These parents have two enemies: fatigue and loneliness.[165] Pastors and their church members begin an effective ministry to handicapped families by gaining a compassionate view and understanding of their burdens and frustrations. Second, in attempting to address the needs, they can join in overcoming those enemies, the fatigue and the loneliness.

In addition to compassion, the various ways in which pastors and church members can effectively minister to handicapped families can be placed under the umbrella service of respite. Respite has been identified as the greatest need of parents of the handicapped. It is given highest priority, and understandably so. Until recently, parents were bound to the

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[164] Deiner, "Systems," 208-209.

[165] Kathryn Morton, "Identifying the Enemy: A Parent's Complaint," in Parents Speak Out: Then and Now, ed. H. R. Turnbull, III and A. P. Turnbull (Columbus, OH: Charles E. Merrill, 1985), 144.

needy family member and had to make plans contingent entirely upon the structure of the life of that handicapped person. The writer visited a family in which the parents had not had one day's respite from their severely handicapped son for twenty-five years. The toll it took on the family, especially on the mother, was enormous and unmistakable. It is a paradox that, in spite of the obvious need and priority rating, parents have shown reluctance in making use of respite services when they have been available.[166]

Such reluctance does not diminish or erase the need for respite care. Nor does it diminish or erase the stress families of the handicapped experience. For many, the problem is compounded by the absence of adequate services. Frustration adds to the stress, for there is a lack of adequate day-care facilities for children. Not only does the handicapped child lose the service, the parents themselves lose the rest and diversion of activities away from the child with special needs.[167] Imbued with compassion, enlightened with insights, and blessed with inexhaustible patience, pastors and church members can make good use of their talents and facilities to fill the gap felt by so many handicapped families.

Just as Neef and Parrish found a paradox in the reluctance of parents to take advantage of respite care that is available, so also an unusual attitude has been shown by professionals who give care to the handicapped. Gallagher and his co-authors found that the need for respite care "seems to come into conflict with the professional's expectations of

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[166] Nancy A. Neef and J. Macon Parrish, "Training Respite Care Providers: A Model for Curriculum Design, Evaluation, and Dissemination," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes, 1989), 175.

[167] David Lillie, "Educational and Psychological Strategies for Working with Parents," in James L. Paul (ed.), Understanding and Working with Parents of Children with Special Needs (New York: Holt, Rinehart, & Winston, 1981), 91-92.

the parents' participation in the program" of caring for the special needs of the child.[168] Just as every handicapped child needs an advocate, so also parents of the handicapped need advocates. The clergy and their church members can, at least in part, fill such a role.

As complex as the world of the handicapped may be, the pastor can fill a role often overlooked but of vital importance. He can be a good listener. He probably will not have the answers to the questions and accusations thrown at him, mentioned above, which may be expressions of fear, of frustration, and of misplaced anger. He can, however, be a good listener. As Hartbauer has written of pastoral care of handicapped families, the pastor's role is largely that of listening. By patient listening, he can then, in appropriate measures, reinforce in the hurting the will to live.[169]

Recommended Reading

On pastoral care to the families of the handicapped, George W. Paterson's book is a rare entry and one of the finest for its brevity and clarity. It is Helping Your Handicapped Child,[170] 1975, and makes easy reading for persons involved in non-professional capacities with the handicapped. The chapter most appreciated by this writer is his conceptual model on suffering, a topic most parents ponder. It cannot exhaust the subject, but gives a good basis for thought and discussion. One of the few in this category was edited by James L. Paul, The Exceptional Child: A Guidebook for Churches and Community Agencies

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[168] Gallagher, Beckman, and Cross, "Families," 16.

[169] Hartbauer, "Understanding," 6.

[170] Paterson, Helping.

(1983).[171] It is largely a practical directive for the specialized ministry rather than serving the families themselves. Related to pastoral care is the Christian orientation of a book like Bonnie Wheeler's 1983 Challenged Parenting: A Practical Handbook for Parents of Children with Disabilities.[172] It is a non-technical handbook, like Paul's collection, but speaks directly to the parents' adjustment to having handicapped children. Journal articles tend to be related to retardation more than to any other disability. One of the best is Welf Wolfensberger's article, "Counseling the Parents of the Retarded," 1967, in Mental Retardation: Appraisal, Education, and Rehabilitation, edited by Alfred A. Baumeister.[173] Another early article which had a large impact on pastoral care for families of the handicapped was G. H. Zuk's 1959 work, "The Religious Factor and the Role of Guilt in Parental Acceptance of the Retarded Child," in American Journal of Mental Deficiency (64:139-147).[174] In 1983, Roy E. Hartbauer edited Pastoral Care of the Handicapped,[175] dealing primarily with the handicapped, but with some insight into working with the families. One of the better articles written in recent years is Bernard Ikeler's "Stresses in

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[171] James L. Paul, The Exceptional Child: A Guidebook for Churches and Community Agencies (Syracuse, NY: Syracuse University Press, 1983).

[172] Wheeler, Challenged.

[173] Wolf Wolfensberger, "Counseling the Parents of the Retarded," in Mental Retardation: Appraisal, Education, and Rehabilitation, ed. Alfred A. Baumeister (Chicago: Aldine Publishing Company, 1967).

[174] Zuk, "Religious."

[175] Roy E. Hartbauer, "Understanding the Pastor's Role in Ministering to the Handicapped," in Pastoral Care of the Handicapped, ed. Roy E. Hartbauer (Berrien Springs, MI: Andrews University, 1983).

Families with Disabled Children" (The Journal of Pastoral Care, Fall 1990, 44:3),[176] with thoughts drawn from his 1986 book, Parenting Your Disabled Child.[177] In Family Ministry, edited in 1980 by Gloria Durka and Jeanmarie Smith, Durka's article offers useful insights: "A Neglected Ministry: Special-Needs Children and Their Families."[178]

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[176] Bernard Ikeler, "Stresses in Families with Disabled Children," The Journal of Pastoral Care (44 Fall 1990), 234-243.

[177] Ikeler, Parenting.

[178] Durka, "Neglected."

CHAPTER 7

SPIRITUAL CARE

Family Drop-Outs

The following attempts to clarify apparent contradictions in the literature about families of the handicapped and their church relations. Barsch found that church attendance among parents of the handicapped was higher than the national average (with the noted exception of parents of the deaf, which was low).[179] Ikeler, on the other hand, wrote that "disability-impacted families tend to drop out of church," suggesting that the experience of being stigmatized prompted them to leave.[180] In contrast with Protestant and Jewish families, a greater segment of Roman Catholics, especially the mothers, were more accepting of their burden. These mothers tended to make more use of their religion than did those of other backgrounds. Furthermore, it has been observed, the Roman Catholic Church teaches that a handicapped child is a sign of a special blessing. Given this emphasis, the parents are absolved of any sense of guilt they may have.[181]

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[179] Barsch, Parent, 286.

[180] Ikeler, Parenting, 239.

[181] Zuk, "Religious," 145.

The Negative Feeling of Guilt

While many Roman Catholics may be relieved of guilt, most others do not have that benefit. Kew said feelings of guilt are "inevitable."[182] While guilt is unfounded, it is prevalent. Wolfensberger warned that it may even lead to maladaptive and/or nonadaptive behavior.[183] In contrast, Petersen commented, however, that "there is always an element of reality in these feelings." He and Smith agreed that the sense of guilt is resolved only in religion and that the church can be a positive influence in the struggle of the parents.[184]

The Parental Use of Religion

Of special interest is the recent appearance of separate articles in the journal Child Welfare, in which the contributors maintained that counselors and social workers ought to be aware of, and actively acknowledge, the importance of the spiritual element in their dealings with counselees.[185] Although addressed below, it is important that a distinction be made between a person's religious faith and his or her association with organized religion. The writer of this paper suggests that research does not always clarify responses on religious matters, whether formal or informal in structure. Parents of the handicapped have indicated that they experienced help in coping by their personal faith, by their belief in God, and by their prayers, rather than by church organizations.[186] Schmitt suggested a

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[182] Kew, Handicap, 41.

[183] Wolfensberger, "Counseling," 331.

[184] Petersen, "Pastoral," 42.

[185] Joseph, "Religion," 443-452; Canda, "Spirituality," 238-247.

[186] Ratcliff, "Counseling," 324.

three-fold grouping of the parents: those who found comfort in religion, those who felt their handicapped child was a punishment from God, and those whose faith was skaken and experienced disappointment in God.[187] Nonetheless, a 1988 study of the cognitive effects of having handicapped children said, of fourteen items listed, the effect listed as high as the fourth place was that the experience strengthened their faith.[188] It seemed apparent to Paterson that adaptation to the stress of having a handicapped child would be the primary function of religion in parents' lives. His research showed that function was fulfilled.[189]

Contradictory Findings

Paterson's finding was probably unique. Wolfensberger suggested an entirely different picture:

> The hypothesis that religious values, outlooks, institutions, and rituals may make retardation more acceptable and bearable to some religious groups than others is a reasonable and attractive one. However, the evidence is grossly insufficient.[190]

Substantiation for his comment may be underscored by the tendency of the more religious of the parents to drop away from benefits derived from group therapy. Wolfensberger referred to families with retarded members. In Ikeler's study of parents with autistic children, pastoral care was considered beneficial, but the "churches were consistently

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[187] Schmitt, "Religious," 83-86.

[188] Jean Ann Summers, Shirley K. Behr, and Ann P. Turnbull, "Positive Adaptation and Coping Strengths of Families Who Have Children with Disabilities," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Paul H. Brookes Publishing Company, 1989), 29.

[189] George W. Paterson, "Ministering to the Family of the Handicapped Child," Journal of Religion and Health 14 (1975), 172.

[190] Wolfensberger, "Counseling," 349, 384.

ranked low" by those parents as a source of support.[191] Most parents apparently cling to hope for their children. When deafness is involved, Barsch's finding is interesting. As indicated above, he discovered the parents of deaf children to be ranked lowest in church attendance. Those same parents also ranked highest of all categories in their grasp of reality as it related to their deaf children's potential.[192] This suggested, for them, a correlation between low hope and low religiosity.

Families and Organized Religion

What happens in the church depends, as Ball has pointed out, on the pastor and his training. The pastor has little to start with, however, for the typical church has only one or two families with handicapped members. Even when church-related efforts are made, families of the handicapped described them as coming only from interested individuals, not from the organization.[193] Churches have even fallen short in allowing and facilitating efforts by the families themselves to work together to provide meaningful programs for their handicapped children.[194] When all elements do come together in coordination, when support from the clergy and the fellow church members is sensed and demonstrated, the families' religiosity increases.[195]

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[191] Ikeler, Parenting, 239.

[192] Barsch, Parent, 234.

[193] Ball, "Pastoral," 135, 145.

[194] Esther L. Middlewood, "Their Families Have Needs Too," International Journal of Religious Education (38 February 1962), 13.

[195] Singer and Irvin, "Family," 10.

Pastors of Families with Handicapped Members

Commitment is usually preceded by personal exposure. In spite of the significant size of the population, the handicapped and their families, pastors tend not to get involved with the handicapped unless they themselves have relatives who are handicapped.[196] (Houts cautions, however, that such personal experience does not, of itself, mean the pastor is better prepared to deal with parents of handicapped children.)[197] Furthermore, the world of the professional is divided and subdivided into specializations together with the complexities of certification. Pastors may tend to see work with the handicapped as out of their sphere of expertise, whatever that may mean. Parents, it would seem, have a similar opinion. Ferguson and Heifetz found that their parent respondents looked for "generic, passive support" from pastors. Parents tended to think of clergy only within the limits of their specialization as pastors.[198] Yet, for those who search for the reasons "why"--why this should happen to their children and to them, they direct the question to pastors. They are the God-experts, they are in constant communion with Him, and they ought to have the explanations for their dilemmas.[199] That inquiry may take on an angry tone of hostility, rejection, and even withdrawal, all of which the pastor ought to try to understand and absorb, without sermonizing, rejecting, or pleading.[200] Does this suggest the need in the church for a highly specialized field of pastoral care? Paterson has said no, and added:

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[196] Murray, "Parent," 30.

[197] Houts, "Pastoral," 109.

[198] Ferguson and Heifetz, "Absence," 55.

[199] Hartbauer, "Understanding," 2.

[200] Houts, "Pastoral," 112.

> What they desired and appreciated most in a minister or priest was not some highly specialized understanding or therapeutic strategy, but warm, understanding concern and availability.[201]

Rather, he suggested that this can be gained by regular pastor visits. In another writing, Paterson said families responded most favorably to the good relationship itself that they had with their clergy. Their recollection, he wrote, was that "the pastor did nothing special; he was there; they knew his concern."[202] As Paul put it, the pastor allows and respects the family's privacy and will simply "be there."[203]

Recommended Reading

On counseling, because pastors will be drawn into some aspect of counseling with the parents of the handicapped in their congregations, a good book on that special involvement is Richard M. Garguilo's 1985 Working with Parents of Exceptional Children.[204] He gives an excellent overview of the approach to be used in such counseling situations. Leo Buscaglia's 1975 book, The Disabled and Their Parents: A Counseling Challenge,[205] described and applied very well the principles of counseling in this specialized field. Because parents have criticized the system for overlooking their needs, together with those of their handicapped children, a book edited in 1983 by Peter Mittler and Helen

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[201] Paterson, "Ministering," 174.

[202] Paterson, Helping, 82.

[203] James L. Paul, "Families of Handicapped Children," The Exceptional Child: A Guidebook for Churches and Community Agencies, ed. James L. Paul (Syracuse, NY: Syracuse University Press, 1983), 57-62.

[204] Gargiulo, Working.

[205] Buscaglia, Disabled.

McConachie is very useful. Entitled Parents, Professionals and Mentally Handicapped People,[206] it offered useful insights into the interactions within the family as well as with the system. David Thomas shed light on parental circumstances in his 1978 book, The Social Psychology of Childhood Disability.[207] Worthwhile insights are provided in the 1976 book edited by Elizabeth J. Webster, Professional Approaches with Parents of Handicapped Children.[208] Webster's own 1977 book is also valuable, Counseling with Parents of Handicapped Children: Guidelines for Improving Communication.[209] Bridging secular counseling and pastoral care is David Miller's 1993 book, Tough Kids,[210] addressing in a Bible-based approach the dilemma parents of exceptional children face.

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[206] Peter Mittler and Helen McConachie (eds.), Parents, Professionals and Mentally Handicapped People (Cambridge, MA: Brookline Books, 1983).

[207] David Thomas, The Social Psychology of Childhood Disability (New York: Schocken Books, 1978).

[208] Elizabeth Webster (ed.), Professional Approaches with Parents of Handicapped Children (Springfield, IL: Charles C. Thomas, 1976).

[209] Elizabeth Webster, Counseling with Parents of Handicapped Children: Guidelines for Improving Communication (New York: Grune and Stratton, Inc., 1977).

[210] Miller, Tough.

CHAPTER 8

SUPPORT GROUPS AND RESPITE

Rationale for Support Groups

Of the several programs possible for a local congregation to establish which may be of benefit to families of the handicapped and for which the typical congregation is suited, the writer strongly recommends the establishment of support groups and the organization of respite programs. The first may take a number of possible formats, but church-supported groups should try to bring together families of the handicapped for spiritual nourishment, encouragement, guidance, and fellowship. The second, respite programs, give families of the handicapped opportunity to have time they can call their own. The handicapped members are taken care of in meaningful ways, and the rest of the family members can use that time as they desire and see fit. The writer's conversations with professionals working with handicapped families gave respite care their highest recommendation.

On a highly professional and structured level, Hawkins and Singer offer three suggested ways to assist families. The first is to decrease distress over the handicapped child's problems by the parents being trained in changing the child's behavior. The second is to use the group as therapy, thus reducing the feelings of isolation, even grief, giving friendship and information, and allowing the distressed parents outlets for expression of their feelings. The third is the development of stress management skills, using behavioral and educational approaches to enable the parents to more effectively cope with their situation.[211]

Local churches, however, are usually not fortunate enough to have highly trained professionals in their memberships who would be able and willing to volunteer their time in the programs Hawkins and Singer suggest. The volunteers available must minister within the limits of the abilities and resources they have. Cooley says volunteers are usually of two categories, those providing needed services and those who are earnestly committed to bringing about social change.[212] In this case, they may be involved in improving the lives and circumstances of the handicapped and their families. The simplest and most obvious way to include handicapped families in group ministry in meaningful ways is to make them participants in existing programs such as Sunday school classes, small caring groups, informal clusters of friends, and special interest groups. Steiner and Steiner describe this as "one primary indicator of inclusion in the life of a congregation."[213] Efforts which require additional expertise, at least in recruiting and organizing, may take the form of self-help organizations, involving the families of the handicapped themselves. As a consequence of perceived needs, they evolve so as to meet those needs by giving mutual support, information, involvement in social action, and even inspiration. They can also give one

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[211] Nancy E. Hawkins, and George H. S. Singer, "A Skills Training Approach for Assisting Parents to Cope with Stress," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes Publishing Company, 1989). 71-83.

[212] Elizabeth Cooley, "Community Support: The Role of Volunteers and Voluntary Associations," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore: Paul H. Brookes Publishing Company, 1989), 143-157.

[213] Steiner and Steiner, "Developing," 87.

another practical assistance such as transportation, which is often desperately needed, and baby-sitting.[214]

Operation of Support Groups

From a professional perspective, Webster lists several types of parents groups. Some are parent-organized as opposed to clinician-organized. The former offers comfort, support, and assistance. The latter offers orientation to a particular problem, which approach, Webster says, is the least effective. Professionally-organized groups are designed for training parents in their tasks.[215] Wheeler provides a simple but comprehensive list of the tasks and purposes of parent-organized groups:

1. share experiences;
2. define goals and strategies;
3. gain information about the children's conditions, learning approaches, and disabilities;
4. share to lessen the feelings of loneliness and isolation many of us feel;
5. maintain a balanced perspective--someone else in the group is always going through a rougher time than we are;
6. feel the political strength in numbers;
7. experience the comfort of sharing with other parents who have already passed through (and survived) our current trauma.[216]

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[214] Seligman, Strategies, 151.

[215] Webster, Professional, 52-56.

[216] Wheeler, Challenged, 169.

To bring such a program into existence and to see it continue to function in a meaningful way, especially in a voluntary association such as the local congregation, leadership is a crucial factor. There are those who believe such groups require highly skilled leaders ("technicians," we might say). Webster says, "The task of an effective group leader is...to relinquish leadership...the counselor helps others to direct or lead the group."[217] Stewart, on the other hand, would have the group led by a counselor experienced specifically in group work. He or she would select the cases beforehand. Homogeneity is the desirable composition of such a group. The size of the group would be fixed, as would the time to be spent. Individuals may still benefit from individual counseling, but provided apart from the group.[218]

Criticism of Support Groups

One must distinguish, in our study, support groups established under the auspices of the institution of the Church and support groups with secular origins. Because the local congregation is a voluntary association, programs attached to its agenda can prove to be a frustration. Too often churches become highly enthused and later experience deflation and disappointment when their offerings are not immediately successful. Recognizing this, Ikeler cautions to keep the big picture, but "begin small and go slow."[219] Several explanations can be offered regarding the seemingly failed efforts in support group ministry. The local congregation tends to enter the scene with too little and too late. The church

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[217] Webster, Counseling, 64.

[218] Stewart, Counseling, 69-70.

[219] Ikeler, Parenting, 124-125.

tends, also, to focus on disadvantaged families, which may or may not be handicapped families. The church programs also tend to be too "categorical," such as offering deaf prospects interpretation of services (and possibly activities) in sign language. Rather, Durka advised, ministry ought to be comprehensive, taking in broader aspects of the total lives of those being touched. She went on to say, however, that today's society is too complex for parents to expect to successfully go it alone. The church is the ideal institution to offer the kind of support and help parents of the handicapped need. It is, she maintains, the ideal bridge between the family and society.[220]

Ikeler, aware of the frustration failed programs generate in local churches, cautioned that "many disabled families prefer to avoid public contact and are frightened at the slightest hint of their being identified and interviewed."[221] It is interesting, in this regard, that even professionals working with handicapped families have been disappointed that participation is seldom as they might expect.[222] In addition, it is not uncommon for members of support groups which have been active over an extended period of time to take on quasi-professional attitudes. Politicization and business-like approaches by the experienced lay leaders have dismayed the uninitiated. Drifting away from their altruistic and idealistic beginnings, parent groups often become part of the establishment, in effect institutionalized.[223]

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[220] Durka, "Neglected," 80-93.

[221] Ikeler, Parenting, 126.

[222] Mori, Families, 217.

[223] Janet M. Bennett, "Company, Halt!" in Parents Speak Out: Then and Now, ed. H. R. Turnbull, III, and A. P. Turnbull, (Columbus, OH: Charles E. Merrill, 1985), 159-173.

Respite Care

Two forms of workable programs are available to the local congregation in its ambition to effectively minister to the families of the handicapped. One is to incorporate the families in, or form new, small groups. The other is to offer forms of respite care. Such ministry allows the burdened parents an opportunity to refresh themselves separated from the child and his or her needs, or to use the time to accomplish tasks the presence of the handicapped child prevented.

Gaventa has emphatically stressed that the time is opportune for the local church to minister to handicapped families with respite care. He has written that such services for families is a new way to effectively permit the religious and secular systems work together:

> . . . respite challenges the local community to act out the professed values of community self-reliance, family, hospitality, and care for "our own." In a religious world, respite care offers a simple, yet profound way to put faith into action; a way to put people into concrete, specific, limited and manageable ministries that can deeply touch the lives of everyone involved.[224]

Gaventa is confident that, in such a partnership, funding can come from the secular segment, with the church contributing the spirit and the commitment.

On the negative side, families in stress, as handicapped families are, do not, in Bossert's words, "attract or reinforce well-intentioned friends."[225] Getting close to such families requires persistence and patience. Yet, the fruits are worth the effort. Fortunately, this kind of outreach requires little training or expertise. Across the nation, small support groups are rendering invaluable service for burdened families. Bossert adds, "self-help groups across the country help to heal persons who might never have been helped by the

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[224] Gaventa, "Respite," 22.

[225] Paula Bossert, "Families," 29-33.

most gifted or professional counselors."[226] The problems of the families are formidable. They include financial stress, the stress of being stigmatized, and the stress of personal care and physical management. Parents' sleep is routinely interrupted. They are, indeed, isolated with limited opportunities for wholesome recreation. The children's behavior problems are continuous sources of frustration and embarrassment when displayed in public. It is no wonder the parents of the handicapped are often characterized by an attitude of pessimism.[227]

In 1983, Ball shared the report of many of those he surveyed that "there were no specific and appropriate services being provided by the church." His respondents said they felt "excluded" and even the ministers were uncomfortable around the handicapped. Churches did not offer programs; interested individuals were involved. The focus tended to be on children, especially the very young.[228] Nonetheless, Singer and Irvin emphasize that intimate social support is important and wrote:

> ...informal social support from extended family members and friends can make an important difference...usually, religiosity is accompanied by social support from clergy and fellow congregants.[229]

It is for the local congregation to make that choice and commitment.

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[226] Bossert, "Families," 29.

[227] Moroney, Robert M., "Public School," 194.

[228] Ball, "Pastoral," 145.

[229] Singer and Irvin, "Family," 10.

Recommended Reading

Brief works which give practical information and instruction regarding specific handicaps are especially appreciated by parents and by other non-technical professionals. A very practical work on deafness is They Grow in Silence: The Deaf Child and His Family (1971) by Eugene D. Mindel and McCay Vernon.[230] Also written for parents is Betty B. Osman's 1979 book, Learning Disabilities: A Family Affair.[231] Attention Deficit Hyperactive Disorder (ADHD) is a latecomer to the list of disabilities covered by P.L. 94-142. Hyperactive children were long considered simply behaviorally (BD) or emotionally disturbed (ED). Recent research has changed that, but relatively little is provided parents and other involved adults other than shorter works published by state departments of education and special interest groups such as Children with Attention Deficit Disorders (CHADD). The Virginia Department of Education, for example, gives a practical handbook in the Task Force Report, "Attention Deficit Hyperactive Disorder and the Schools" (no date given).[232] In sharp contrast is the abundance of publications on mental retardation. Robert Perske's 1981 Hope for the Families: New Directions for Parents of Persons with Retardation or Other Disabilities[233] is highly recommended as a short introduction.

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[230] Vernon and Mindel, They Grow.

[231] Betty B. Osman, Learning Disabilities: A Family Affair (New York: Random House, Inc., 1979).

[232] Task Force Report, "Attention Deficit Hyperactivity Disorder and the Schools" (Richmond, VA: Virginia Department of Education, n.d.).

[233] Robert Perske, Hope for the Families: New Directions for Parents of Persons with Retardation or Other Disabilities (Nashville, TN: Abingdon Press, 1981).

CHAPTER 9

PUBLIC LAW AND THE HANDICAPPED

History of P.L. 94-142

The appendices of Paul's 1981 book, Understanding and Working with Parents of Children with Special Needs, contain helpful listings of the developments relating to the handicapped in American society since, in some cases, its beginning. He outlined the historical view of exceptionality. He then highlighted the several steppingstones in history which served to strengthen the position of parents of the handicapped. His final appendix lists the service delivery systems in America since 1890 which touched the lives of the handicapped and their families--the educational, mental health, social welfare, legal correctional, religious, and counter institutions.[234] This chapter draws on Paul's groundwork.

Society's concern for the non-normal is reflected in such productions as Darwin works on evolution and the survival of the fittest and the social Darwinism which followed in the late 19th century. The Kallekaks, written in the early years of the twentieth century, purportedly traced feeblemindedness to a genetic origin. Concern for the feebleminded led to their societal restraint and even to their sterilization to protect society. Their institutionalization expanded the greatest in the period from 1925-1950. By 1940, schools

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[234] James L. Paul, ed., Appendices A-F, Understanding and Working with Parents of Children with Special Needs (New York: Holt, Rinehart and Winston, 1981), 276-288.

already had the right to exclude the "uneducable," In 1959, a reawakening of professional interest in training exceptional children occurred, and shortly thereafter programs for training teachers for special education were begun. The White House Conference of 1960 gave strong support for programs and research. In 1963, P.L. 88-164 and P.L. 88-165 called for comprehensive MR centers. By 1969, the movement away from institutionalization began, and in 1970, another White House Conference called for comprehensive health services, advocacy systems, and integration for the handicapped. In 1975, P.L. 94-142 was signed into law.

Parental Roles and Organization

In 1900, parents were blamed as the cause of children's problems, often being made the scapegoats. By 1920, public education was looked upon as the tool to "immunize" children from parental permissiveness. In the early 1930's, however, a group of mothers in an Ohio community expressed their indignation that their children were excluded from school. They proceeded to form a special class. By 1949, parents began to demand of local boards and state legislators that their handicapped children receive an equal education. Indeed, by 1955, legislators and policy makers turned to parents for information and advice. Organizations became established by the 1950's--National Association of Parents and Friends of MR Children (1950); Association for Children with Learning Disabilities (1960-1964); National Society for Autistic Children (1965); International Association of Parents of the Deaf (1965); Epilepsy Foundation of America (1967). When P.L. 94-142 was passed in 1975, it set the standards for parents' involvement in the educational process of their children.

Public Law 94-142 (1975) and its Implementation

Deinstitutionalization and the mainstreaming of handicapped children were both significant milestones in their assimilation into the community. The following is based on the 1990 book, Negotiating the Special Education Maze, by Winifred Anderson, Stephen Chitwood, and Deidre Hayden, written as an aid to parents of handicapped children.[235]

P.L. 94-142, the Education for All Handicapped Children Act of 1975, was foundational for later federal legislation in this area. Most significant is its legitimization of parent involvement in the process of their disabled children's education. Their parental role was, in fact, mandated, making them equal partners with the other professionals in the educational decision-making procedure. Henceforth, parents were to be "educational advocates."[236]

The law specifically covered mental retardation, hearing impairments, deafness, visual impairments, speech or language impairments, serious emotional disturbances, orthopedic handicaps, and other health impairments such as autism, serious heart conditions, and learning disabilities. Its six major provisions included the following:

1. all children will be served (since 1990, ages 3 through 18; some states, from birth);
2. children will be tested fairly to determine if they will receive special education services (non-discriminatory testing (language, etc.);
3. schools have a duty to provide individually designed, appropriate programs for every child at no cost to their parents (Individualized Education Program (IEP); for the very young, amendment PL 99-457, parents work with specialists in writing Individualized Family Service Plan (IFSP) for intervention services (family training, counseling, direction for the child);

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[235] Winifred Anderson, Stephen Chitwood, and Deidre Hayden, Negotiating the Special Education Maze (Rockville, MD: Woodbine, 1990).

[236] Anderson et al., Negotiating, vii-viii.

4. children with disabilities will be educated with children who are not disabled (mainstreamed), guaranteed services in the least restrictive environment;
5. the decisions of the school system can be challenged by parents (due process--third party; right to challenge and right to notice about any change);
6. parents of children with disabilities participate in the planning and decision making for their children's special education[237]

An important amendment, P.L. 101-476, was passed in October of 1990. The name of the education for the handicapped was changed to Individuals with Disabilities Education Act (IDEA). The act added autism and traumatic brain injury as disabilities to be covered by its provisions. "Transitional services" were given new definitions for the change from school to work. To that end, the student would, at age 16, have an individualized transition plan (ITP), much as his educational plan had earlier been constructed on an individual basis (IEP).[238]

Before the law can be applied, children must be identified as having the need for such special services. To that end, "Child Find" has been part of P.L. 94-142 for several segments of the community. The community is to know that every qualified child with special needs will receive an education meeting his or her needs without cost to the parents. The parents are to be aware of this and where such programs are obtained. Thus, each school division must identify, locate, and evaluate everyone from birth through age twenty-one who is in need of special education services. In 1986, PL 99-457 was enacted

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[237] Anderson et al., Negotiating, ix-xii.

[238] Anderson et al., Negotiating, xiv.

to benefit preschoolers with developmental delays (ages 3-5) and developmentally delayed infants and toddlers, ages birth to 2, were included in early comprehensive services.[239]

Parents must learn both how decisions are made by the schools and when. Timing is very important and strict attention given to it is mandated of the school system. The cycle for the parent travels from awareness of the need for special education to gathering pertinent information. Once the child is accepted, his or her plan is constructed and then carried out in a program. After this, it is important that the parents faithfully check on the program implementation. That, in turn, leads to awareness and the cycle begins again. For the school system, the cycle consists of referral, evaluation, determining eligibility, and constructing the child's IEP and placement. The child needs an instructional plan and this comes under annual review, which, like referral, starts the cycle in motion again.[240] Anderson and her co-authors describe the confusion so common to parents of children in special education.

> Over the years parents have often been confused, frustrated, and generally perplexed in their attempts to understand how school officials make decisions about the education of their special children. As parents talk with teachers and administrators and hear of evaluation and eligibility procedures, IEPs, learning disabilities, and due process hearings, they often feel that schools have built a complex special education maze through which only educators can find the way. Parents frequently have not known how to take the first step toward negotiating this maze.[241]

As the new year begins for the child and parents, the annual planning cycle gets underway. The process never ends. The IEP must be reexamined and revised where necessary. This concerns educational goals, objectives, and services needed. New data must be gathered.

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[239] Anderson et al., Negotiating, 40.

[240] Anderson et al., Negotiating, 2-5.

[241] Anderson et al., Negotiating, 204.

New law changes must be studied. New personnel must be met. Changes in services must be brought about. New strategies must be invented by the parents.[242]

P.L. 94-142 and the Civil Rights Movement

The Civil Rights Movement of the 1960's was intended to eradicate discrimination against minority groups, primarily African-Americans. Gliedman and Roth have pointedly observed, "The stigma of handicap bears many general resemblances to the stigma of race."[243] "Minority groups" eventually expanded to include many sub-groups within American society--women, homosexuals, the elderly, and the handicapped.[244] Warren and Warren point out that parents of the developmentally disabled are noteworthy for their efforts to guarantee those rights for their children, as well.[245] Mandell and Fiscus also note parental impact, as parent advocacy groups, on the quality of special education and the eventual maintstreaming of their children.[246]

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[242] Anderson et al., Negotiating, 204-206.

[243] Gliedman and Roth, Unexpected, 22.

[244] Seymour R. Sarason and John Doris, Educational Handicap, Public Policy, and Social History: A Broadened Perspective on Mental Retardation (New York: The Free Press, 1979), 357.

[245] Frank Warren and Sandra Hopfengardner Warren, "The Role of Parents in Creating and Maintaining Quality Family Support Services," in Support for Caregiving Families: Enabling Positive Adaptation to Disability, ed. George H. S. Singer and Larry K. Irvin (Baltimore, MD: Paul H. Brookes, 1989), 60.

[246] Mandell and Fiscus, Understanding, 3, 95.

Short-Comings of Pl 94-142

The handicapped certainly gleaned benefits from the Civil Rights Movement and legislation which passed concurrent with public sentiment social problems of the 1960's and 1970's. With that benefit, however, came the realization that the handicapped do not actually constitute a social group with its own identifiable and unique status, as do those subgroups identified by race, culture, gender, or even life style. Thomas has commented that such a circumstance intensifies the isolation of the handicapped and problems which ensue tend to be regarded by the handicapped as their own personal inadequacy.[247] The advantages of special education finally met the expectations of the work place. One is inclined to agree with Gliedman and Roth, however, that the benefits of improved education may have changed the handicapped applicant but they did not change the bias of the employer.[248]

Another criticism is leveled at the educational system itself, as finely honed as it may be. Walker has noted the free exchange of information between parent and teacher in informal, face-to-face, day-to-day encounters and relationship and negotiation building. Within the mandated process of the IEP, the information exchange may, Walker said, actually be hampered.[249] A few years after P.L. 94-142 was enacted, Gliedman and Roth said the shortcomings of P.L. 94-142 were two-fold. The parents were, as laypersons,

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[247] Thomas, Social Psychology, 11.

[248] Gliedman and Roth, Unexpected, 273.

[249] Barbara Walker, "Strategies for Improving Parent Professional Cooperation," in Support for Caregiving Families, ed. Singer and Irvin (Baltimore: Paul H. Brookes, 1989), 104.

without free translators to make sense of the hearings and the school records. The second weakness was in the lack of dispatch in the review procedure.[250]

In his historical overview of service delivery systems, Paul included the religious system. The picture is, basically, one of a major institution in society relinquishing its involvement with the handicapped to the state and secular agencies. In the early years of the twentieth century, the religious bodies were in conflict with secular agencies regarding the delivery of services to children with special needs. In 1913, religious education for parents was regarded as essential. By 1950, religion-based support was withdrawn from social systems, and, a decade later, religious considerations had become even less important than professional competency. In the 1970's, Protestant agencies came to view themselves as simply a part of the total community.[251]

Recommended Reading

For special education, Joseph N. Murray and Caven S. McLoughlin edited Childhood Disorders: Preschool and Early Elementary Years[252] (1984), a good collection of articles on various disabilities. For teachers, Gary Best's 1978 Individuals with Physical Disabilities: An Introduction for Educators[253] is a good overview. A good collection of articles on education was compiled by editors Craig T. Ramey and Pascal L. Trohanis in

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[250] Gliedman and Roth, Unexpected, 193.

[251] Paul, "Appendix F," 285-288.

[252] Murray and McLoughlin, Childhood.

[253] Best, Individuals.

1982, Finding and Educating High-Risk and Handicapped Infants.[254] A book that is highly regarded is by Seymour R. Sarason, together with John Doris, Educational Handicap, Public Policy, and Social History: A Broadened Perspective on Mental Retardation.[255] Since the passage of Public Law 94-142 in 1975, mandating the provision of appropriate education for each individual handicapped child, a very fine guide was compiled by Winifred Anderson, Stephen Chitwood and Deidre Hayden, under the auspices of the Parent Educational Advocacy Training Center. Written in 1990, it brings one up-to-date in procedures and legislation relating to special education. It is Negotiating the Special Education Maze: A Guide for Parents and Teachers.[256] Milton Seligman is a very good source for teachers in their position of straddling special education and counseling. His book, written in 1979, is Strategies for Helping Parents of Exceptional Children: A Guide for Teachers.[257] A systems perspective of the family-school relationship is found in the book edited by Marvin J. Fine and Cindy Carlson, The Handbook of Family-School Intervention: A Systems Perspective.[258]

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[254] Craig T. Ramey and Pascal L. Trohanis, eds., Finding and Educating High-Risk and Handicapped Infants (Baltimore, MD: University Park Press, 1982).

[255] Seymour R. Sarason and John Doris, Educational Handicap, Public Policy, and Social History: A Broadened Perspective on Mental Retardation (New York: The Free Press, 1979).

[256] Winifred Anderson, Stephen Chitwood and Deidre Hayden, Negotiating the Special Education Maze: A Guide for Parents and Teachers (Rockville, MD: Woodbine House, 1990).

[257] Seligman, Strategies.

[258] Marvin J. Fine and Cindy Carlson, eds., The Handbook of Family School Intervention: A Systems Perspective (Boston: Allyn and Bacon, 1992).

CHAPTER 10

CHILD ABUSE AND THE HANDICAPPED

Abused Handicapped Children

In 1984, the editors of Exceptional Parent poignantly asserted that it is time to stop pretending that abuse of handicapped children does not happen.[259] In Seattle, WA, a two-year study discovered that approximately 500 mentally and physically disabled children and adults were victims of sexual abuse each year in that city.[260] The observation has been made that negative attitudes toward the vulnerable contribute to the victimization of the handicapped and disabled. Cruz and co-authors say this actually "increases the likelihood that they will be victimized."[261] As Korbin has written,

> while children in general may be highly valued by a cultural group, there are categories of children who are more vulnerable to mistreatment. These include illegitimate children, adopted children, deformed or retarded children, high birth order children, and female children.[262]

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[259] Editorial [M.J.S./S.D.K.], "Abuse of Children with Disabilities--time to Stop Pretending," Exceptional Parent 14 (September 1984) 13-14.

[260] Janice Daur Watson, "Talking about the Best Kept Secret: Sexual Abuse and Children with Disabilities," Exceptional Parent 14 (September 1984) 15-20.

[261] Virginia Kiehlbauch Cruz, Douglass Price-Williams, and Linda Andron, "Developmentally Disabled Women Who Were Molested as Children," Social Casework 69 (September 1988) 411-419.

[262] Jill E. Korbin, Jill E., ed., "Introduction," in Child Abuse and Neglect: Cross-Cultural Perspectives. Los Angeles, CA: University of California Press, 1981.

Precipitating Factors of Abuse of Handicapped

Even though parents of the handicapped wish the best for their children, the circumstances can become so frustrating some become child-abusers. This is especially true as they may find their own needs, emotional, physical, and social, unfulfilled. Taylor commented that this is one outgrowth of the community's ignorance of the burden of parenting a handicapped child. She says, "Parents literally are victims of abuse, which is brought about by the tensions created by a handicapped child."[263]

The issue of child abuse raises the question of violent treatment as the possible cause for the disability. In wrestling with this question, Mandell and Fiscus found evidence to suggest that, as handicapped children are, indeed, at risk for abuse, there may be a causal relationship with the disabling condition.[264] Martin reported that treatment of retarded children suggests not so much that abuse caused the retardation but that it brought abuse about. While it is not possible, at this time, to say that a child is affected mentally by physical abuse, there is no doubt that it can lead to such an injury.[265]

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[263] Lonnia C. Taylor, "Project Cope," in Professional Approaches With Parents of Handicapped Children, ed. Elizabeth J. Webster (Springfield, IL: Charles C. Thomas, 1976), 146-190.

[264] Mandell and Fiscus, Understanding.

[265] Harold P. Martin, "Which Children Get Abused: High Risk Factors in the Child," in The Abused Child: A Multidisciplinary Approach to Developmental Issues and Treatment, ed. Harold P. Martin (Cambridge, Mass: Billinger Publishing Company, 1976) 27-41; similar concerns were expressed by Norman S. Ellerstein (1981), "Central Nervous System Injuries," Child Abuse and Neglect: A Medical Reference (New York: John Wiley & Sons).

Definition of Abuse

Abuse takes several forms. It may be physical, emotional, sexual, or neglect.[266] Primarily, abuse is thought to be emotional and psychological in nature.[267] Sexual abuse is especially hateful but when requires careful description. Cunningham offers this clarification:

> Sexual assault means the forcing of sexual contact. The contact may involve handling of the child's genitals, or requests for sexual handling by an older child or adult. Sometimes the contact is oral sex. It includes attempts at penetration of the vagina or anus and may involve actual penetration.
>
> Or there may be no physical contact. A child may be forced to look at the genitals of an older person, or may be asked to undress or otherwise expose himself.
>
> The key word is force . . . The force is not necessarily physical. Force can include . . . taking . . . the advantage of age . . . bribery . . . threats . . . withdrawal of affection . . .
>
> When we see what force can involve...it is estimated that 85% of sexual assaults on children are made by people known to them... approximately 50% of all sexual assaults occur within the family.[268]

Abusive Environment

Is abuse of children, and especially those who are handicapped, to be found only, or primarily, in families of lower social and economic standing? Or can it be as prevalent in all classes and on all levels? Abuse occurs in every class and at every level. It is the

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[266] Mandell and Fiscus, Understanding, 423.

[267] Marla R. Brassard and Ilia M. Apollaniz, "Abusive: Theory and Intervention," in The Handbook of Family-School Intervention: A Systems Perspective, ed. Marvin J. Fine and Cindy Carlson (Boston: Allyn and Bacon, 1992), 217.

[268] Marilyn Cunningham, Helping the Sexually Abused Child: A Guide for Foster Parents (San Rafael, CA: Marin County Department of Health and Human Services, 1982), 6-7.

experience of those who deal with crisis, however, that the more frequent occurrences are among the disadvantaged. Gelles described the domestic situation in this way: 90 percent of abuse within the family is related to poverty, to marital conflict, to social isolation, or to the overwhelming burden placed upon the mother. The mother and her husband are typically young and immature, inexperienced at coping with the complexities of life and with the responsibility of parenthood, as well.[269]

Gelles has noted that the highest rate of child abuse is found among housewives with children aged 3 to 4. These women also had next to the highest rate of overall violence. (Women who were part-time workers and older children, ages 5 to 9, were more excessively violent.) On the other hand, the lowest rate of abuse was found among mothers with full-time jobs and preschool children, followed by full-time workers with teen-aged children. Interestingly, fathers' abusive actions varied with the working lives of their wives. If the mothers did not work, fathers tended to be more abusive. It was, as Gelles described, the "Wait 'til your father gets home!" syndrome.[270]

Pallone and Malkemes add pertinent information to our understanding of the abusive family and its makeup. The family is characterized by isolation and a lack of independence. Within the family, low self-esteem on the part of the parents leads to the paradoxical reversal of roles with the children, who are usually the victims of their abuse. Yet, in addition to the impulsiveness of their behavior and the void of meaningful and

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[269] Richard J. Gelles, Family Violence (Newbury Park, NY: Sage Publications, 1987), 99.

[270] Gelles, Family, 101.

fulfilling social experiences, the parents tend toward excessive control and a low tolerance for frustration. Overall, their lack of adequate parenting skills leads to disaster.[271]

According to Brassard and Apellaniz, the incidence of child abuse reported in 1986 was 16.3 per 1,000 (over a million). The rate with endangerment was higher, 25.3 per 1,000 (1.5 million). It was estimated in that year that only 46 percent of the incidents were actually reported. (The Seattle study, referred to above, stated that only 26 percent of the incidents were actually reported.)[272] Additionally, female victims were abused four times the rate of male victimization. The researchers found that, when income level was considered, those parents in higher levels tended to engage only in physical abuse, while the poorer parents engaged in both physical abuse and neglect.[273] There has been a reduction in reported abuse. Noting the statistical change between 1975 and 1985, Geiser suggests that there is an unwillingness to report abuse to researchers, or that it has lost its previous acceptance in American society. Yet, he allows, there may, indeed, be an actual change in behavior.[274] Such change, however, does not reduce the concern of society and of the Church for the victims, especially since the majority are not as yet identified by reporting or by records.

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[271] Sharon R. Pallone and Lois C. Malkemes, Helping Parents Who Abuse Their Children: A Comprehensive Approach for Intervention (Springfield, IL: Charles C. Thomas, 1984), 8.

[272] Watson, "Talking," 15-20.

[273] Brassard and Apellaniz, "Abusive," 217-218.

[274] Robert L. Geiser, The Illusion of Caring: Children in Foster Care (Boston: Beacon Press, 1973), 24-26

Treating Abuse

Pallone and Malkemes have stated that abusive parents fall short of the several developmental stages outlined by Erik Erikson. They have not achieved a basic sense of trust nor a sense of autonomy. Falling short of initiative, they also lack in the industriousness needed to master the task at hand. They also lack a sense of identity.[275] Brassard and Apellaniz suggest that these parents can develop the necessary skills by what they term "social learning approaches." They claim it is successful in improving the parents' control of their anger and in developing interpersonal skills.[276]

The problem requires extensive work with both the abused children and with the abusing parents. Brassard and Apellaniz strongly urge that a capable therapist be involved, but they add a warning. The work is so difficult and so often discouraging, if the person involved in the training and healing is not capable, it is better not to attempt the venture. Rather, that person ought to aid in finding other resources.[277] At the time of crisis, however, removing the child from abusive parents is the first consideration. This procedure, Mandell and Fiscus inform us, is not as frequently pursued as might be assumed. The first concern is the medical attention to be given the victim; then, the home situation is investigated. Alternatives for state action are several, should the parents be found incompetent: foster homes, group homes, extended family, and institutional care.[278]

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[275] Pallone and Malkemes, Helping, 9.

[276] Brassard and Apellaniz, "Abusive," 220.

[277] Brassard and Apellaniz, "Abusive," 227.

[278] Mandell and Fiscus, Understanding, 431.

CHAPTER 11

FOSTER CARE MINISTRY WHEN PARENTING FAILS

The focus of this paper is primarily on parents, particularly those who are parents of handicapped children. In the United States, nearly half a million children are in state-funded care away from their homes and birth parents.[279] Of these children, 90 percent are cared for under direct public auspices, the rest, by sectarian agencies.[280] As for the caregivers, Geiser wrote that five out of every thousand children in America are in foster care, three-fourths of them in foster homes.[281] Little reliable data are available about handicapped foster children, but, in 1983, Barsch and co-writers decried the failure of the system in general to adequately provide for the needs of the increasing numbers of foster children with special needs.[282]

In the last century, children in need of basic necessities such as food and shelter, who could not live in their own homes, were provided those necessities by government

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[279] Children's Rights Project of the American Civil Liberties Union, A Force for Change (New York: ACLU Public Education Department, 1993), 11.

[280] James R. McGraw, "Foster Care in New York: Church, State and the Kids," Christianity and Crisis 34 (1975), 308.

[281] Elizabeth T. Barsch, Judith A. Moore and Leo A. Hamerlynck, "The Foster Extended Family: A Support Network for Handicapped Foster Children," Child Welfare 62 (July-August 1983), 349-350.

[282] Robert L. Geiser, The Illusion of Caring: Children in Foster Care (Boston: Beacon Press, 1973), vii.

systems. By 1960, the federal government decreed that unfit parents receiving welfare benefits would lose both the benefits and the custody of their children. The number of such foster children has been increasing by five percent annually. The number of qualified foster parents, however, has declined in recent years. Between 1984 and 1993, their numbers dropped from 134,000 to 100,000.[283]

While all those in foster care are, in one way or another, children at risk, this is especially true of handicapped foster children. Foster children in general may suffer externally because of their parents' unemployment and poverty, or from severe physical illnesses in the family. Internal stress is suffered because of mental illness, emotional conflicts, and personality inadequacies.[284] It ought to be pointed out, however, that the enrollment of foster children in special education may not be due to disabilities, as ordinarily understood. Such children typically come from dysfunctional families and/or disadvantaged families. They tend to need specialized attention suitable for meeting their deficiencies. Furthermore, the longer children are in the foster care system, the more likely are they to be in special education in school.[285]

As the needs of handicapped foster children come to the attention of the local church, in keeping with the emphasis of this paper it is important that the foster parents and their special needs be given attention, as well. As birth parents of handicapped

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[283] Children's Rights, Force, 2.

[284] Children's Rights, Force, 11.

[285] Paula A. Sinanoglu, "Working with Parents: Selected Issues and Trends as Reflected in the Literature," in The Challenge of Partnership, ed. Anthony N. Malluccio and Paula A. Sinanoglu (New York: Child Welfare League of America, 1981), 10.

children become labeled by their linkage with their own children, foster parents also become so labeled. A consequence for such parents, birth or foster, is isolation.[286] A further frustration is the effects of giving care to children as if they were one's own who are, in fact, not genetically related. In a normal family setting, parents expect their children to succeed. When that is not realized, the investment of those significant persons in the children's lives becomes lost. The principle is true even when the bond between adult and child is weak, as in foster care. As will be developed below, such frustration can lead to child abuse.[287]

To repeat, foster children are placed outside their homes because they are at risk. This is especially true if they are handicapped. Realization of the danger is sharpened by statistics, that of the million children abused each year, 2,000 die.[288] Another study shows that, in 1993, three children die each day as the result of abuse or neglect, and that maltreatment reports reached three million in the 1992-1993 period. Tragically, a third of those reported received no services at all.[289] The same source published findings by the GAO (General Accounting Office) that foster children are increasing in numbers rapidly, that this is fueled in part by growing substance abuse, and that such children are entering

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[286] Robert M. George, John Van Voorhis, Stephen Grant, Katherine Casey, and Major Robinson, "Special-Education Experiences of Foster Children: An Empirical Study," Child Welfare 71 (September-October 1992): 423.

[287] Barsch, et al., "Foster," 351.

[288] Richard J. Gelles, Family Violence (Newbury Park: Sage Publications, 1987), 43.

[289] Virginia D. Ratliff and J. Bill Ratliff, "Abused Children," in What Children Need from Significant Adults, ed. Andrew D. Lester (Philadelphia: The Westminster Press, 1987), 126.

the system earlier and with more serious problems.[290] Taylor wrote that, when the parents' needs, emotional, physical and/or social needs, are not met, they may become child-abusers. A handicapped child oftentimes frustrates even the most balanced of parents. Frequently, that frustration spills over into harmful action. Taylor wrote,

> Parents literally are victims of abuse, which is brought about by the tensions created by a handicapped child...Little attention was paid to parents' needs.[291]

Providing foster care is stressful for the caregivers. We do well to consider the problems and uncertainties carried by the foster child. He usually comes from a dysfunctional family, which usually means he has a negative self-image. The major difficulty for the child, however, is in his relationship with others. This is especially true of his relationship with his foster parents. He tends to see all adults placed over him, including child care workers, teachers, social workers, and any others in authority, as he saw his birth parents.[292]

Although their family background may have been inadequate, even dangerous, and although foster children may have been placed outside the home for their own good, as they usually are, the separation is nonetheless extremely painful.[293] Geiser reminds us that

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[290] Child Welfare League of America (reporting results of the annual 50-State Child Abuse Survey by the National Committee to Prevent Child Abuse), Children's Voice 3 (Summer 1994), "New Studies Document Children's Plight, Propose Solutions," 8-9.

[291] Lonnia C. Taylor, "Project Care," in Professional Approaches with Parents of Handicapped Children, ed. Elizabeth J. Webster (Springfield, IL: Charles C. Thomas, 1976), 148.

[292] Geiser, Illusion, 42-43.

[293] Arthur Mandelbaum, "Parent-Child Separation: Its Significance to Parents," in Children Away from Home: A Sourcebook of Residential Treatment, ed. James K.

(continued...)

"loving parents is not the same thing as wanting to become like them."[294] Thus the foster child brings many psychological maladjustments into the foster home. Geiser also described the child as fearful, suspicious, demanding, distrustful, complaining, and defiant of adults, oftentimes behaving with aggressiveness, hostility, and hyperactivity. He maintained that "the major area of damage" for them is in forming new relationships.[295]

What can the local church do in foster care ministry? Certainly, for those church members equipped to assume such responsibilities, the church ought to offer encouragement. The writer reminds the churches, however, that the needs of foster parents are even greater than parents with their own, or even adopted, children. In interviews with professional workers, the writer received suggestions parallel to that which this paper gives in support of parents of handicapped children. Whether the foster children are handicapped or not, the foster parents need respite time. They also need the mutual support that comes from groups of foster parents.

The first interview was with a social worker employed by the Lynchburg Social Services. She offered five suggestions.

First, let a church gives its care to one child. The foster family with whom the child would live would receive the needed training, while others would be supportive with needed respite care and transportation.

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[293](...continued)
Whittaker and Albert E. Trieschman (New York: Aldine Publishing Company), 383.

[294] Geiser, Illusion, 78.

[295] Geiser, Illusion, 42-43.

Second, let the church be a neutral ground for meetings of the birth parents and the foster parents, a process now strongly encouraged in foster care programs. If needed, a member of the church could be on hand to supervise.

Third, a church in Virginia can participate in VEFC (Volunteers for Emergency Family Care) through which emergency shelter is provided, the stay lasting only up to 21 days. (VEFC also provides tutoring for the children.)

Fourth, the church can be the base for support groups. It would be helpful to have support groups for the birth parents themselves, just as it would be helpful for foster parents to have their own support groups.

Fifth, the church can provide a friendship family. On one weekend per month, the birth parents would have an opportunity to be in a normal family setting and to gain parenting experiences not otherwise afforded.

The social worker also referred to a congregation in the Lynchburg community at which birth parents could learn parenting skills, and improve themselves (such as earning the GED).[296]

The second interview was with a counselor in a residence in the City of Lynchburg for foster girls from central Virginia. She began with the premise that proper training of the children of American society is in decline. The current efforts being made to provide schools with materials for teaching ethics and values is inappropriate. The only major institution in society which is equipped to instill such ethics and values is the church, the local congregation. The counselor said that, although the churches failed and continue to

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[296] Sheila Krull, interview by writer, Lynchburg, Virginia, 28 September 1994.

fail to do so, this does not diminish the fact that the teaching is needed and the Church is the only major institution in society equipped to carry out the task.

Together with the problem of the children is the collapse of the family, especially among the disadvantaged. The circumstances which contribute to that collapse are not improving, in spite of governmental efforts to shore up the family and those who are dependent. Again, it is, in her view, the local congregation which is the institution best suited for such work. As with children at risk, so also with families at risk, the churches have failed, and still fail, to do so. The local congregation nonetheless remains the institution best equipped to turn things around.

The first step, according to this counselor, is to begin within the congregation itself, before reaching out into the community. In so doing, the congregation (especially its leaders) ought to be aware that some member-families are hurting and are, or are soon to become, dysfunctional. With that overview, a needs assessment would be conducted with a simple, one-page questionnaire, possibly included in the church newsletter. It would ask non-threatening questions regarding awareness of any individuals or families in the congregation who are in need of special help (although to be unnamed). With the information gathered, the responsible board and pastor(s) would contact those known by them to have problems (although not named by the questionnaire) and ask in what ways the church can be of assistance to them.

Drawing upon her own experience with dysfunctional families, the counselor suggested respite (hours, a day, a weekend) for the parents caught in stressful situations. Let "friendship families" offer to take the children home for that period of time. In many single-parent families, which may or may not be as yet dysfunctional, the male role model is missing. Both boys and girls need the unique contribution males give to their development and perspective toward themselves and toward the world. Men, therefore, ought to deliberately be made a vital part of ministry to families at risk.

While many families at risk may be resistant to acts of charity, a concerted effort ought to be made to draw them into the congregational family, to share the tasks of the church, and to give them a sense of belonging and of responsibility. Such families may, however, be in great need of development. Parenting skills may need to be taught as well as practical planning and budgeting within the family. These and other practical skills can be taught before the stress of family life becomes so great the members are torn apart and remediation becomes even more difficult.

Only after the congregation takes care of its own, according to the counselor, should the members look outward to other families with special needs to whom similar assistance might be offered. The counselor was emphatic in depicting the local congregations as the instruments for family improvement in American society. She would like to see each church share the vision and assume the challenge, first within their own circles and then beyond, in the community.[297]

Foster care, then, brings to the congregation in concentrated and dramatic form all the needs and challenges of caring for the families of handicapped children. There is no mistaking those needs and challenges by the local church members. There is also no acceptable ground for denying those needs and challenges by the families involved.

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[297] Vicky Maphis, interview by writer, Lynchburg, Virginia, 25 October 1994.

Bringing the numbers to awareness, the local church can, within the limitations of its resources, address the issues. As stated above, there is a need for advocates to bring that awareness about, from which appropriate action can ensue.

CHAPTER 12

SEMINAR

Description

The purpose of the project is to inform and sensitize church leaders, especially clergy, about the presence of the handicapped and their families in the community, perhaps in their congregations. When made aware of their existence and of their needs, it is hoped that the pastors will lead in outreach in meaningful and effective ministry to that segment of the population, which, as indicated above, is of significant size. Practical suggestions on the direction along which church programs ought to proceed are discussed in the seminar, as well as materials for a model forum, useful in the congregation either for sensitivity training or for use in small groups or Sunday school. Because the purposes of the seminar and forum are to inform and sensitize, they not only instruct but try to stimulate participants to further study. To that end, a booklist of significant publications is provided, as well as information on organizations and agencies which serve the handicapped and their families in a multitude of ways.

The seminar consists of introductory remarks, four sections dealing with aspects relevant to the topic of ministry to families with handicapped children, and a final list of possible applications in the local congregation.

In the presentations, worksheets are distributed for each part. As the material is presented, the participants fill in the key words in the blanks. The words are chosen to generate response and discussion. The entire seminar takes one hour plus time for discussion, or it may be divided into several smaller sessions.

To test the value of the seminar, parents of the handicapped were recruited by the writer to participate in a presentation of the material and to critique its content. In addition to parents, a few interested professionals (teachers and social workers) who serve the handicapped also agreed to participate and give their evaluations and suggestions.

A form was provided asking basic information about themselves and then for their input. They were asked to critique the presentation itself and to provide suggestions for outreach to families with handicapped members.

The church body to which the writer belongs is divided into geographical units, the smallest of which is the circuit. It consists of five to ten congregations. The pastors of the circuit meet on a monthly basis. The writer was included in the agenda of a meeting of the circuit of which he is a member. Four pastors took part. Their critique was from the viewpoint of pastors for whom the seminar is intended.

The forum materials were distributed to the clergy for use in their congregations. They include information for professionals and parents interested in agencies and organizations which assist or serve the needs of the handicapped and their families. A set of relevant brochures is also provided, primarily from the writer's denomination. Almost all denominational headquarters have additional information or programs developed for the specialized work applied to their local congregations.

The seminar is developed specifically with church workers in mind. The material can be used, or adapted, for local or regional gatherings. Each segment referred to resources, which are listed at the end of the seminar material. (For ease of understanding by another user, the list is given in the APA format.) The suggested forum is intended for increasing awareness of the handicapped and their families, to be conducted within the congregation. In addition to the handout, outlining the presentation, and printed materials available from churches, state offices, and organizations serving the handicapped, videotaped materials can also be used. (For example, Bethesda, the Lutheran home for the mentally retarded located in Watertown, WI, has excellent videotapes and printed materials useful for such seminars and discussion groups.

The benefit hoped for from the seminar contained herein, it is to be remembered, is for the expanded ministry of churches to include the families of the handicapped, not primarily the handicapped themselves.

Responses to the Presentation

Nine persons representing parents and professionals were recruited to critique the seminar, four men and five women. Six were parents without professional involvement. One was a professional working with handicapped children in the school system. Two were both, parents of handicapped children and also professionals working with the handicapped and their families. The handicaps represented by the eight parents included ADHD, hearing impairment, autism, and an orthopedic disorder. They were asked to indicate, if they felt free to, their degree of activity in organized religion, past and present.

Noone had no contact with the church. Seven have been active past and present. One parent was not active and became so recently. One, a combined parent and professional, was active in the past but fell away from activity.

All four of the participating clergy have or have had meaningful contacts with the handicapped. One pastor has given pastoral care to the mentally retarded. One pastor's wife has a retarded sister. His wife was at one time the director of an agency which provided group homes for the retarded. They frequently had retarded adults as guests in their home. Two pastors are fathers of children with special needs. One has a daughter he described as LD/ED. He chaired Adult Activity Services, a day program for mentally handicapped adults. The fourth pastor had served a retarded church member in the past and presently has six ADHD children in his congregation. He also adopted a son who is AD/ED.

All thirteen participants gave a positive evaluation of the seminar. Specific suggestions were interesting and helpful in refining the shape of the instrument used. One layman, a parent, thought the section on the Bible might not be necessary, that clergy are aware of its references to the handicapped. (This was later posed to the clergy, but they felt that it needed to be included.) Another parent suggested reversing parts two and three, giving the "why?" discussion first and then the biblical references. The non-parent professional, who is also a teacher, suggested that the handout be less "busy" and easier to follow. A pastor suggested using an overhead in the presentation. Another pastor suggested that, when time allows, stories would make the presentation more meaningful for the clergy in the seminars.

A parent suggested including reference grandparents in the seminar presentation. One parent-professional, who changed from active to inactive in church involvement, expressed the feeling that the clergy ought to offer support (her emphasis) to the family. The other parent-professional, who happens to have been consistently active in the church, suggested working toward the establishment of circles of friends for the families of the handicapped. One pastor suggested a deeper look into the link between poverty and disability, which was brought out in the presentation. He also suggested a closer examination of the emotional side to church members non-involvement with the handicapped and their families. As for ways to reach clergy with the seminar and its message, the clergy all suggested that it be given at pastoral conferences. One pastor suggested a newsletter.

Several interesting revelations came out of the seminar critiques. The writer had a concern that he may have been overstating his case with regard to parents or that, even if he had not, the parents participating might object to his statements. This proved not to be the case. The first statement of the presentation asserted: "Parents never stop grieving." All the parents of the handicapped, lay and clergy, agreed with the statement. Such agreement is highly significant when one considers that the group consisted of those who have their lives in control, that they are well-educated, and that they are knowledgeable about the complexities of handicaps and their ramifications.

The writer was uncertain about what responses to expect to a statement contained in part three, the things parents talk about. Again, the parents tended to agree with what was presented. (The clergy made no comment.) The statement was that parents talk about four topics: their own unhappiness, their families, professionals, and the road to recovery. One can see the underlying connection with the introductory statement of part one, that parents never stop grieving. As stated earlier, outsiders see the parents as carrying on their daily lives with aplomb, while the stressful difficulties they experience remain hidden and are usually never completely resolved.

The writer found the study of theodicy intriguing, that one searches for reasons for the way of God with mankind. He feared, however, that it might be confusing for the parents and that they would reject that part. They did not. He then feared that the clergy would take exception to the philosophical constructs as used by the writer, but they registered fascination with the topic in much the same manner as had the writer.

Not surprisingly, none of the participants, lay or clergy, had well-defined suggestions for reaching either unchurched families with handicapped members or for effectively involving clergy. The clergy themselves mentioned conference presentations as an obvious method. Other than that, little of significance was offered. Attention had been given to the handicapped themselves, but little or no thought had been given to the families.

APPENDIX A

SEMINAR

APPENDIX A

SEMINAR

Introduction

Introduction

I. CONCEPTS
    A. Problem
        1. Crisis of/at diagnosis
        2. Unserved by church
    B. Bible
        1. OT concern for handicapped
        2. NT concern for handicapped
Application

II. BASIS
    A. Model
        1. Question "why?"
        2. Four-fold analysis
    B. Church
        1. Attitude/uninformed
        2. Structure/program
Application

Develop guidelines

This four-part series will cover the areas outlined to the left. It is intended to help develop guidelines for churches and clergy--to inform and sensitize them to the presence and needs of the handicapped and their families.

Many thanks to you for your willing-ness to participate in this effort. We earnestly hope and pray that it will be a blessing and benefit to all.

Please fill out the following information (as much, that is, as you feel you can). There is no attempt (or intent) to identify individual participants.

We will be happy to provide you with a summary of the results if you wish.

Please share this information with us

Name (optional)____________________M___F___Phone number (optional)____________

Please describe experience(s) you (or other members of your extended family) have had with those who are (or were) handicapped.

____

____

____

Please indicate your involvement with organized religion.

In the past: active___ somewhat active___ inactive___ no involvement___

At present: active___ somewhat active___ inactive___ no involvement___

SEMINAR

Part 1

Parents never stop grieving. This is not, however, readily apparent, and therein lies part of the difficulty of parenting a handicapped child. Parents tend to appear well-adjusted and therefore receive little help with their feelings. The grief goes on without relenting.(Kratochvil & Devereax, 1988)

I. CRISIS OF/AT DIAGNOSIS

The birth of a handicapped child is a crisis. Here we give attention to the reaction of the parents to that event and to its impact on their lives.

Parents register initial reactions to having handicapped children, which may be divided into three phases. The first and primary reaction is shock, grief, and depression. This gives way to the second phase of ambivalence, guilt, anger, shame, and embarrassment. Finally, in the tertiary phase, they engage in futile bargaining, but manage to adapt and reorganize their lives, and even reach a sort of acceptance and adjustment. (Gargiulo, 1985) Essentially, the reactions are <u>negative</u> in character.

Help is necessary for parents fully as much as it is for their handicapped children. Appropriate help, however, is not always easy to find. The irony of their circumstances as been described in these words, "The more crisis-laden the child and the family, the less likely they are to find help." (Seligman, 1979) Intensity <u>varies</u> with the handicap.

With the entrance of a handicapped child, every aspect of family life is changed. The system of family life is rearranged. The relationship of husband and wife is not the same, nor is that of non-handicapped siblings with their parents, with each other, to a degree, and with the extended family. The place of the family within the community becomes one of isolation. One observer said, "One could say without exaggeration that the very foundations of the family as a social unit are threatened." (Kew, 1975) The family <u>changes</u>.

Further irony in the new family situation is the varying ways in which the disability is accepted. With the challenge of a severe handicap, obvious to all observers and obvious in the magnitude of care to be given, the parents and their family do accept the situation. There is no escape. On the other hand, when the handicap is mild, even possible to mask or ignore, the family finds acceptance more difficult. Among other things, parents always hold out hope for a miracle cure, a new medical development, or that the child will "grow out of it," as so many doctors are prone to promise. (Ross, 1964) The duration of the process of acceptance varies with the severity of the handicap.

Ross tells us that, "more often than not a parent settles for the kind of treatment of his child which is most congruent with his own personality needs." (Ross, 1964)

II. UNSERVED BY THE CHURCH

Religion may be important to the parents of handicapped children, but must be distinguished from organized religion. In the churches, the families are not involved. Moreover, when their needs are served, it is more by accident than deliberate.

Parents of handicapped children have declared that they gain support in their circumstances from personal religious beliefs. Such beliefs are personal and internalized, but are not to be confused with religion as an organization, such as a congregation. One study found that the parents tended, in fact, to not gain support from organized religious groups. (Fewell, 1986) The families of the handicapped, for the most part, are unchurched.

One of the experiences of life for the family of a handicapped child is isolation. Many have listed this, with its loneliness, is be a heavy burden to bear. (Jeffree & Cheseldine, 1983) The families of the handicapped tend, for the most part, to withdraw from social contacts.

That families of the handicapped are not part of organized religious activities is indicated by the finding that the average congregation in American society has only one or two handicapped members. (Ball, 1983) This is neither the fault chiefly of the churches nor of the families of the handicapped. The former tend to offer their ministry to those they see. Those in their circle of contacts do not, as a rule, include the isolated families of the handicapped. They serve those they see.

It is obvious that any form of professional work with the handicapped is not simple. As other conditions which are not normal, such as diseases and accidents, the departures from the expected and the normal require special and appropriate attention and ministry. Even among the professionals involved with the handicapped, such as doctors, counselors, therapists, etc., the tendency has been noted to push off responsibility for the complicated case of the handicapped person. As one described, "someone else" ought to be sought for the answers to the parents' questions. (Best, 1978) The churches, also, push off the responsibility to "someone else," church specialists, wherever they may be. Thus it is apparent that churches tend to serve those who are independent.

As noted earlier, parents never stop grieving. After working through the phases described above, do they ever really accept the inescapable? Some say not. He has written, "Parents may intellectually understand the problems of the handicapped child, but it is seldom that they truly accept them emotionally." (Love, 1970)

A key concept to the role of religion in the lives and hearts of the parents of handicapped children is that of "theodicy." Theodicy explains the occurrence of bad things in the lives of those who believe in a good God. It addresses the question of "why bad things happen to good people." It has been said, however, that proper pastoral care does, indeed, deal with theodicy and is "a key factor in the psychological health of disabled families." (Ikeler, 1986)

SEMINAR

Part 1

THE CHALLENGE: Parents never stop grieving.

I. THE CRISIS OF/AT DIAGNOSIS OF A CHILD'S HANDICAP

A. Reaction

Parental reaction is in phases. Essentially, the reactions are______________ in character.

"The more crisis-laden the child and the family, the less likely they are to find help."
Parental intensity of reaction__________ with the handicap.

B. Impact

With a handicapped child, "the very foundations of the family as a social unit are threatened." The family undergoes___________________.

It is ironic that it is___________ difficult for parents to accept a mild disability than a severe one.

II. GENERALLY, FAMILIES OF THE HANDICAPPED ARE UNSERVED BY THE CHURCH

A. Families are not involved

Parents of handicapped children gain support from___________ religious beliefs but not from_______________ religion.

The family of a handicapped child is in isolation. The family tends to_______________ from _________________________.

B. Ministry is accidental, not deliberate.

The average church has only one or two handicapped members. Churches have a tendency to serve the people they____________.

Professionals (including clergy) tend to push off responsibility to "someone else." It is preferred to work with people who are_______________________.

"Pastoral care in regard to theodicy can be a key factor in the psychological health of disabled families."

Theodicy:____

SEMINAR

Part 2

The principle of homogeneity is, in part, that like associates with like. People of the same age, or income bracket, or race, or culture, tend to prefer the company of others with whom they can identify, with whom they have something in common. Even though a tenth of the world's population is, in some way, handicapped, we tend to choose not to be in frequent contact with them. The adult handicapped tend also to be unemployed or in the lower income brackets. They are not the success stories our society admires. Thus, the words of St. Paul are the more significant: "Do not be proud, but be willing to associate with people of low position." (Romans 12:16)

I. THE OLD TESTAMENT CONCERN FOR THE HANDICAPPED

In several instances within the Pentateuch written by Moses, God drew special attention to the handicapped, to their vulnerability, and to the judgment that awaits those who exploit the disadvantaged and the handicapped. In Leviticus 19:14-15, God's people are instructed:

> Do not curse the deaf or put a stumbling block in front of the blind, but fear your God . . .Do not pervert justice; do not show partiality . . .

By the firm expression of His will, God <u>protects</u> the <u>vulnerable</u> and sternly forbids the <u>exploitation</u> of the same.

The Old Testament looked forward to the fulfillment of the Messianic prophecies. The Prophet Isaiah wrote, in several places, of the Suffering Servant would be bear the sins of the world. More than once, Isaiah made it clear that the Messiah would identify with the <u>handicapped</u>. One such statement is in the 35th chapter, which also has the <u>promise</u> of <u>heaven</u>:

> Strengthen the feeble hands, steady the knees that give way; . . . your God will come . . .. Then will the eyes of the blind be opened and the ears of the deaf unstopped. Then will the lame leap like a deer, and the mute tongue shout for joy . . . (Isaiah 35:1-10)

II. THE NEW TESTAMENT CONCERN FOR THE HANDICAPPED

Jesus is the principal model for expressed and demonstrated concern for those who are less fortunate. When St. Peter was sent to share the Gospel with the centurion Cornelius and his household, the apostle referred to the life of Jesus for His identification:

> "You know the message . . .telling the good news of peace through Jesus Christ . . .He went around doing good and healing all who were under the power of the devil, because God was with Him." (Acts 10:34-38)

The work of Jesus Christ was directed to the healing of man's bodies as well as their souls. His was a ministry of healing. Furthermore, He revealed by the special efforts He made among the multitudes, that the less fortunate are important to Him. He endowed value upon the vulnerable.

Jesus said that disciples are to be like their master. The apostles, therefore, would also show compassion for the handicapped and endeavor to relieve their conditions and suffering. A unique person in the early constellation of apostolic stars was one who was not an apostle, but rose to chair the Apostolic Council of Jerusalem. He was the brother of Jesus, James, who came to faith following Jesus death and resurrection. His words are very meaningful:

> Religion that God our Father accepts as pure and faultless is this: to look after orphans and widows in their distress and to keep oneself from being polluted by the world . . .. Don't show favoritism. (James 1:26-2:1)

Like Jesus, the apostles opposed bias and favoritism, and elevated the individual, even though disadvantaged and/or disabled.

St. Paul gave a summation of the life and example of Jesus by his words written to the Philippians:

> In humility consider others better than yourselves . . .. Your attitude should be the same as that of Christ Jesus: . . . being in very nature God . . .taking the very nature of a servant . . .. He humbled Himself. (Philippians 2:3-7)

The organized churches of Christianity today can do no less than imitate the ministry of its Founder, Jesus Christ. Thus, the biblical principles in interpersonal relations, especially as they apply directly to the handicapped, do not change:

> To the weak I become weak, to win the weak. I have become all things to all men so that by all possible means I might save some. (1 Cor. 9:22)

SEMINAR

Part 2

THE CHALLENGE: "Do not be proud, but be willing to associate with people of low position." (Romans 12:16)

I. THE OLD TESTAMENT CONCERN FOR THE HANDICAPPED

A. Mosaic Law

"Do not curse the deaf or put a stumbling block in front of the blind, but fear your God . . .Do not pervert justice; do not show partiality . . ." (Leviticus 19:14f)	1. God____________ the __________________ 2. God also forbids

B. The Messiah

" . . .Strengthen the feeble hands, steady the knees that give way; . . .your God will come . . .Then will the eyes of the blind be opened and the ears of the deaf unstopped. Then will the lame leap like a deer, and the mute tongue shout for joy . . ." (Isaiah 35:1-10)	1. He_______________ with the____________ 2. He_______________ __________________

Note: "Speak up for those who cannot speak for themselves, for the rights of all who are destitute. Speak up and judge fairly; defend the rights of the poor and needy." (Proverbs 31:8-9)

II. THE NEW TESTAMENT CONCERN FOR THE HANDICAPPED

A. Jesus

" . . .You know the message . . .telling the good news of peace through Jesus Christ . . .He went around doing good and healing all who were under the power of the devil, because God was with Him." (Acts 10:34-38)	1. He has a__________ of________________ 2. He gave__________ to the________________

B. Apostles

" . . .Religion that God our Father accepts as pure and faultless is this: to look after orphans and widows in their distress and to keep oneself from being polluted by the world . . .Don't show favoritism." (James 1:26-2:1)	1. He opposed_________ and_________________ 2. He elevated the_______ ________________

Note: " . . .in humility consider others better than yourselves . . .Your attitude should be the same as that of Christ Jesus: . . .being in very nature God . . .taking the very nature of a servant . . .He humbled Himself . . ." (Philippians 2:3-7)

Biblical principles do not change: "To the weak I became weak, to win the weak. I have become all things to all men so that by all possible means I might save some . . ." (1 Corinthians 9:22)

SEMINAR

Part 3

One cannot assume that religion is a positive force in the lives of families with handicapped members. It may, in fact, be negative. (Kew, 1975) This part discusses significant aspects of this topic. In terms of membership in organized religion, most parents of handicapped children, like the rest of the American population, identify themselves as churched. And like the rest, some are regular and some are not. We distinguish these parents in what follows.

I. WHEN CRISIS OCCURS, WE ASK THE QUESTION "WHY?"

In their spiritual reaction to having handicapped children, parents tend to assume a perspective relating to a divine Being. Some accept it as God's will for their good, while others accept it as a punishment from God. Still others experience an anger with God. (Schmitt, 1978) For these parents, "hope springs eternal." By and large, they tend to accept the situation and simply resign themselves to it. Parents react with either acceptance or anger.

It has been observed, however, that those parents with the greatest apparent difficulty in accepting or resigning to the condition of their children are, in fact, those for whom religion had been a more meaningful part of their lives. Their God had been revealed to them as loving and merciful, but the crisis of their handicapped children seemed to contradict what they had been taught to believe. Their anger, one parent has written, "poses a heavier problem: it cuts them off from a powerful sustaining force in the moment when they most need support." (Featherstone, 1980) For religious parents, the difficulty of the crisis is, or can be, greater than for others.

For those parents for whom religion is apparently not of central importance, and this is as true of this category of parents as it is for the rest of American society. Their children's disabilities shape their concerns and the things about which they are willing to talk. They talk about their own unhappiness, then about their family, then about professionals, and last, but not least, about the road to recovery. (Featherstone, 1980) For the religiously inactive, church is inconsequential.

The family of the handicapped has been described as having two enemies: fatigue and loneliness. (Morton, 1985) The irony is that organized religion offers as one of its highest values the fellowship of its members. More than that, brethren of the congregational family express, at least in recited words, the obligation they own to bear one another's burdens. This aspect of church life will be discussed in a later session, but, in this context, the fatigue and loneliness of the families of the handicapped is increased, in part, because of their own refusal to become involved. This is a two-way street. As for church affiliation, most of these families are separated from it and that separation tends to become hardened over time.

The life of the family with a handicapped member becomes centered in that one with special needs. Parents and siblings, together with the disabled member, can accurately be labeled "the handicapped family." (Kew, 1975)

II. A FOURFOLD ANALYSIS MODEL OF SUFFERING

The following is a conceptual framework of the meanings of suffering, as developed by George W. Paterson. One must consider whether or not suffering is fundamentally an experience and condition which is beneficial or harmful. Central to that question is another question: the place of God in suffering--is He or is He not the Author of such painful experiences? Paterson suggests that there are four approaches to the problem: suffering is either retributive, redemptive, providential, or absurd.

To regard suffering as retributive, one acknowledges that all things, good and bad, come from God. As unworthy sinners, it is for the sufferer to submit to God's will with due penitence.

From the redemptive perspective, God may allow evil to enter one's life, but it is intended for discipline. Believing that, one accepts suffering, cooperates in the plan of God for man, and shows gratitude for His ways which are beyond human understanding.

One holding the providential view maintains that God is not the Author of suffering. He does, however, take such circumstances and turn them into a benefit for the victim. The victim, in turn, responds with faith, patience, and hope.

Finally, and least attractive, is the notion of suffering as absurd. Suffering is therefore the unpredictable aspect of nature, or explainable error, or it is even demonic. One is left to either resist the absurd or to comply and endure.

Paterson cautions that these views of suffering are not mutually exclusive or incompatible. The parents of the handicapped may swing from one view to another. Paterson comments, "It is not illogical to suppose that different kinds of suffering could be found to fit each of these four interpretations." (Paterson, 1975)

SEMINAR

Part 3

THE CHALLENGE: As a force in the lives of families with handicapped members, religion varies as positive or negative.

I. WHEN CRISIS HITS, WE ASK THE QUESTION "WHY?"

A. Regular church members

The spiritual reaction of parents is to 1) accept it as God's will, 2) accept it as punishment from God, or 3) experience anger with God. Which is to say that they react to the crisis with either ________________ or ________________.

"For religious parents, anger poses a ______________ problem: it cuts them off from a powerful sustaining force in the moment when they most need support."

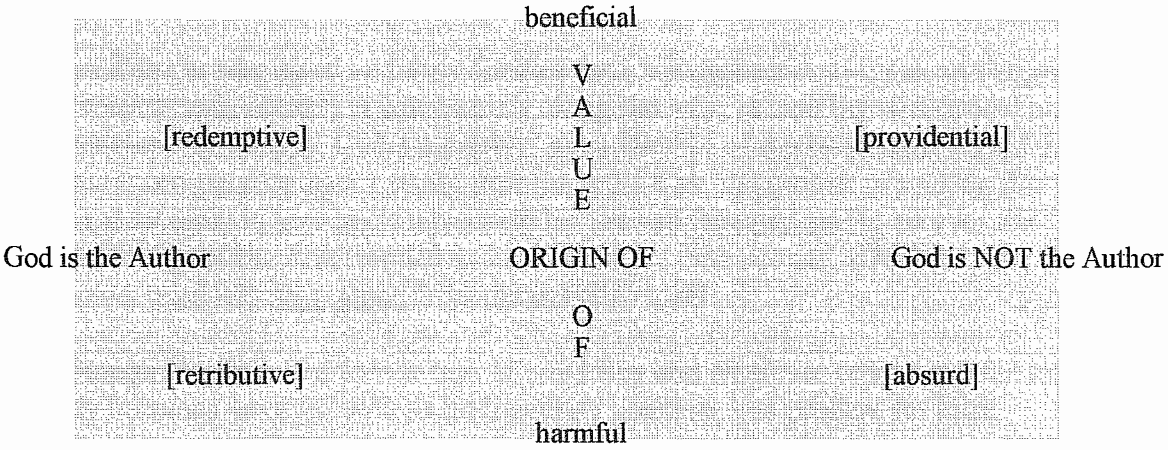
B. Non-regular church members/non-members

"In reflecting on their child's disability, parents talk about four things: their own unhappiness; their family; professional; the road to recovery." But church is ________________________.

The family of the handicapped has two enemies: fatigue and loneliness. For unchurched families, their ___________________ is ____________________.

II. A FOURFOLD ANALYSIS MODEL OF SUFFERING

Conceptual framework of the meanings of SUFFERING (Paterson)



[retributive]
    all is from God
    penitent submission
[redemptive]
    intended for discipline
    accept, cooperate, gratitude

[providential]
    God not the cause, but benefits
    faith, patience, hope
[absurd]
    nature, error, demonic
    resist to overcome or endure

SEMINAR

Part 4

To make significant progress requires clout in one form or another. In the areas of legislation, President John F. Kennedy had a retarded sister and Vice President Hubert Humphrey had a retarded grandchild. One can trace the special attention given to the needs of the handicapped in recent decades to that personal, familial experience by persons in positions of influence. This is also true of the church. One looks in vain among the clerical advocates for the handicapped to find persons other than those whose families had been impacted upon by handicapped children or relatives. (Murray, 1962)

I. ATTITUDE OF THE UNINFORMED

Over the centuries, the public has tended toward a judgmental attitude toward the handicapped and their families. There has been some modification in recent years that the parents were not to blame for their children's handicaps. but the situation has not greatly improved even in this age of enlightenment. (Paul, 1981) Many continue to suspect a moral deficiency in the family of the handicapped.

Pastors are expected to provide plausible answers to the questions why children are born with, or develop, handicaps. However the parents may struggle with theodicy, "why bad things happen to good people," many tend to harbor the notion that God is, in fact, punishing them. (Steiner and Steiner, 1984) They look to the pastors for clarification and reassurance about divine punishment.

Even if the handicapped and their families escape judgmental attitudes on the part of the rest of society, they cannot, at some points along the way, escape the widespread ignorance of others about handicaps. Understandably, most families of the handicapped tend to withdraw from social contact outside their homes. Of all institutions of society, the church is best suited to assist in serving as advocates for the handicapped and to reorder the interrelationship of the handicapped and their families with society. (Durka, 1980) Otherwise, they remain relatively segregated from the outside world.

Although ideally suited for the task of advocacy and whatever other ways the institution naturally becomes involved with an intermediary position, it is prudent for local congregations to carefully weigh the cost of involvement. The church is, after all, investing itself in such a venture. Five areas have been suggested for consideration. First, knowledge: does the congregation know enough about handicaps and their challenges? Second, values: is it part of the priorities of the church to assist the less fortunate in long-term programs? Third, resources: while the church may be willing, is it weak in the wherewithal to carry out projects focused on the handicapped? Fourth, commitment: among the many worthy causes calling for attention and long-term commitment, is the care of the handicapped so important that it will be tended to as of great importance? Fifth, willingness to make mistakes: in contrast with previous attempts which failed and were abandoned, is the church aware of the probability of failure and of the probable need to use various methods to achieve the goals? (Rostetter & Hamilton, 1982) The church must consider the return on investments.

Religion is important in the lives of many families with handicapped members. One study found that 73 percent of those surveyed affirmed that importance. (Paterson, 1975) This is not to say, however, that organized religion met their needs and proved satisfactory to their expectations. The following suggests a few ways in which the Main streaming of the handicapped can be facilitated.

II. STRUCTURE AND PROGRAM

The first "structure" to come to mind in reference to the handicapped is physical in nature, i.e., building access. This is fundamental, basic, and obviously practical. The National Organization on Disability (NOD), located in Washington, D.C., provides extensive information on the need and also on ways in which corporations can most effectively and economically facilitate the use of their buildings. Another office, that of the National Information Center for Children and Youth with Disabilities (NICHCY), also provides extensive information and practical guidelines for the handicapped and those who are in their lives. Each state also has offices which provide needed assistance and information. Each church body also has materials for obvious special needs such as works in braille for the blind and tapes, educational materials for the retarded, etc.

As racial integration took place following the Civil Rights Movement, so also the Main streaming of the handicapped has gradually taken place in virtually every institution of society. To be sure, those obstacles are often invisible attitudes over against the disabled and their families. The effort has nonetheless gotten underway. In the churches, the key persons are the clergy. They set the tone and the pace. It has been written that "for all families, a pastoral willingness to share their suffering was perceived as crucial, whether they had received it or not." (Ferguson & Heifetz, 1983) As a beginning, all members of organized religious groups ought to undergo some form of sensitivity training regarding the handicapped.

More than the endorsement of national headquarters of church bodies for the Main streaming of and ministry to the handicapped and their families, it is essential that that assimilation be felt and enacted on the local level. For such incorporation, small group ministry serves as an excellent means, as do programs of respite care.

Groups have been shown to be useful to address the needs within a church membership or within society at large. The grand daddy of small groups of the self-help kind is AA (Alcoholics Anonymous). In recent years, small living room groups have sprung up in congregations throughout the nation. Groups are important for these purposes: 1) to share;

2) to define the goals of a group; 3) to learn; 4) to break the loneliness (of the handicapped and their families); 5) to keep in balance; 6) to gain strength that comes with numbers; 7) to comfort. (Wheeler)

It should be noted that, while small group ministry conceptually fits so ideally in meeting the needs of the families of the handicapped, attempts to bring this about have been disappointing. One researcher has written:

> Frequently, professionals are disappointed in parent participation in formalized groups. Parents may resist participation because they are not yet ready to listen to others' problems, because they feel their needs are already being met by the professional, or because they do not realize the benefits that sharing may afford. (Mori, 1983)

At this point in time, as halting and frustrating as the process may be, small groups are the only practical way to incorporate and assimilate families in need in the congregation. The church is the ideal institution to make the program workable.

The second program the local congregation ought to seriously study for implementation is respite care. For the parents of the handicapped, who are typically isolated and lonely, the church can provide a "time out." The format for respite care can vary from as short as an hour or two to the length of the parents' vacation time. This varies with the needs of the parents and the resources of the congregation.

In these two ways the church can most directly and continually be in meaningful ministry to families of the handicapped: small group ministry and respite care.

As a final thought, the church needs to constantly be aware of the numbers involved. According to the National Advisory Committee on the Handicapped, at least 12 percent of the children in America are handicapped. (Mandell & Fiscus, 1981) Add to that number the immediate and extended family members, as well as friends and neighbors, and the total is impressive and defies being ignored.

SEMINAR

Part 4

THE CHALLENGE: Usually, the church and the clergy become involved with the handicapped only if there is a personal experience with them, such as members of the church leaders' families.

I. THE ATTITUDE OF THE UNINFORMED

A. Tendency toward being judgmental

Only recently has the notion been modified that the parents are to blame for the child's handicap. It was suspected that they had a__________ ____________

Pastors are expected to answer "why" questions; why divine punishment? Such crises are often thought of as____________ ________________.

B. Ignorance

The church is actually best suited to assist in advocacy and to reorder the interrelationship of the handicapped and their families with society. Until it happens, the families will be somewhat_________________.

The church must weigh the risk factors of ministry (knowledge, values, resources, commitment, willingness to make mistakes). Customarily, the church looks at_____________ on__________________.

Note: One study showed that 73% of the families found religion helpful in facing the problems surrounding their children's handicaps.

II. STRUCTURE AND PROGRAM

A. Practical--handicapped accessible

______(National Organization on Disability) and_________(National Information Center for Children and Youth with Disabilities) make materials available to assist with making buildings accessible for the handicapped and for informing the non-handicapped about the special needs.

B. Main streaming

"For all families, a pastoral willingness to share their suffering was perceived as crucial, whether they had received it or not." Members of the church ought to receive____________________________.

Groups are important to 1) share, 2) define goals, 3) learn, 4) break loneliness, 5) keep balanced, 6) gain strength in numbers, 7) comfort. The local church would do well to establish two forms of ministry for the families: _____________________ ministry and_____________________ programs.

Note: About participation, "Frequently, professionals are disappointed in parent participation in formalized groups. Parents may resist participation because they are not yet ready to listen to others' problems, because they feel their needs are already being met by the professional, or because they do not realize the benefits that sharing may afford.

SEMINAR

Conclusion

In this final part, we are asking for the participants' overall evaluation of the presentation. Following the introductory section, the next four were in two broad areas: concepts and the basis of religious involvement.

Part 1 focused on the problem addressed: the crisis of the diagnosis or the crisis at the time of diagnosis. It also noted that the families tend not to be served by the church at that critical time.

Part 2 looked at the Bible itself. Both the Old and New Testaments demonstrated great concern for the handicapped. The anticipated Messiah identified with the handicapped as, indeed, He did in Jesus Christ.

Part 3 offered a model in response to the question "Why?" Parents of the handicapped ask for a rationale for the theodicy: a loving God allowing a painful event to occur. The model was in the form of a matrix.

Part 4, then, considered that which the church on the local level can do for families of the handicapped. Most, in and out of the church, are poorly informed about the handicapped' existence and their needs.

We ask for brief evaluations of each of these segments. Finally, we ask that you share your thoughts on the following questions:

What area of handicapped-family life was omitted or insufficiently dealt with?

What area of the presentation, if any, was superfluous (unnecessary)?

How would you suggest informing and sensitizing churches on this subject?

How would you suggest informing and sensitizing clergy on this subject?

How would you suggest effectively reaching families with handicapped families?

Many thanks and blessings for your cooperation and participation!

SEMINAR

Critique

Introduction

I. CONCEPTS

- A. Problem
  1. Crisis of/at diagnosis
  2. Unserved by church
- B. Bible
  1. OT concern for handicapped
  2. NT concern for handicapped

Please share your evaluation of the presentation

Part 1: ____________________

Part 3: ____________________

Application

II. BASIS

- A. Model
  1. Question "why?"
  2. Four-four analysis
- B. Church
  1. Attitude/uninformed
  2. Structure/program

Part 2: ____________________

Part 4: ____________________

Application

Develop guidelines

What area of handicapped-family life was omitted or insufficiently dealt with?

____

What area of the presentation, if any, was superfluous (unnecessary)?

____

How would you suggest informing and sensitizing churches on this subject?

____

How would you suggest informing and sensitizing clergy on this subject?

____

How would you suggest effectively reaching families with handicapped members?

____

MANY THANKS AND BLESSINGS FOR YOUR COOPERATION AND PARTICIPATION!

SEMINAR

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APPENDIX B

FORUM

APPENDIX B

SAMPLE FORUM ON ADVOCACY AND SENSITIVITY TRAINING

The suggested model below is composed of four parts, or sessions. The first discusses "the status of the handicapped," which is of a general nature. The second focuses on the family, "the home and the handicapped," and concerns both attitude and spirituality. The third session is on "the role of the handicapped" themselves. For this, one looks to the ministry of Jesus and the prominence of the handicapped in the eyes of God, as shown in Scripture. The final segment addresses "the congregation and the handicapped." It makes church members mindful of ways in which ministry can be both practical and effective. It strongly encourages the inclusion of the handicapped in the fellowship of the church. Bible study suggested for the parts are these. The status of the handicapped is dealt with in Leviticus 19:14-15 and Deuteronomy 27:18-19. The family of the handicapped and the awkwardness the non-handicapped members experience within themselves and in the eyes of others is shown in the story of Jesus' healing of the blind man, John 9. The role of the handicapped in Jesus' ministry is clearly expressed in His words in Matthew 25. Finally, the congregation may be sensitized to the need for inclusion in the story of the healing at the Pool of Bethesda, John 5. Jesus addressed the cripple and his personal needs, but his circumstance contains a lesson for the organized church and its need to be aware of, and reach out in ministry to, the handicapped. The program also allows the use of printed and visual aids.

SESSION 1

The Status of the Handicapped

Leviticus 19:14-15: "Do not curse the deaf or put a stumbling block in front of the blind, but fear your God. I am the Lord. Do not pervert justice; do not show partiality to the poor or favoritism to the great, but judge your neighbor fairly."

Deuteronomy 27:18-19: "Cursed is the man who leads the blind astray on the road . . .Cursed is the man who withholds justice from the alien, the fatherless or the widow."

- Terminology
  - Definition
  - Description
- Main streaming
  - Education
  - Employment

As in every specialized field, there is a glossary of terms applicable to the life of the handicapped and those who attend their needs. A brief list of terms and definitions are provided below. The "world" of the handicapped extends beyond definitions. In many ways, it is a sub-culture. Because of the impact of the handicapped individual, even the rest of the family comes to be known as "the handicapped family." The term "Main streaming," like racial "integration" and cultural "assimilation," is highly significant. In contrast with European society, the handicapped are made a part of American education and work.

SESSION 2

The Home and the Handicapped

John 9: Behavior 1 "As He went along, (Jesus)saw a man blind from birth. His disciples asked Him, 'Rabbi, who sinned, this man or his parents, that he was born blind?' 'Neither this man nor his parents sinned,' said Jesus . . . [Jesus then healed the man. Behavior 2 This led to an investigation by the Pharisees. They interrogated the parents.] "'Is this your son . . . the one you say was born blind? How is it that now he can see?' . . . 'Ask him. He is of age; he will speak for himself.'"

Attitude

Society–toward the family

Family –toward society

Spirituality

Leave the church

Lacking moral and spiritual support

Because of legislation in behalf of the handicapped, "accessible" buildings are now labeled as such. Physical barriers, such as stairs and narrow doors, can prevent the handicapped from entry and participation in normal places of activity. Equally formidable are the attitudes non-handicapped people harbor over against the handicapped. As the Bible story shows, even the family feels unwanted pressure because of the special-needs member. A sad and widespread effect of the negative attitudes held about the handicapped, they and their families tend to drop away from organized religion and its spiritual support.

SESSION 3

The Role of the Handicapped

Matthew 25: [Judgment Day to the saved] "'I was hungry and you gave Me something to eat, I was thirsty and you gave Me something to drink, I was a stranger and you invited Me in, I needed clothes and you clothed Me, I was sick and you looked after Me, I was in prison and you came to visit Me . . .Whatever you did for one of the least of these brothers of mine, you did for Me.'"

- The role of Jesus
  - Our ministry--to the glory of God
  - Persons with special needs--object of care
- Their prominence in the eyes of God
  - Isaiah prophesied about the caring Servant
  - The apostles told of Jesus the Healer

To establish the role of the handicapped in the life of the congregation, Christians must first study the role they played in the ministry of Jesus the Savior. As Jesus pointed teaches in His picture of judgment, ministering to the less fortunate is ministering to Him. They were, from beginning to end, a major focus of His own service. We are to do likewise. Jesus the Christ, is the fulfillment of the Old Testament prophecies of the Messiah, both "anointed" to save the world. Isaiah's description of the Messiah as the "Suffering Servant" includes His identification with, and compassion for, the handicapped.

SESSION 4

The Congregation and the Handicapped

John 5: [Bethesda pool] "Here a great number of disabled people used to lie--the blind, the lame, the paralyzed. One who was there had been an invalid for thirty-eight years. When Jesus saw him lying there and learned that he had been in this condition for a long time, He asked him, 'Do you want to get well?' 'Sir,' the invalid replied, 'I have no one to help me into the pool when the water is stirred. While I am trying to get in, someone else goes down ahead of me.'"

Things--accommodation/accessibility

- The church building
- The means of communication

People--fellowship

- We are not to show favoritism
- We are to show loving kindness

Law now requires that public buildings be accessible to the handicapped as contained in the 1990 Americans with Disabilities Act (ADA). More than granting easier access to physical structures, however, the church joins with other institutions of society in facilitating understanding and participation on the part of the handicapped. They need to know the communication used. They have a right to become a part of any segment of congregational life to which members are entitled or qualified. Beyond the obvious lowering of barriers, Christians are to be in the lead to demonstrate in word and deed the love they know in Jesus Christ.

Extensive material is now available from agencies and organizations about the handicapped and about handicapping conditions. The following is available to the public from Goodwill Industries of America, Inc., drawn, in turn, from The President's Committee on Employment of People with Disabilities and Functional Assessment in Rehabilitation:

General Guidelines

Put the person before the disability. For example, use "people with disabilities" as opposed to "disabled people" or "the disabled."

Do not use phrases such as "confined to a wheelchair,""crippled," "afflicted,""victim of" or "suffers from a disorder." These references diminish the individual's dignity and magnify the disability. Instead, refer to "the person who uses a wheelchair" or "the person with an emotional disorder."

Avoid portraying people with disabilities as superhuman, courageous, poor or unfortunate. Remember, people with disabilities do not want to be, nor should they be, measured against a separate set of expectations.

Avoid using trendy euphemisms to describe people with disabilities. Expressions such as "physically challenged,""special" and "handi-capable" generally are regarded by the disability community as patronizing and inaccurate. Stick with simple language, such as "people with disabilities" or "the person who is deaf."

Guidelines on Specific Terminology

It is probably unnecessary to mention a person's disability. If a person's disability is not in any way relevant to the story or the issue, leave it out.

However, if a person's disability is relevant to a story or issue, it is important to understand the difference between impairment, disability and handicap.

Impairment is used to characterize a physical, mental or physiological loss, abnormality or injury that causes a limitation in one or more major life functions. For example, "the loss of her right arm was only a slight impairment to her ability to drive."

Disability refers to a functional limitation that affects an individual's ability to perform certain functions. For example, it is correct to say, "Despite his disability, he still was able to maintain employment."

Handicap describes a barrier or problem created by society or the environment. For example, "The teacher's negative attitude was a handicap for her." Or, "The stairs leading to the stage were a handicap to him."

When necessary to refer to a person's disability, use the following list as a guide:

Deaf refers to profound hearing loss. Hearing impaired may be used to describe any degree of hearing loss, from slight to profound. Use hearing impaired instead of antiquated terms such as "hard of hearing."

Blind most frequently is used to describe a severe vision loss. Either blind or visually impaired are acceptable terms to describe all degrees of vision loss.

Developmental disability is any severe mental and/or physical disorder that began before age 22 and continues indefinitely. Individuals with mental retardation, autism, cerebral palsy, epilepsy and other similar long-term disabilities may be considered to have developmental disabilities.

Mental illness is a term describing many forms of illnesses such as schizophrenia, depression and emotional disorders. Use "person with a mental disability" rather than referring to an individual as "deranged" or "deviant." Clinical terms such as "neurotic" and "psychotic" should be used only for clinical writing. Other terms such as "demented," "insane,""abnormal,""deranged" and "mad" often are used incorrectly and should be avoided.

Non-disabled is the correct way to refer to people without disabilities. Do not use "normal,""able-bodied" or "healthy" to describe people without disabilities, as these words imply a person with a disability isn't normal.

Speaking and Writing About People With Disabilities

Enactment of the Americans with Disabilities Act (ADA) of 1990 has dramatically heightened the nation's awareness of disability issues, and established a strong commitment to ensuring that the civil rights of people with disabilities are protected. Just as other derogatory references to ethnic and racial minorities have passed from our lexicon, it is time that individuals with disabilities are afforded similar courtesies.[298]

Similar brochures are available from organizations such as Easter Seals.

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[298] People With Disabilities Terminology Guide, brochure available from Goodwill Industries of America, Inc., 9200 Wisconsin Avenue, Bethesda, MD 20814 ((301) 530-6500, FAX: (301) 530-1516, TDD: (301) 530-9759. Publication #5032.10 (1992).

Glossary

In addition to the terms defined and the items described in the preceding brochure extract, one does well to recognize terms used in special education. The parents of handicapped children in the church will be wrestling with their comprehension. Although church leaders are not expected to be experts in the field, a few terms (in addition to those given in the brochure extract) ought to be recognized, such as the following, selected from a special needs publication glossary.[297]

Advocacy: Speaking or action on behalf of another individual or group.

Developmentally Delayed: Term used to describe an infant or child whose development is slower than normal in one or more areas of development.

Developmental Disability (DD): Any severe disability, mental and/or physical, which is present before an individual becomes eighteen years old, which substantially limits his activities, is likely to continue indefinitely, and requires life-long care, treatment, or other services. Examples of developmental disabilities include Down Syndrome, autism, and cerebral palsy.

Early Intervention: Providing services and programs to infants and toddlers (under two) with disabilities in order to minimize or eliminate the disability as they mature.

Education for All Handicapped Act (EHA): Often referred to as P.L. (Public Law) 94-142, this act mandates a free, appropriate public education for all children and youth with handicaps.

Education of the Handicapped Act (EHA): A collection of several federal, special education statues, including P.L. 94-142 and P.L. 99-457, providing grants to states for initiating, expanding, and improving programs for the education of children with disabilities. Changed by P.L. 101-476 to "Individuals with Disabilities Education Act (IDEA)."

Education of the Handicapped Act Amendments of 1986: Known also as P.L. 99-457, this act authorizes an early intervention program for handicapped infants and toddlers (0-2) and their families.

FAPE: Free, appropriate public education--phrase from P.L. 94-142 describing the education to which handicapped children are entitled. The term "appropriate" refers to an educational program that meets the needs of a student with disabilities.

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[297] Anderson, et al., Negotiating, 211-253.

Fine Motor Skills: Body movements which use small muscles; for example: writing, eating, or tying shoes.

Gross Motor Skills: Body movements which use large muscles; for example: walking, running, or throwing a ball.

Handicapped Children's Protection Act: The law providing for the reimbursement of reasonable attorneys' fees to parents who win their cases in administrative proceedings under the Education for All Handicapped Children Act, P.L. 94-142.

Independent Living Skills: Basic skills needed by disabled people to function on their own, with as little help as possible. Skills include self-help (e.g., bathing, dressing), housekeeping, community living (e.g., shopping, using public transportation), etc.

Individualized Education Program (IEP): A written statement for each student in special education describing his present level of performance, annual goals including short-term objectives, specific special education and related services the student is to receive, dates for beginning and duration of service, and how the IEP will be evaluated.

Individualized Family Service Plan: A written statement for each infant or toddler receiving early intervention services that includes goals for the child, goals for the family, and a transition plan for the child into services for children over age 2.

Least Restrictive Environment (LRE): Placement of a student with disabilities in a setting that allows maximum contact with non-disabled students, while appropriately meeting all of the student's special education needs.

Main streaming: The concept that students with disabilities should be educated with non-disabled students to the maximum extent possible.

Section 504 (Rehabilitation Act of 1973): Section 504 affirms a handicapped child's right to a free, appropriate public education and stipulates that individuals may not be excluded from participating in programs and services receiving federal funds because they are disabled. It also prohibits job discrimination against people with disabilities.

Sheltered Workshop: A work setting in which persons with disabilities do contract work usually on a piece-rate basis and productivity is at least 50 percent of a non-disabled workers.

Social Worker: In an educational context, a school social worker provides a link between school personnel and the families of disabled children through activities such as individual pupil evaluation, parent interviews, and contact with community support services.

Triennial Review: Every three years, a student in special education has a completely new evaluation/assessment and determination of eligibility for continued special education services.

Official Sources of Information/Assistance

Federal Department of Education

Office of Special Education and Rehabilitation Services
(202) 732-1245

Office of Special Education Programs
(202)732-1007

Rehabilitation Services Administration
(202) 732-1282

330 C Street, SW
Mary Switzer Building
Washington, D.C. 20202

Office for Civil Rights
303 Independence Avenue, SW
Washington, D.C. 20201
(202) 245-6118

Region III: Office for Civil Rights (Virginia)

Gateway Building, 6th Floor
3535 Market Street, P.O. Box 13716
Philadelphia, PA 19101

Other Federal Offices (selected)

Administration on Developmental Disabilities
Office of Development Services
330 C Street, SW, Room 3070
Washington, D.C. 20201
(202) 245-2890

National Council on Disability
800 Independence Avenue, SW
Washington, D.C. 20591
(202) 267-3846

National Institute of Education
Brown Building
19th and M Streets, NW
Washington, D.C. 20208
(202) 254-5740

President's Committee on Mental Retardation
330 Independence Avenue, SW
Washington, D.C. 20201
(202) 245-7634

Program Information and Coordination Staff
Clearinghouse on the Handicapped
Switzer Building, Room 3132
330 C Street, SW
Washington, D.C. 20202-2319
(202) 732-1723/1245/1250

State Offices (Virginia)

Director, Department of Rights for the Disabled
James Monroe Building
101 N. 14th St., 17th Floor
Richmond, VA 23219
(804) 225-2042; 800/552-3962 (in Virginia)

Commissioner, Department of Rehabilitation Services
Commonwealth of Virginia
P.O. Box 11045
4901 Fitzhugh Ave.
Richmond, VA 23230
(804) 257-0316

Parent Educational Advocacy Training Center
228 S. Pitt St., Suite 300
Alexandria, VA 22314
(703) 836-2953

National Organizations (listing)

Accent on Information (AOI)

American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD)

American Coalition of Citizens with Disabilities

AFT Teachers' Network for Education of the Handicapped

Association for Persons with Severe Handicaps (TASH)

Center for Law and Education

Center for Special Educ. Technology

Children' Defense Fund

The Council for Exceptional Children (CEC)

Disability Rights Education & Defense Fund, Inc.

Education Resources Information Center ERIC

Foundation for Science and the Handicapped Inc FISH

HEATH Resource Center Post-secondary Education

Independent Living Research Utilization Project ILRU

Mexican-American Legal Defense & Education Fund

National Health Information Clearinghouse (NHIC)

National Information Center for Orphan Drugs and Rare Diseases (NICODARD)

National Information Center for Children and Youth with Handicaps (NICHCY)

National Juvenile Law Center

National Library Service for the Blind and Physically Handicapped (NLS)

National Association of the Deaf Legal Defense Fund

National Center a Barrier- Free Environment

National Center for Educ in Maternal & Child Health

Natl Comm of Citizens in Ed

National Organization for Rare Disorders (NORD)

National Rehabilitation Information Center(NARIC)

Registry of Interpreters for the Deaf, Inc. (RID)

Sibling Information Network

STOMP (Specialized Training of Military Parents)

United Together (UT)

World Institute on Disability (WID)

Organizations which serve specific populations(listing)

Allergies
Autism
Birth Defects
Blind and Visually Impaired
Cerebral Palsy
Chronic Illness
Deaf and Hearing Impaired
Diabetes
Down Syndrome
Emotional Disorders
Epilepsy
Head Injury
Learning Disabilities
Mental Retardation
Muscular Dystrophy
Respiratory Diseases
Speech and Language Disorders
Spina Bifida
Tourette Syndrome

Information on these organizations and general information can be obtained from the following major sources;

National Information Center for Children and Youth with Disorders (NICHCY)
P.O. Box 1492
Washington, D.C. 20013-1492
(703) 893-6061; (800) 999-5599 (recorded message)

National Organization on Disability (NOD)
910 16th Street, NW, Suite 600
Washington, D.C. 20006
202/293-5960; FAX: 202/293-7999; TDD: 202/293-5968

Computers and their uses with the handicapped are not reserved for the expensive and complex applications. In education, they close the gap, as the name of one such dedicated organization indicates:

Closing the Gap
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Henderson, MN 56044
612/248-3294; FAX: 612/248-3810

Church Bytes, Inc.
562 Brightleaf Square #9
905 West Main Street
Durham, NC 27701

Parents of the handicapped would do well to use the PC in their homes.

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