To the Graduate Council:

I am submitting herewith a dissertation written by Susan Parker entitled "Parents with Mentally Retarded Down's Syndrome Children: Their Experiences with the Child and the Impact of a Short-Term Educationally Oriented Group on Their Adjustment." I recommend that it be accepted in partial fulfillment of the requirement for the degree of Doctor of Philosophy, with a major in Psychology.

William S. Verplanck, Major Professor

We have read this dissertation
and recommend its acceptance:

Accepted for the Council:

Vice Chancellor
Graduate Studies and Research

PARENTS WITH MENTALLY RETARDED DOWN'S SYNDROME CHILDREN: THEIR EXPERIENCES WITH THE CHILD AND THE IMPACT OF A SHORT-TERM EDUCATIONALLY ORIENTED GROUP ON THEIR ADJUSTMENT

A Dissertation

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Doctor of Philosophy

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Susan Parker

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ABSTRACT

Professional articles published about parents with mentally retarded children have usually been theoretical and speculative, rather than empirical. Neither detailed descriptions of parents' experiences nor methodologically sound studies of typical parents are to be found.

Ten families, each with a young child with Down's Syndrome, participated in a two-year study of parents' experiences with their retarded child and the impact of an educational group meeting on their adjustment. Subjects were an exhaustive population of parents with a young Down's Syndrome child who lived in the geographic area under study. Each child's diagnosis had been confirmed through chromosomal analysis and the parents had been informed of the child's prognosis prior to initiation of the current study.

Parents participated in three semi-structured interviews. During the first interview, parents discussed the diagnosing interview, during which they had first been informed of the child's diagnosis, their initial understanding of retardation and their current life with the retarded child. Results of the first interview indicated that the majority of the parents had been exposed to inadequate counseling procedures and had been given little professional support during the early adjustment period. At the time of this first interview, parents had little knowledge of the retarded child's condition or of available training facilities, and were usually not involved in training the retarded child. They reported a restriction of ordinary social activities

due to the retarded child. Parents also had little awareness of the retarded child's probable accomplishments, although they were realistic about the child's future limitations. Parents who attended the educational group sessions were initially more distressed about the child's condition and had more negative stereotypes about the retarded than parents who did not attend.

On the basis of the needs expressed in the first interview, a five-session educational group was organized, which was attended by five of ten couples. A second semi-structured interview was conducted one month after the conclusion of the group sessions. Data obtained from the second interview indicated that attending parents had enrolled their retarded child in training programs, had significantly increased their knowledge of the child's condition, had read books about retardation, and had continued social contact with other group members. There had been no change in behavior of nonattending families.

Two years after the initiation of the study, parents participated in a third and final semi-structured interview, which assessed their experiences with their retarded child through the intervening years and assessed the long-range effect of participation in the educational group sessions. Compared to nonparticipating parents, participating parents were more satisfied with the retarded child's progress, reported enhanced social relationships within and outside of the family, and reported a willingness to rear a second child with Down's Syndrome. Nonparticipating parents were resigned to the retarded child's limitations.

The data included both experiences that were unique to single families and those shared by these families in rearing a retarded child.

Representative quotes from parents were reported. A Fisher's Exact Test was used to compare participating and nonparticipating couples on each variable.

Subjects' recommendations for improving the counseling given to other parents when learning their retarded child's diagnosis were also summarized.

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CHAPTER I

STATEMENT OF THE PROBLEM

Purpose of the Study

The current study of parents' adjustment to their young child with Down's Syndrome was designed with two major objectives. The first objective was to describe parents' experiences with a mentally retarded child in detail. These experiences included events during the diagnosing interview during which the parents were first informed of the child's prognosis, their initial conceptions of the child's disability and their concerns about living with and caring for a retarded child. Parents were interviewed on three occasions over a two-year period, and had an opportunity to describe changes in their adjustment to the retarded child during this time period. The second objective was to assess the impact of educational group sessions on parents' adjustment to their child.

Need for the Study

Detailed descriptions of events which have a significant impact on people's lives are of inherent scientific importance; they are required for the development of generalizations. Accurate description of parents' experiences with their retarded child is of special importance. Although many articles have been written about parents with a retarded child, there have been almost no methodologically sound studies which describe typical parents as they adjust to their retarded child. Inaccurate

beliefs about retardation are prevalent among both professionals and laymen. The retarded child's condition is frequently assumed to be unalterable; such misconceptions discourage parents from providing early training experiences that might significantly increase the retarded child's level of functioning. Parents of the retarded are often assumed to live with an enduring burden to which adjustment is difficult, if not impossible. Parents are consequently assumed to suffer from guilt, depression, and great anxiety about the retarded child. Such presumed emotional reactions frequently become the focus of professional interventions which attempt to improve parental adjustment. Data are needed to describe the problems actually faced by parents with a retarded child rather than to assume their existence.

Accurate description is also essential in planning services for parents of the retarded. The current study describes services which were provided to parents and the parents' assessment of the impact of these services on their adjustment. These descriptions could indicate which services are beneficial to parents and which practices interfered with parents' adjustment to the retarded child. Deficiencies could then be rectified.

Descriptions of parents' concerns and problems could also provide suggestions for nonexisting services which would be beneficial to parents and to their retarded child.

Assumptions of the Current Study

The current study assumes that the participants provided valid and reliable information about their adjustment to their retarded child.

Parents' perceptions of events, such as the diagnosing interview, were assumed to be a valuable source of information, since information as they recalled it, rather than information as it was presented to them, served as a foundation for parents' interactions with the child with Down's Syndrome.

This current study also assumes that there are at least five components critical to parental adjustment to the retarded child. These five components are: (1) information about Down's Syndrome, (2) training of the retarded child, (3) accommodating to the child's special needs, (4) quality of interpersonal interactions, and (5) realistic expectations for the child's future. There is a value judgment in the definition of "adjustment" as follows: Parents with accurate knowledge of Down's Syndrome, who actively train the retarded child, who meet the child's special needs, who have few disruptions of their interpersonal relationships, and who are realistically optimistic about the retarded child are assumed to be more adjusted than parents who do not demonstrate these characteristics.

Limitations of the Current Study

One limitation of the current study is the small number of participating parents. This population is determined by the small number of children with Down's Syndrome born each year in the area covered by an agency which provides comprehensive diagnostic and evaluation services.

Because of the small number of participating parents, it was not possible to match parents who attended the parents' educational group sessions with a complete control. Inability to match subjects necessarily

limits the generalizability of findings about the impact of the educational group sessions.

Generalizability

Class of Retardation

The current study includes only parents of a child with the diagnosis of Down's Syndrome. Without further research, the results of this current study should not be applied to parents of children with other types of mental retardation.

Cultural Values

Caudill (1962) and Weller (1961) have stated that the values of residents of Appalachia are more religious and family-oriented than the values of residents of other regions of the country. Nineteen of twenty participating parents had been reared in East Tennessee and presumably shared these values. To the extent that participants hold these values and to the extent that these values influence adjustment to a retarded child, the results of the current study must be generalized to parents living in other regions of the country only with caution.

Cohort

Results of the current study also may not generalize to parents of retarded children born in another era. Participating parents' children were all born at approximately the same time and were consequently exposed to fairly similar social attitudes toward the retarded. Retarded children born in an earlier, less accepting era, for example, were characterized as the stigma of genetically defective families and the children in

question were placed in institutions and the females sterilized. These social attitudes probably contributed to a different adjustment of parents to the retarded child moreso than that typical of parents in the current study. Similarly, results of the current study cannot be applied to retarded children born at some future time if social attitudes differ significantly from the attitudes of the present era. It is emphasized, however, that the results of this and similar research should play a role in determining how children with Down's Syndrome should be treated by their parents and by social institutions.

CHAPTER II

REVIEW OF THE LITERATURE

Limitations of Methodology Previously Employed

Articles on parents of the mentally retarded typically present professional speculation rather than the results of methodologically sound research. The investigator in the current study located 90 articles written about parents of the retarded which had appeared in a variety of English language, professional journals. These 90 articles are listed in Appendix E. Of these articles, only 23 (28%) contained empirical evidence of any sort. The remaining 72% of the articles were speculative-theoretical papers which occasionally were supported by references to selected case studies. When the author did not indicate the representativeness of the case study, the article must be rated as speculative. Articles seemed to be written to provide support for the theoretical orientation of the authors rather than to describe accurately parents' behaviors, including feelings, concerns and interests. Thus, the great majority of articles did not present results upon which sound conclusions could be based.

Even in published empirical studies, deficiencies in methodology are common. Wolfensberger (1967) stated that most studies written about parents of the retarded failed to use appropriate control groups, failed to use reliable or valid measures, did not yield quantifiable results, and were too inadequately described to be replicated. He also criticized

the biased samples of parents studied; subjects were typically white, upper middle-class mothers of young, low-functioning retardates who were already receiving services. Because of these biases, results cannot be applied to more representative parents of the retarded.

There are few published descriptions of the experiences of typical parents. A few educated and/or famous individuals have written accounts of their experiences with their retarded child (Buck, 1950; Frank, 1951; Rogers, 1952; Hunt, 1972). Although these reports are of anecdotal interest, experiences of notable individuals cannot be applied to parents of all social classes. A few parents who have been active members of the National Association for Retarded Children have published addresses about their experiences (Boyd, 1951; Murray, 1959). However, parents actively involved in a parents' organization are also likely to represent a biased sample. Both Zwerling (1954) and Roith (1963) solicited descriptions of parents' experiences with their retarded children by a mailed questionnaire. Printed questionnaires with written answers undoubtedly did not fully sample responses of less educated parents.

In summary, both the theoretical and empirical literature on parents of the mentally retarded have serious deficiencies. Speculative papers inherently express biases and there is no way to evaluate the applicability of conclusions to the full population of parents. Inadequate methodology and unrepresentative sampling limits the generalizability of most of the empirical studies in the literature. Since there are limited valid data available on parents of the retarded, there is clearly a need for accurate description of representative parents. Such descriptions have not previously been published.

Descriptions of Functioning of Parents of the Retarded

The professional literature reflects two divergent views concerning parents of the mentally retarded. The first, and apparently more prevalent, view is pessimistic about both the potential of retardates and the capacity of parents to adjust to a retarded child. In fact, Hersch (1961), Michaels and Schuchman (1962), and Rychman and Henderson (1965) have stated that acceptance of the retarded child's condition endangers parents' mental health because parents are unable to live with the depressing truth of the child's condition. Indeed, theorists adopting this view argue that an apparently good adjustment is "superficial" and hides even deeper pathology.

Proponents of this first view assert that parents of the retarded are mentally ill, either as a response to rearing the child or prior to the child's birth. For example, in their speculative article on parents of the mentally retarded, Mandelbaum and Wheeler (1960) stated:

> The impact of a defective influences neurotic tendencies and may call forth latent conflicts. . . . On the simplest level and parents will recall unconscious aggressive thoughts, frustrated dependency needs and ambivalent wishes. . . . Some (parents) even speak of their own sense of confused sexual identify. . . . (Parents) have difficulty in separating reality from unreality.

Also reflecting this view, Goshen (1963) stated flatly that two-thirds of parents with a retarded child had a continuing, serious psychiatric disorder. Thurston (1960) described parents of retardates as "highly sensitive, suspicious, anxious and unhappy individuals" who were, he reported, more handicapped than their retarded child.

According to this view, parents develop and demonstrate several common pathological responses to the retarded child. For example, Olshansky (1962) stated that parents of the retarded are chronically depressed. He understands parental depression as an internalization of anger that would otherwise be directed toward the retarded child. Consequently, he stated that parental depression could only be relieved by the death of the retarded child. Parents are also said to be irrationally hostile (Olshansky, 1966; Roos, 1975). At times authors have assumed that hostility is directed toward the retarded child and is manifest in death wishes toward the retardate. Smith (1952) stated that death wishes were evident in every parent with a retarded child. Other authors stated that parental hostility is expressed in unwarranted attacks on professionals who inform parents of the retarded child's prognosis (Olshansky, 1966). Parents are also said to be overwhelmed by guilt. In fact, Menolascino (1968) referred to parental guilt as a "classic standby, a universal construct for understanding parents." Parental guilt is either seen as a manifestation of repressed anger at the retarded child or as an expression of primitive fears about punishment for past behavior (Hunter, Schuchman & Friedlander, 1972).

A second, contrasting view of parents of the retarded assumes that parents are adequately functioning adults who undergo a temporary crisis when they learn that their child is mentally retarded. Emotional reactions to the diagnosis are expected and recognized as a reasonable response to the parents' understanding of the event and not as an expression of latent psychopathology. For example, parental depression is seen as a reasonable reaction to the unexpected diagnosis. Moreover,

it is a reaction to the parents' misconceptions about the limitations of their retarded child. Similarly, guilt is understood as an attempt to maintain a belief in an orderly and predictable world in the face of the child's diagnosis. It is attributable, then, to the "just world" view. On parental guilt, Roos (1975) wrote:

> In our desperate search for an answer to this question (about the cause of the child's condition), we are likely to consider two alternatives: either we "sinned" greviously and are getting our "just rewards" or we are living in a world in which fairness and justice are fictitious constructs, unrelated to reality. The former alternative leads to guilt, remorse and self-recrimination; the latter threatens our ethical, moral and religious beliefs.

Roos (1975) and Stubblefield (1965) argued that guilt may facilitate parents' adjustment to the retarded child since parents must maintain a sense of living in a meaningful, just world, so that they can and will believe that the retarded child will benefit from physical stimulation and hence undertake training of the child.

It is striking that there have been almost no empirical studies to document the existence of any of these presumed parental reactions to the retarded child. There has also been no attempt to empirically evaluate the validity of the assumptions underlying these two divergent views of parents of the retarded.

The single aspect of parental functioning which has been extensively researched is the impact of the retarded child on the family. Speculative articles have typically assumed that parents with a retarded child have shown family relationships which are chronically disrupted. Mandelbaum and Wheeler (1960) have referred to the retarded child as "a dangerous infection to the family, causing severe emotional crippling." Michaels

and Schuchman (1962) speculated that parents' "repressed mutual antagonisms" lead to "a highly complicated framework of suspiciousness, fear, distrust, hostility and ensuing guilt."

There have been three, large-scale empirical studies of the impact of a severely retarded child on the family. Two of the studies were interpreted by the authors to indicate that the retarded child did produce great changes in the family relationships. In the first study, Schonell and Watts (1956) studied Australian families who were receiving no assistance in training their severely retarded child. The authors reported significant changes in almost every aspect of the families' lives, including alterations in eating, sleeping and shopping arrangements, visits outside of the home and vacation plans. However, the authors did not indicate the extent to which changes would have occurred if a normal, additional child had been born. Nor did they report on the parents' willingness to make accommodations to the retarded child. The authors concluded:

> It is strikingly clear from the evidence collected that the effects on family life may be economic, social or emotional and that they may be far reaching and intensely restrictive and disruptive in nature. . . . They (the mothers) were in the slough of frustration and helplessness, with the mothers' mental health in constant jeopardy.

However, the authors' conclusion is contradicted by these authors' subsequent study which reevaluated these families after the retarded child had been enrolled in a training program (Schonell & Rorke, 1960). After enrollment, authors reported a marked improvement in the quality of the parents' lives, a significant increase in parents' leisure time and an improvement in social relationships between the retarded child and

other retarded children. The data, therefore, did not indicate that the presence of a severely retarded child is necessarily a "disruption" to the family. Rather, the data indicated that parents who are not provided with constructive, professional services may have serious difficulties adjusting to and rearing a retarded child.

Holt (1958) undertook a second, large-scale study of families with a severely retarded child. He studied all 201 families with a severely retarded child who lived in Sheffield, England. Families were not receiving any assistance in training their retarded children. Holt reported that the presence of the retarded child resulted in serious restriction of the parents' social lives and interfered with the pursuit of ordinary activities. He also reported that parents' health was adversely effected and that the retarded child had a negative impact on normal siblings in the family. Holt concluded:

> It is not possible to talk to parents of these children without realizing the deep disturbances created by their child's condition. In not one family I visited did I consider that the parents had made a full emotional adjustment to the problem and were able to lead a normal life within the community.

It is striking that Holt blamed parents for having failed to make "a full emotional adjustment to the problem." He apparently assumed that parents' emotional problems prevented a normal life with the retarded child. Holt did not consider the possibility that training programs and child care services might restore the parents' ability to lead a normal life.

A final large-scale study of parents with a severely retarded child undertaken by Kramm (1958) studied 50 American families with a school-age child with Down's Syndrome. The author reported that 67% of the

participating parents stated that they had benefited from living with the severely retarded child. Forty-two percent of the parents reported that the retarded child had increased closeness between the parents. Only 24% of the families reported a severe restriction in the parents' social lives. Finally, the author reported that the presence of the retarded child had typically delayed, but not changed, parents' decision to have subsequent children.

Several authors had discussed the impact of the retardate on normal siblings. Authors have often assumed that siblings are adversely affected by the experience. For example, Jordan (1966) predicted that exposure to a retardate would interfere with the adjustment of normal siblings throughout their lives. Cohen (1962) stated that normal siblings typically felt guilty about the child's retardation and that they also had serious difficulties in explaining the retarded child's condition to peers. Cohen (1962), Hunter, Schuchman and Friedlander (1972), and O'Neil (1965) have stated that normal siblings require psychotherapy to deal with their feelings about the retarded child.

In contrast, empirical studies indicate that normal siblings typically adjust to the retardate and even benefit from their experiences with the retarded child. Schripper (1959) reported that three-quarters of the siblings of Down's Syndrome children she studied were well adjusted. Caldwell and Guze (1960) reported that siblings of both institutionalized and home-reared retardates were well adjusted. These siblings reported that they had no fewer friends because of the retarded child. They also reported that their experiences with the retarded child had made them more understanding of other people and had made their

families more cohesive. Similarly, Schriber and Feely (1965) reported that normal siblings of retardates "had developed greater maturity, tolerance, patience and responsibility than is common among children their age."

In summary, there are two widely divergent views of parents of the mentally retarded. The first view assumes that they are emotionally disturbed individuals who display various kinds of psychopathology in their interactions with the mentally retarded child, with each other and with other people in the community. The second view assumes that parents are well-functioning individuals who undergo a temporary crisis when they first learn of the child's retardation. Most traits ascribed to parents of the retarded by adherents of either group have not been empirically investigated. Only the impact of the retarded child on the family has been researched. Contrary to assumptions of the majority of professional literature, evidence suggests that if services are provided to families with a retarded child, parents and normal siblings are able to integrate the retarded child into their lives in a satisfactory manner.

Counseling Parents of the Mentally Retarded

The two views of parents of the retarded lead to different assumptions about parents' needs and the aims of counseling. Authors who assume that parents are emotionally disturbed emphasize parents' resistance to the idea that the child is retarded and their unwillingness to acknowledge their "real" feelings about the child. Many behaviors have been described as manifestations of parental denial. For example, Hunter, Schuchman and Friedlander (1972) stated that parents use denial

when they state that delayed speech is the retarded child's only major problem. Dalton and Epstein (1963) stated that parents believe that the retarded child may "catch up" in his development "to defend themselves against what they see and know." The authors fail to recognize that few parents have a knowledge of normal child development and that parents' statements may reflect ignorance rather than "psychopathology." Schripper (1959) emphasized parental pathology when she stated:

> The physician can precipitate a series of events that disrupt family living (with inadequate counseling); on the other hand, his valiant efforts to maintain the mental health of the family are doomed if parents' adjustment is immature or marginal.

According to this view of parents, counseling primarily aims to overcome parental resistances and to allow for expression of negative emotions. For example, Weingold (1952) stated that counseling should relieve the extreme guilt, anxiety, shame and isolation from which parents of the retarded are assumed to suffer. Sheimo (1950) also reflects this emphasis on parental feelings:

> It seems important to the author not to underestimate the intense repressed forces which become mobilized in parents who have mentally defective and/or handicapped children. At such times, to center one's attention on the defective child, rather than toward the parental conflict, may be attempting to deal with the least relevant factor in the total situation.

The second, contrasting view of parents of the mentally retarded assumes that the aim of counseling is to mobilize parents' strengths and develop their skills so that they can deal with the immediate crisis of the child's diagnosis. Kanner (1953) stated that counseling should provide a sympathetic endorsement of parents' human and parental abilities and relieve parents of unnecessary blame for the retarded child's

condition. Mathney and Vernich (1969) stated that the aim of counseling is:

> . . . the clear transmission of accurate, honest information about the child's condition, its implications for the child's future and the necessary concrete steps to deal most effectively with the problem.

The authors explicitly avoided "pervasive exploration of suspected emotional disorders" since the authors assumed that parents with a retarded child were seeking information, rather than psychotherapy. Menolascino (1968) stated that parents' reality crises are frequently ignored by professionals who wish to explore parental feelings and that parents seeking specific information may even be referred to psychotherapy to find out why they are "really" seeking help.

Various authors have provided suggestions to facilitate transmission of information about the child's diagnosis and prognosis. First, they have recommended that information be presented in a language that the parents can easily understand (Bryant, 1961; Hersch, 1961; Murray, 1959; Roos, 1965; Solomons, 1965; Schonell & Watts, 1956; Zook & Unicov, 1968). Second, they recommended that counseling include repeated contacts with parents (Bryant, 1961; Carr, 1970; Doll, 1953; Gordon, 1972; Hersch, 1961; Murray, 1959; Sarason, 1959; Solnit & Stark, 1961; Wolfensberger, 1965; Zook & Unicov, 1968). Repeated counseling sessions would allow parents to ask new questions and allow the counselor to assess parents' understanding of information already provided. Third, Sarason (1959) recommended that counseling include the establishment of concrete goals for the family in their work with the retarded child. Woodmansey (1971) recommended that the counselor assess if the family was following

suggestions related to these goals and that he should help the family resolve any misconceptions or emotional reactions that interfere with compliance. Fourth, Gordon (1972) stressed the need to include some optimistic information about the retarded child's prognosis in any discussion of the child's future limitations.

Authors have also debated which professional should counsel the parents of the retarded. Puescnel and Murphy (1960) stated that the pediatrician, who typically presents this information, is not an appropriate professional to present this information. They pointed out that parents who are being informed of the child's diagnosis during the neonatal period are unlikely to know the pediatrician. Consequently, the authors recommended that the obstetrician, who has had regular contact with the family, present information about the child's condition. In contrast, Thurston (1960) stated that physicians are often poorly trained to provide counseling and he recommended that counseling be provided by a psychologist, social worker or minister who is better trained to respond to parents' needs. Drayer and Schlesinger (1961) recommended that the counselor be able to continue to work with the family as the retarded child matures, and that only professionals who can meet this requirement should counsel parents.

The majority of parents with a retarded child are informed of the child's diagnosis after the child has lived with his family for months or years. During this time, parents have developed an attachment to the child and, in many cases, have begun to suspect that the child's development is slow. In contrast, parents of a child with Down's Syndrome are usually informed of the child's diagnosis in the first days of the

child's life (Berg, Gilderdale & Way, 1969; Carr, 1970; Denhoff, 1960; Oberman, 1963). Consequently, the child's diagnosis is presented before the parents have reason to suspect that the child is developmentally delayed and before they have been able to come to know and love him. Some parents with a child with Down's Syndrome may be informed of their child's diagnosis before they have any contact with the child.

Diagnosis of unexpected retardation is a shock to parents (Beck, 1959; Boyd, 1951; Carr, 1970; Condell, 1966; Smith, 1952). Consequently, counselors need to be especially sensitive to the needs of parents with a newborn Down's Syndrome child.

Therapeutic Groups for Parents of the Retarded

One response to the needs of parents of the mentally retarded has been organization of therapeutic groups. Wolfensberger (1967) stated that parents' groups can be placed on a continuum from "psychiatric-cathartic" to "educational-didactic." Groups at one end of the continuum assume that parents require depth psychotherapy which explores repressed, internal conflicts, only some of which are related to the retarded child. Groups at the other end of the continuum present parents with factual information about the child's condition. The type of therapeutic group organized appears to be related to the assumptions of the group leader rather than to the wishes and needs of the parent-participants. Typically, group leaders do not screen parents who are included in the therapeutic groups, may have had no prior contact with the parent, and may have no specific information about the parents' retarded child.

Several authors have reported findings on the impact of parent groups that fall toward the "psychiatric-cathartic" end of the continuum. For example, Cummings and Stock (1962) organized two ten-to-twelve-session groups for three to five mothers with a young retarded child. The therapists had no contact with the mothers or the retarded child prior to initiating the group meetings. Premeasures were administered to mothers at the inception of the group. The premeasures allowed the authors to eliminate mothers who were reportedly unlikely to profit from the parent group. Unsuitable mothers included mothers seeking concrete assistance with management of the retarded child and mothers who were unable to look inside themselves for the causes of hurt, frustrated and hostile feelings. Authors stated that mothers' interest in practical problems with the retarded child "typically mask a variety of resistances." Content of the group meetings were inadequately described. The authors did report that early sessions focused on the mothers' hopes, fears and problems with the retarded child. Later sessions shifted attention to mothers' hostility, narcissitic hurt and guilt. The authors reported that this shift would help to increase mothers' acceptance of themselves and their retarded children. The authors concluded that the group sessions had a positive impact on the participants. However, they also reported that they became increasingly aware of the rigid and brittle defenses of the mothers and discontinued the group sessions rather than tamper with the mothers' defenses. Postmeasures were taken three months after the conclusion of the group meetings, but the results were not presented. Consequently, the authors' claims of enhanced maternal adjustment cannot be substantiated.

Rankin (1957) organized a six month series of group sessions for mothers of retarded children who had been evaluated in a Washington, D.C. clinic. The group sessions were intended to be "exploratory, expressive, ventilative, cathartic and qualifiedly interpretative." Premeasures included a group Rorschach and an attitude scale modified from an instrument used to study mothers of schizophrenic children. The content of the group session was only loosely described, although the author did report significant remarks made by the participants during the sessions. The author reported that the group meetings were beneficial since participating mothers became more aware that "very much of one's problems lie in one's self and in one's difficulties from past experiences" than they had been prior to the group sessions. No postmeasures were taken to validate this impression of the group's positive impact.

Blatt (1959) organized a weekly, intrapsychically oriented group for eight to fourteen parents with a mentally retarded child. The author attempted to increase parents' understanding of their attitudes toward their retarded child so that the child could benefit more fully from the training program in which he was enrolled. The author did not present any evidence that parents' attitudes were, in fact, interfering with the child's schooling. The content of the group sessions was not described and presumably no pre- or postmeasures were taken. Nevertheless, the author concluded that parents benefited from participation in the group sessions.

Yates and Lederer (1961) organized a three-session, nondirective group experiences for parents with a young child with Down's Syndrome. Meetings were held during an evening hour to encourage fathers' attendance.

The goal of the parents' group was "to restructure the (parents') way of living" so that they could include the retarded child in their lives. The authors offered no evidence that the families had not included the child in their lives, nor did they explain why they used a nondirective approach to achieve this aim. The authors reported that parents were angered by the nondirective approach and by the leaders' refusal to respond to requests for specific information. Nevertheless, the leaders did not adjust their approach to the parents' wishes.

Several authors reported findings on the impact of parents' group meetings falling toward the "didactic-educational" end of Wolfensberger's continuum. Educational groups have often been criticized by authors on the basis of their various assumptions about the needs of parents of the retarded. For example, Blatt (1957) stated that educational group meetings were appropriate only for parents who did not have sufficient ego strength to tolerate investigations of their feelings toward the retarded child. Gianni and Goodman (1963) stated that educational group meetings were appropriate only for low income and uneducated parents. In view of these biases, it is not surprising that there has been only one study which compares the effectiveness of educational and insight-oriented groups for parents of the retarded. Its results clearly demonstrated the superiority of the educationally oriented approach (Tavormina, Hampson & Luscomb, 1976); the conclusion is not limited to low income and uneducated parents. It is striking that when participants were asked for suggestions that would improve the quality of future groups, they requested that additional, specific information be presented. They were especially interested in information about coping with community reactions to the

retarded child, expectations for the child's future, location of resources for the child, the meaning of IQ and the probable effects of the retarded child on other family members.

Popp, Ingram and Jordan (1954) organized a didactic group for 22 parents whose children were waiting for admission to a state institution. Group sessions included information about the causes of mental retardation, the intellectual and social limitations of the retarded, the needs of the retarded child and the role of parents in meeting the child's needs. The authors reported that parents benefited from this information. However, no independent measures of the impact of the group sessions were taken and, consequently, the authors' statements are not substantiated by data.

Coleman (1953) organized an educationally oriented parents' group for 20 to 35 parents whose retarded children were enrolled in a training center. The sessions attempted to coordinate home with school activities. To accomplish this, the author provided a short presentation on some aspect of the child's program at school and then led a discussion about this topic. There was no analysis of the impact of this intervention.

Bitter (1963) carried out one of the better designed studies of group sessions for parents of the retarded. He organized two seven-session groups. Pre- and postmeasures included a Semantic differential, a child-character-trait list and a 50-item test about mental retardation. Group sessions included a discussion of special education, recreation for the retarded child, speech and language development, vocational potential and suggestions for home training for the retarded child. Bitter found that the group intervention did have a significant impact on

parents' performance on the Semantic differential. However, he also found a significant decrease in accurate knowledge about mental retardation, for which he could not account. The study did not assess whether the intervention had an impact on parents' behavior with the retarded child.

Contact with Other Parents as a Therapeutic Intervention

An alternative method to parents groups is to attempt to assist parents with a retarded child by introducing parents to other families with a similar child. Contact with other parents has been reported to facilitate parents' adjustment (Auerbach, 1961; Cohen, 1962; Goodman, 1964; Gordon, 1972; Linder, 1970; Murray, 1959; Patterson, 1956; Schonell & Watts, 1960). These contacts reportedly helped parents overcome feelings of isolation. Auerbach (1961) reported that parents are able to share with each other concerns that they were unwilling or or unable to discuss with professionals. Linder (1970) reported that what other parents say about their handicapped child provides an important frame of reference against which parents can assess their own child's progress.

Parents with a retarded child appear to be eager for contact with other parents with a similar child. Thurston (1959) reported that 86% of parents with an institutionalized child whom he studied thought that contacts with other parents would be helpful. Roith (1973) reported that 50% of his sample believed that contacts would be helpful. However, parents apparently do not know how to arrange for these contacts on their own. Schonell and Rorke (1969) reported that mothers whose retarded

children attended the same training program quickly established social contacts outside the program; 82% of the mothers they evaluated reported that these contacts were useful in their adjustment to their retarded child. However, if the child was not enrolled in a training program, parents had little opportunity to meet. Ehlers (1966) reported that only 9% of the mothers she studied had succeeded in establishing contact with another parent of a retarded child. Remarkably, there has been no systematic application of this approach which introduces parents to one another to facilitate adjustment to a retarded child.

Summary

Theoretical assumptions and speculation rather than methodologically sound research have dominated the professional literature on parents of the retarded; there have been few description studies of typical parents of the retarded. There have been two divergent theoretical views of parents. The first view asserts that parents are emotionally ill individuals who manifest their psychopathology in interactions with the retarded child. This view assumes that parents require interventions which overcome their resistances and allow them to express their depression and hostility about the retarded child. The second, contrasting view, assumes that parents of the retarded are well-functioning individuals who undergo a temporary crisis when they learn that their child is retarded. This view assumes that parents require support and accurate information about the child's condition. Parents' groups have been organized on both sets of assumptions. However, studies of these "cathartic" and "educational" groups have been poorly designed, and it

is consequently difficult to assess the effect of either type of group intervention. A second approach to assisting parents with a retarded child is to introduce families to other parents with a similar child. Although some articles have speculated about the benefits of this approach, there are no research data.

CHAPTER III

METHOD

Subjects

Participating parents were all known families with a Down's Syndrome child under the age of 3 years living in the greater Knoxville, Tennessee, area. Parents were recruited from a roster of families who had received services from the Birth Defects Evaluation Center of the University Hospitals of Knoxville. This agency provides comprehensive diagnostic and evaluational services to all genetically handicapped individuals in East Tennessee, and is the only agency in that area that can and does provide chromosomal analysis as a component of diagnosis. Charges for services are flexible. Referral to the agency is most frequently made by a physician or health care agency who has questions about an atypical individual, although parents may also make a referral to the agency. The range of services provided and the absence of other agencies providing comprehensive diagnostic services suggest that the agency's roster is a nearly comprehensive list of all diagnosed cases of Down's Syndrome in the region.

The demographic characteristics of the 10 participating couples are presented in Table 1. Since the agency's roster appears to be nearly exhaustive and since all listed families agreed to participate, there is every reason to believe that the participating families are representative of parents with a young Down's Syndrome child. However, it is remarkable

Table 1

Demographic Description of 10 Families with a Down's Syndrome Child at the Time of First Contact in Current Study

Variable	A*	B	C	D	E	F	G	H	I	J
Child's age (years)	0-8	1-0	1-4	1-4	1-5	1-6	2-1	2-8	3-0	3-0
Child's sex	M	F	M	F	F	M	M	M	F	M
Mother's age (at child's birth)	32	25	26	36	24	43	26	20	20	40
Mother's education	15	12	16	12	12	10	13	10	14	12
Father's age (at child's birth)	32	27	26	36	21	60	25	25	25	36
Father's education	15	10	15	12	12	12	12	10	14	10
Family annual income	18,000	37,000	15,000	8,200	6,300	3,000	8,000	4,700	12,000	7,500
Number of siblings	1	1	0	2	0	4	0	1	3	2
Religions affiliation**	FP	FP	OP	FP	FP	FP	FP	FP	RC	FP
Religious activity***	++	±	o	++	+	+	++	+	++	++
Length of home interview****	H	L	M	H	M	L	M	L	H	M

*Families are identified by letter to protect their identity. There is no relationship between these letters and the numbers used in the remainder of the study.

**FP-Fundamentalist Protestant; OP-Other Protestant; RC-Roman Catholic.

***++ = very devout; + = devout; o = indifferent.

****H = high; M = moderate; L = low.

that the majority of participating mothers were younger than 30 years of age when the infant with Down's Syndrome was born. The youth of the participating mothers is inconsistent with previous research findings which associated the birth of a child with Down's Syndrome with advanced maternal age. The data are, however, consistent with the findings of Marmol, Scriggins and Vollman (1969), who suggested that maternal age is bimodally distributed for mothers who give birth to a child with Down's Syndrome. The authors stated that there is one peak for mothers between 20 and 24 and a second peak for mothers in the age range of 40 to 44.

Procedures

Prior to the first contact in the current study, all parents had received genetic confirmation of the retarded child's diagnosis and had been counseled by one or more physicians about the child's prognosis. At the initiation of the current study, parents were sent a letter indicating the investigator's interest in organizing an educational group for parents of children with Down's Syndrome. Parents were informed that the group sessions would be structured around the parents' interests and that the investigator wished to meet each family and discuss their interests prior to the initiation of the group meetings. The letter was followed by a telephone contact. Each of the 10 families agreed to a home visit and a visit was arranged at a time that was convenient for both parents.

During the first home visit, the investigator met the parents, the retarded child and his siblings, and had an opportunity to observe their interactions. After rapport was established, the investigator requested permission to tape discussions with the family. The request was granted

in each instance. Parents were then interviewed, using a semi-structured format. Topics covered in the first home interview are presented in Appendix A. The interview typically lasted for two hours. At the conclusion of the interview, each family was again invited to the educational group sessions.

The educational group sessions were organized into five, weekly meetings. Information obtained during the first home interview provided suggestions for topics and the investigator also introduced other topics that were assumed to be useful to parents. Meetings were held at the evaluation center and were held at an evening hour so that both mothers and fathers could attend. Parents were encouraged to bring their child with Down's Syndrome to the group meetings so that parents had an opportunity to meet other children similar to their own child. Free babysitting services were provided. Meetings typically lasted about one and one-half hours and at the conclusion of each session coffee was served to facilitate socialization among the parents.

Of the 10 families invited to the educational group sessions, 5 families attended all sessions. One other family discontinued after the first meeting. Four remaining families did not attend any of the group sessions, despite a weekly reminder note encouraging participation.

One month after the conclusion of the fifth session, all families were contacted and a second home interview arranged. The semi-structured interview discussed changes which had occurred since the first home interview. Topics included in the second home interview are presented in Appendix B.

Two years after the first home interview, the 10 families were contacted again and a third semi-structured interview was arranged. The final interview explored parents' experiences with their now older, retarded child. Topics included in the final home interview are presented in Appendix C.

Data Anslysis

Each of the parents' interviews was completely transcribed and an analysis was made of these transcripts. Data were first divided into content categories which reflected significant aspects of the couples' experiences. Each of the 10 couples' transcript was then rated for the presence of a content category mentioned by any of the families. The analyses, therefore, reflect experiences common to the couples as well as noteworthy experiences that were unique to a single family. A Fisher's Exact Test provided nonparametric tests of significance of differences between groups. This test compared five couples who participated in the educational group sessions to four couples who did not attend. Results indicate the exact probability of the obtained distribution of events. The remaining couple was excluded from analysis because the parents attended only one of the group sessions. Finally, representative quotes from families are presented. Quotes were selected because they were representative of families' experiences or, when indicated, were noteworthy, although they were reported by only one couple. Extraneous material is deleted from quotes, but no material was deleted that might alter the meaning or quality of the parents' remarks.

Three other variables were also measured: (1) quality of parents' experiences with the retarded child by the conclusion of the current study, (2) parents' knowledge of Down's Syndrome, and (3) activity in training the retarded child. Quality of parents' experiences with the retarded child was assessed for each family by rating the presence or absence of 12 positive and 13 negative experiences with the retarded child. The list of positive and negative experiences was derived from parents' statements made during the home interviews. Items are presented in Tables 2 and 3. Knowledge of Down's Syndrome was assessed through the administration of a 40-item, nontechnical test of facts about the condition. Items are included in Appendix D. The test was administered to all 10 families on two occasions, once during the first home interview and again after the conclusion of the educational group sessions during the second home interview. Parental activity in training the retarded child was assessed on the basis of the retarded child's enrollment in training program, of training of the retarded child in the home under the supervision of a professional, and of reading books about mental retardation.

Table 2

Frequency of Occurrence of 12 Positive Experiences with a Child with Down's Syndrome at the Final Home Visit

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
1. At least one set of grandparents likes child	X	X	X	X	X	X	X	X	X	X	10	--
2. Realistic optimism about future	X	X	X	X	X	X	X	X	X	X	10	--
3. Little anxiety, depression about child	X	X	X	X	X		X		X	X	8	.44
4. Satisfied with child's progress	X	X	X	X	X	X	X		X		8	.17
5. Report strangers treat child well	X	X	X	X	X		X		X		7	.17
6. Willingly make accommodations to child's needs		X	X	X	X	X		X	X		7	.17
7. Sibs like child (6 families)	X	X	X		X		X		X		6	
8. Enjoy contact with other families with retardate	X	X	X		X	X					5	.06
9. Increased parental closeness due to child		X	X		X						3	
10. Positive personality change due to child		X	X			X					3	.28
11. Would have another Down's child if pregnant		X	X			X					3	.28
12. Siblings want to work with retarded as a profession			X			X					2	.56
Sum for each family	7	10	11	6	9	8	5	3	7	3	74	

*P compares attending and nonattending families on each variable and indicates the probability of the obtained distribution as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one of the educational group sessions.

Table 3

Frequency of Occurrence of 13 Negative Experiences with a Child with Down's Syndrome at the Final Home Visit

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
1. At least one set of grandparents rejects child						X		X			2	.44
2. Continued anxiety, depression about child						X					1	--
3. Dissatisfaction with child's progress							X	X	X		3	.05
4. Decline in parental closeness due to child						X					1	--
5. Child seen as major inconvenience	X										1	.56
6. Excessive sensitivity to strangers' reactions to child						X					1	--
7. Avoids other parents with a retarded child								X			1	.44
8. Spouse stays away from home due to child						X					1	--
9. Put child to bed early to get away from him	X										1	.56
10. Unrealistic pessimism about future											0	
11. Unrealistic optimism about future											0	
12. Negative personality changes due to child											0	
13. Siblings dislike child											0	
Sum for each family	2	0	0	0	0	5	1	3	1	0	12	

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one of the educational group sessions.

CHAPTER IV

RESULTS

Quality of Parents' Experiences at the Final Home Visit

At the conclusion of the current study, an assessment was made of the quality of parents' lives with their young child with Down's Syndrome. For this purpose, a list of evaluative items was generated. The items explored a range of topics that reflected potential positive or negative experiences. Each of the 10 families was rated for the presence of 12 positive and 13 negative items concerning their experiences with the retarded child. In all, 84 items were rated as present among the 10 families. Of these ratings, 74 ratings (86%) indicated a positive experience with the retarded child and only 12 ratings (14%) indicated a negative experience with the retarded child. Data on positive and negative experiences is presented in Tables 2 and 3. Thus, ratings indicate that parents' evaluation of their experience with the child with Down's Syndrome was overwhelmingly positive.

Although parents had a positive experience with the retarded child in the final home interview, their positive evaluation was not the consequence of early positive experiences with the child. In fact, parents' experiences (described in the following section) were negative and could be expected to interfere with the development of a positive attachment to the retarded child.

Pregnancy and Birth of the Child with Down's Syndrome

Families who participated in the current study had little reason to anticipate the birth of a child with a serious birth defect. Serious birth defects are typically associated with maternal age over 35, or the presence of defects in members of the extended family. As indicated in Table 1 (page 27), 70% of the participating mothers were younger than 35 years when the infant with Down's Syndrome was born. No members of the couples' immediate families had a history of mental retardation. Of the six couples who had other children, five had produced normal, healthy children. The one remaining family had previously given birth to a child with a heart defect.

Data on parents' reports of pregnancy with the child with Down's Syndrome are presented in Table 4. Although parents' accounts of pregnancy might be expected to emphasize unusual occurrences or a sense of foreboding, eight of ten families reported that there were no unusual events during pregnancy. Of the two families who did report unusual events, one family reported that they had moved to a new home and the other family reported that an adult son entered the U.S. Navy during that time. No family reported an unusual event that they believed contributed to the child's defect.

There was a significant association between mothers' reports of health during pregnancy and attending the educational group sessions. Four of five mothers who attended the educational group reported that their health was good during pregnancy. The remaining mother reported a chronic, mild depression during this time. In contrast, only one of

Table 4

Retrospective Accounts of Pregnancy Made by Mothers Who Gave Birth to a Child with Down's Syndrome

Variable	Attending					Nonattending					Sum	p*
	1	2	3	4	5	6	7	8	9	10		
REPORT OF PREGNANCY:												
Felt fine	X	X	X	X						X	5	.16
Minor physical illness											0	
Minor depression					X						1	.56
Major physical illness						X	X	X	X		3	.05
REPORT OF WORRIES:												
No serious worries	X	X	X	X			X	X		X	7	.73
General worries									X		1	.44
Worries about child					X	X			X		2	.56
EXPECTED CHILD WITH LOW BIRTH WEIGHT			X		X						2	.28
UNUSUAL EVENTS REPORTED:												
Yes								X	X		2	.17
No	X	X	X	X	X	X	X			X	6	.17

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution using a Fisher's Exact Test. Analysis excludes Family 6 who attended only one session of the educational group.

the four nonattending mothers reported good health during pregnancy. The remaining three mothers reported major physical problems during pregnancy, including debilitation nausea and water retention. The mother who attended only group session also reported severe nausea and weakness during pregnancy. There are at least two possible explanations for the association between reports of serious illness during pregnancy and nonattendance of the educational group sessions. First, it is possible that the mothers' difficult pregnancies and their children's defective condition may have overwhelmed these mothers and resulted in an apathy that made them unwilling to engage in further activities that would have benefited the retarded child. Second, nonattending mothers may have retrospectively exaggerated their illness during the pregnancy so that their memory of pregnancy was consistent with their later disappointment with the child. Some support for this possibility is suggested since mothers who were rated as having the least enjoyment of their child were mothers who reported serious illness during pregnancy. The limited population size of the current study does not allow for further clarification of the association between reports of serious illness during pregnancy and nonattendance.

No family reported unusual worries during pregnancy. Two mothers had been told to expect an infant with low birth weight. However, these mothers were apparently not informed of the implications of this prediction and they did not report worries resulting from this information. Thus, even mothers who were told to expect a small infant or who reported serious illness during pregnancy stated that they did not believe that these events were a warning that the child would be defective.

In summary, families anticipated the birth of the child with excitement and hope. They assumed that they had little reason for concern.

Parents' Reports of the Diagnosing Interview

Data on the diagnosing interview reflect only parents' views of this counseling. Information recalled, rather than the full information that may have been presented, were the foundation for parents' interactions with the retarded child.

Eight of ten families were informed of the child's diagnosis on the day of the child's birth, or on the following day. The remaining two families were not informed of the child's diagnosis until weeks later. One family reported that their pediatrician withheld the diagnosis from them. The other family reported that their physician did not recognize the child's diagnosis when the child was born. In nine of ten cases, the diagnosis was presented by the child's pediatrician. In the remaining cases, both the child's pediatrician and the mother's obstetrician presented the diagnosis to the couple.

Parents' reports indicate that counseling physicians attempted to provide a brief, technically accurate summary of the child's condition and prognosis during the diagnosing interview. However, there were three major areas of deficiency in this counseling. First, although all but four of the parents had completed at least 12 years of schooling, the parents reported that they were unable to understand the terms used by the physician counselor. As indicated in Table 5, parents had little

Table 5

Parents' Recognition of Diagnostic Labels Used During the Diagnosing Interview

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
TERM "MONGOLISM" RECOGNIZED:												
by neither parent			X				X	X	X	X	5	.12
by one parent											0	
by both parents	X				X						2	.28
unclear; probably did not recognize		X		X							2	.28
TERM "DOWN'S SYNDROME" RECOGNIZED:												
by neither parent	X		X		X	X	X	X	X	X	7	.56
by one parent		X									1	.56
by both parents				X							1	.56

*p compares attending and nonattending families on each variable and indicates probability of this distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one session of the educational group.

recognition of the term "mongolism" and 17 of the parents had no recognition of the term "Down's Syndrome."

A second area of deficiency was physician counselors' emphasis on pessimistic information about the child's prognosis. As indicated in Table 6, parents recalled being informed of 30 facts about their child's condition during the diagnosing interview. Of these facts, 63% were rated by the investigator as pessimistic, 27% were neutral and only 10% were optimistic. Emphasis on negative information is reflected in the following report of the total information given to a mother about her son:

> Well, that evening the doctor came in and he said that my son was Down's. And, really, I didn't know what it was. He explained it to me. He said that he (the child) would be slower than most kids. That he would be sickly. He said that he had heart problems. I called my mother and told her. And she said she couldn't believe it 'cause she had seen the baby and it looked perfectly normal to her. He (the doctor) said, "His appearance." You know, he told me when I was in the room, "Look at his hands. Mostly at his hands."

Parents were rarely informed of encouraging facts about their child. Only one family was reassured that the child had no life-threatening defects. One of the 10 families was informed of the influence of environmental stimulation on the child's functioning, but even this one family was not given specific suggestions. No family was directed to a training program for retarded infants.

A third deficiency in physician counseling was insensitivity to experiences that caused needless upset to parents. Counseling experiences to which parents were exposed are presented in Table 7. One example of insensitivity was inappropriate timing of the diagnosing interview. Two mothers were aroused from the anesthesia of childbirth to be informed

Table 6

Information Eight Families Recalled Having Been Given About Their Child with Down's Syndrome During the Diagnosing Interview

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	NA	5	6	7	NA	9	10		
OPTIMISTIC INFORMATION:												
child was healthy	X										1	.56
stimulation would improve child's functioning	X										1	.56
name of helping agency					X						1/3	.56
PESSIMISTIC INFORMATION:												
child was retarded	X	X	X		X	X	X		X	X	7	.73
had atypical appearance	X	X	X			X	X			X	5	.60
would be sickly					X	X	X			X	3	.41
may need institutionalization					X	X					1	.56
would not live to adulthood			X			X					1	.56
no known cause of condition					X						1	.56
no organization for parents	X										1/19	.56
NEUTRAL INFORMATION:												
name of child's condition	X	X	X		X	X	X		X	X	7	.73
would test intelligence later	X										1/8	.56

*P compares attending and nonattending families on each variable and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excludes Families 6 and 8 who were not informed of the child's diagnosis at birth and Family 6 who attended only one of the group sessions.

Table 7

Parents' Reports of Their Experiences During the Diagnostic Interview Concerning Their Child with Down's Syndrome

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	NA	5	6	7	NA	9	10		
Saw child prior to diagnosis		X	F		F	F				X	5	.06
Did not see child prior to diagnosis	X		M		M	M	X		X		6	.60
Delayed seeing child due to fears of child's appearance			M		M	M			M		4	
Mother awakened from anesthesia to be informed of diagnosis	X		X								2	.28
Plans to delay informing mother disrupted by physician					X	X					2	.44
Parents informed of diagnosis separately	X	X	X		X	X	X		X	X	7	.17
Parents informed of diagnosis together											0	--
Only mother informed of diagnosis							X		X		1	.44

*p compares attending and nonattending families on variables and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excludes two families who were not informed of the child's diagnosis at birth and Family 6 who attended only one group session.

F = father only; M - mother only.

that the child was retarded. There was no apparent reason why the information could not have been presented at a more suitable time. In two other cases, the child's father requested that the mother be informed of the diagnosis only after she had recovered from childbirth. However, the request was disregarded and the physician proceeded to inform the mother. Counselors were also insensitive to parents' need for support. For example, two husbands were never informed of the child's diagnosis by the physician. Instead, the wife was obligated to relay this disturbing information and its implications to her spouse. Finally, counselors needlessly alarmed some parents about the child's atypical appearance. Only seven parents saw their child prior to diagnosis. None of these parents suspected that the child's appearance was unusual and none of the parents were distressed by the physicians' statements about the child's appearance. Thirteen of twenty parents had not seen their child prior to diagnosis and had no knowledge of the child's appearance before it was described as atypical by the counseling physician. Parents later reported that they imagined deformities far more severe than the child's actual condition. One mother reported that she feared that her child was "something decrepit and deformed" but was relieved when she saw her child. Four other mothers delayed seeing their child for several days due to their fears of imagined deformities. In one extreme instance, a mother was reportedly urged to immediately institutionalize the newborn without ever seeing the child. The mother reported that she was so frightened by the deformities she imagined, that she intended to comply with the physician's advice. However, this mother

eventually saw her child and found she was quite attractive, so decided against institutionalization.

Parents' descriptions of the counseling they received indicated a wide range in the quality of this counseling. One family, who was highly satisfied with their experience, reported that their physician was consistently compassionate and sensitive. His counseling was characterized by accurate information about the child's potential which was presented at a slow enough pace that the parents could assimilate it. The mother described the first counseling session with this physician:

> Well, he come in. There was another bed in the room, but there wasn't a patient in it at the time. And he had a nurse with him. And he sat down on the bed and asked me how I was getting along. And he said, "we're concerned about the baby. We're going to have some tests run on it." And I still didn't think about the seriousness of it, then. And he asked me if I had heard of Down's Syndrome. And I told him "no." And I told him that it seemed to me that maybe I had heard those words somewhere and I thought maybe it was a birth defect, but I really didn't know what it was. And so he explained it to me, you know, that she had slanted eyes and the small ears and the flat bridge and her big toe, the space between it and the others. And her hands, the little finger being crooked. And he said that she had some of the features of one. Of course, I still didn't really think—Well, I just thought, "well, she's not." Well, I remember he told me that where your other children sat alone at six months, she may be nine months. He said she may be a little slower. He never really did say no really hard words that hurt, I don't guess. Well, I mean, he didn't say "retarded" or "mongolism"—those words that sort of hurt you.

Other parents' experiences were much less adequate than the preceding example. For example, in one instance, a physician counselor disregarded the husband's request that the wife be allowed to recover from childbirth before she was informed of the child's condition. The physician approached the mother and presented only pessimistic information about retardation, including misinformation about the need to

institutionalize the retarded. The mother described her counseling experience:

> Well, he came in that morning and he woke me up to tell me. He set down on the foot of the bed and showed me a book (with pictures of Down's children) and all this. And he just told me, "I never held anything back from you with your other babies," and he said, "and I'm surely not going to lie to you." And he came out and told me that (my son) was mongoloid. Well, it just kinda started ringing in my ears, you know. And I had seen children that were mongoloid. In fact, I went to school with a boy that was mongoloid. And this boy I had gone to school with was the first that came into my mind. And, I didn't know, it just had to sink in for a few minutes. And then he told me, you know, what the name was because I didn't know the name was Down's. And so he left. And he did tell me before he left that there were institutes that could take care of children like him if I thought it was too much for me. That it would be my choice what to do.

Inadequacies of the initial diagnosing interview were not corrected in later contacts with the child's pediatrician. In fact, three families had no contact with a physician after the initial counseling session. Consequently, these families had no opportunity to obtain more information about the child's condition, to clarify misconceptions or to gain professional support. These families were forced to wait three months for another professional contact, which they received when the child's diagnosis was confirmed. Five couples reported that they had a number of meetings with their pediatrician while the child was still in the hospital. They reported that these additional meetings allowed them to ask questions and to obtain more information about the child's condition. However, the information they received was not encouraging and would not inspire hope in their future with their retarded child.

Parents' Understanding of Mental Retardation at the Birth of Their Retarded Child

Each of the families reported that they were informed that the child was mentally retarded when they were first informed of the child's condition. However, none of the physician counselors discussed the meaning of retardation. After parents had acquired more accurate information about the retarded child's expectations, parents reported that their initial expectations had been inappropriately low.

Many initial expectations were based on contact with individuals whom the parents assumed were mentally retarded. These individuals were often unable to manage simple, self-care skills and were a burden on their caretakers. For example, one father described a child whom he believed exceeded the level of functioning he could expect from his child with Down's Syndrome:

> This couple had a kid that was brain damaged. She's five or six and she can't talk. I mean, she's fairly smart; she can do things. But, to me, the way she grunts and cries, it bothers me a lot.

A mother described a retarded child who attended her church:

> During the service at church, they (the retarded child's parents) would let him get up and wander around, to go up in the choir during the songs and he would mimic the preacher. He'd get down on the floor like he was praying. And his nose was always dirty and his shirt was always out. His face was always dirty. You know, it was just all these bad thoughts that would come into my mind. And he wouldn't talk. He'd make a sound, but you couldn't understand it. It really made me sick for a while. I got to so I could go back to church, and I'd have (my son) on my lap. And I'd see this little fellow running around. Oh, there was a long time that I couldn't sit still. I'd get sick to where I would throw up and I'd have to leave.

Nine of ten mothers, but only four of ten fathers, reported such exposure to a person whom they considered to be retarded. Their reactions to the person they assumed to be "retarded" were almost exclusively negative. Seven of nine mothers and three of four fathers reported reacting negatively to a person they had identified as retarded. Since mothers were more likely than fathers to report contact with a retarded person, mothers were especially likely to have responded negatively to a person they considered retarded.

Parents' Adjustment Prior to Confirmation of the Child's Diagnosis

Parents were informed of the child's diagnosis when it was first suspected by a physician. In nine of ten cases, physicians did not express any doubts about the accuracy of the diagnosis. In the remaining case, parents were informed that the attending physicians disagreed about the child's diagnosis. Each of the families was informed that the child's diagnosis could be conclusively confirmed only after the child's chromosomes had been cultured and analyzed. Chromosome culture and analysis requires about three months.

Table 8 shows a significant difference between mothers and fathers in their acceptance of the validity of the child's diagnosis prior to confirmation. It is possible that mothers' prior negative experiences with retardates interfered with acceptance of the child's diagnosis.

Parents' differences in acceptance of the child's diagnosis contributed to disagreements between the spouses in the period prior to confirmation. One father described the difference in parental reactions:

Table 8

Parental Acceptance of the Diagnosis of Down's Syndrome
Prior to Confirmation by Chromosome Analysis

Variable	Attending Families						Nonattending				Sum
	1	2	3	4	5	6	7	8	9	10	
Both parents accepted	X										1
Mother only				X						X	2
Father only		X			X	X	X	X	X		5
Neither			X								1
Physicians disagreed			X								1

> Like I said, I accepted it right off. Course, I knew. I saw (my daughter) just a couple of minutes after she was born. And I knew right off that there was some sort of problem. You could sense that. But I didn't have any problem accepting it. Now, (my wife) did for months. She'd say, "well, it can't be." But I really didn't have that. I had a dejected feeling, you know. Sad. It was almost like a death, you know. But there was never any doubt in my mind that she (the daughter) was different and I don't think I had any problem accepting it.

During the three month waiting period, parents had no contact with a professional who could provide support and answer questions. They attempted to learn more about the child's prognosis by using whatever resources were available to them. Two families visited a residential center for the retarded. These parents were not informed that some of the limitations they observed occurred because the residents had not been given early, intensive training. Another mother had only a dictionary as a source of information. She reported:

> When I came home (from the hospital), just repeatedly, I would look it (the word "mongoloid") up in my dictionary. And I would look at that little, tiny baby and she was eating and drinking and wetting and all, just like any other baby. And I thought, "now, how can it be that she is an idiot?" And things like that, that just horrified me.

Parents reported a variety of intense emotional reactions during the first months with their retarded child. Parents' described emotional states appeared to have three separate origins: (1) the presence of a serious birth defect in a child that the parents assumed would be normal, (2) symptoms resulting from the child's specific defect, and (3) erroneous information/assumptions about life with a child with Down's Syndrome. Table 9 presents data on parents' emotional responses.

Parents had anticipated the birth of a normal child and, instead, delivered a child with a serious birth defect. In response to this event,

Table 9

Parents' Emotional Reactions to the Child with Down's Syndrome Mentioned During the First Home Interview

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
REACTION TO PRESENCE OF BIRTH DEFECT:												
Depression	X	X	X	X	X	X	X	X		X	8	.44
Anger at "unfairness"	X	X						X			3	.48
Envy of others	X	X							X		3	.56
Guilt	X							X			2	
Avoidance of others	X										1	
REACTION TO SPECIFIC DEFECT:												
Anxiety	X				X	X					2	.56
Depression					X						1	.56
REACTION TO MISCONCEPTION ABOUT MENTAL RETARDATION:												
Anxiety	X	X	X	X	X	X	X		X		7	
Depression	X	X	X	X	X	X		X		X	7	
CONCERNS ABOUT PRESENT:												
Child's health	X	X	X		X	X	X	X	X	X	8	
CONCERNS ABOUT FUTURE:												
Child's limitations	X	X	X		X	X	X	X			6	
Social rejection of child		X	X					X	X		4	
Placement if parents died	X	X			X				X		4	
Availability of training	X	X		X				X			4	
Might imitate retarded if placed in training		X	X								2	
Future appearance	X										1	

*p compares attending and nonattending families on each variable and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excluded Family 6 who attended only one of the educational group sessions.

parents reported feelings of depression, anger, envy at parents with normal children, and a desire to avoid other people. For example, one mother described her depression and anger at the perceived unfairness of having given birth to a defective child:

> You get so dejected because you've got this kid and why didn't it happen to so-and-so and why did it happen to you. And I'd cry, you know. . . . Well, I got to thinking, well, of all the kids that are running around and the kids that are illegitimate and everything and their babies are beautiful. Their's are perfectly healthy. And here you are, trying to do right and live right and here you pop up and have a kid like this. And then you get to thinking on the other side, that if the kid had been born in another home, it wouldn't have a chance, either.

Three couples reported either anxiety or depression in response to the retarded child's specific defects. Children with Down's Syndrome are more susceptible to lung infections than other children and often have wheezing respirations. One mother reported her anxieties about this condition, about which she had not been warned:

> When I got home (from the hospital), I got so scared. When you've got a family and your husband travels, you're left alone. I had a fear, a fear that she (the retarded child) was going to die on me right then. And I stayed awake all night long, listening to her breathe, because you could hear the rooftop come off when she'd breathe.

Each couple reported either anxiety or depression in response to their misconceptions about life with a retarded child. Parents had not been informed that training would have a significant impact on the child's level of functioning. Consequently, parents assumed that they could not influence the child's prognosis. One father described the resulting sense of depression and futility:

> It's really hard to explain your feelings, I think. You know, it's a big let-down, just kind of like letting the air out of a balloon, you know. You just feel rejected and helpless. I

> guess, really, that's the best word I can think of to explain my feelings. Because there was nothing I could do, you know. Just wait and see, you know.

Another mother reported a prolonged, severe depression which had apparently been a response to her belief that the child would not develop any self-care skills. She stated:

> Everything went dark as far as I was concerned. I thought that I was penned in for the rest of my life. . . . Oh, I screamed, I yelled, I cried every day. I washed clothes and I cried; I did dishes and I cried. I carried (the child) around the house and cried. It didn't do any good. Either you're going to give up a child like that, or you're going to keep it. And the best thing I've ever done was to keep her. Because if I had given her up, look at what I would have given up.

Parents also reported a variety of concerns for the child. Most parents' only concern about the present was worries about the child's poor health, especially lung infections. In contrast, parents expressed many concerns about the future with the retarded child.

Parents who attended the educational group reported a greater number of emotional responses and concerns than did nonattending parents. Evidently, parents who were more distressed about the child's condition were more likely to decide to attend the group meetings that promised some relief. Alternatively, attending parents may have been more verbally communicative and hence more likely to describe their emotional reactions to their child at length, as well as to enter into a discussion group.

Events Helping Parents Adjust to the Retarded Child

After analysis of the child's chromosome was completed, each family was counseled by a genetist, who confirmed the child's diagnosis and provided information about the child's prognosis. Four families reported

that this counseling was helpful in their adjustment to the child's condition.

Parents identified three other events which increased their acceptance of the retarded child: (1) the child's development of unexpected skills, (2) meeting other parents with a handicapped child, and (3) religious faith. Frequency of each reported event is presented in Table 10. Attenders and nonattenders did not differ in this respect.

Table 10

Events Parents Reported as Helping Them Adjust to the Child with Down's Syndrome

Variable	1	2	3	4	5	6	7	8	9	10	Sum	p*
Child's development of unexpected skills		X	X	X		X			X		4	.32
Meeting other parents of handicapped child			X	X		X			X		3	.48
Religion					X	X				X	2	.56

*p compares attending and nonattending families on each variable and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6, who attended only one of the group sessions.

Initially, parents had assumed that a child with Down's Syndrome would be incapable of developing any abilities. Consequently, parents were amazed by the retarded child's ordinary accomplishments. For example, one father stated:

> He cried. That tickled us to death when he did. It was on a Thursday or Friday and he was getting to be a month old. So

> one day he was crying and he was back in the back bedroom. And he cried louder and louder and louder. I wouldn't let my kid cry. I never did with (the other child). But we sat here and started laughing, didn't we? To hear him crying so loud. It was just like music. We were real tickled that he could make a sound.

Five of ten couples reported that the retarded child's accomplishments encouraged them to believe in the child's potential. In two of these five cases, the child's emerging skills had a positive effect on the parents' interactions with the child. Reassured by the child's skills, the parents became more actively involved in stimulating the child's development. However, in the remaining three cases, the child's developing skills had a negative effect on the parents' willingness to train the child. These parents assumed that the child's skills indicated that the child was not seriously delayed, that the diagnosis was in question, and that the child's prognosis was normal. Consequently, they made no effort to provide additional stimulation for the child.

Four couples reported that meeting other parents with a handicapped child was an important influence in their acceptance of their retarded child. Other handicapped children were used as a standard of comparison and for prediction of the retarded child's future abilities. Parents of a handicapped child were also a source of information and suggested reading materials. Parents in the current study had been given no professional guidance in establishing contacts with other families. Hence, at times, they inadvertently compared their own child to a handicapped child with a significantly different prognosis than a child with Down's Syndrome. For example, one mother compared her retarded child to a blind, cerebral

palsied child. At other times, contacts with handicapped children were encouraging to parents. One father stated:

> A little boy came in over there and he had muscular dystrophy. And he couldn't move or anything else. We seen him and then we seen (our daughter), and how she looked around and was so alert and everything. It helped us out a lot. Because we could appreciate the way she was then.

Three couples identified religious faith as an important contributor to their adjustment to the retarded child. They reported that religious faith helped them appreciate the child. For example, one mother stated:

> But we love her (the retarded child) like she is, even if there is a limit on her intelligence. I remember when I was in the hospital, some of the first thoughts that I had was that the things we want for our children is happiness and a home with the Lord. And she's got a guarantee on those two things. None of my other children do.

In no instance did parents suggest that their faith encouraged resignation to the child's condition. Eight of ten families reported that the retarded child was a special responsibility from God and five of the eight families stated that God had caused them to have a retarded child because they were more able to assume the responsibilities of the retarded child's special needs than other couples.

Quality of Parents' Adjustment at the Time of the First Home Visit

During the first home interview, five areas of adjustment were assessed: (1) knowledge of Down's Syndrome, (2) activity in training the retarded child, (3) accommodation to the child's special needs, (4) quality of interpersonal interactions, and (5) realistic hope in the future.

Parents' Knowledge of Down's Syndrome

Parents' knowledge of the child's condition was assessed in three ways. First, knowledge was measured on a 40-item test of Down's Syndrome. Second, parents were asked to describe the cause of the child's condition. Third, an assessment was made of the appropriateness of parents' characteristic manner of interacting with the retarded child.

As indicated in Table 11, parents had little knowledge of Down's Syndrome as measured by the 40-item test at the first home interview. They correctly responded to between 14 and 6 items, with a mean of only 9 items answered correctly.

Responses indicated that nine of ten families had a rudimentary understanding of the biological causes of the child's condition. Parents understood that the condition was related to a chromosome defect and two families also understood that the condition is often associated with advanced maternal age. However, parents did not understand the nature of a chromosome or the number of chromosomes the child had. One family had almost no understanding of the child's condition. Parents explained that the child "had something wrong in his blood," apparently because confirmation of the child's condition had been based on blood samples. Results of the 40-item test also indicated that parents had little knowledge of training programs available for young, retarded children. Each couple knew the name of only one training program and parents typically did not know the eligibility requirements of the agencies whose names they knew.

Although some parents had a fairly accurate understanding of the biological cause of the child's condition, it is striking that none of

Table 11

Parents' Knowledge of the Child's Condition and Activity in Training the Retarded Child at the Time of the First Home Visit

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
KNOWLEDGE:												
Score on 40-item test on Down's Syndrome	11	11	9	6	6	10	9	14	7	7		
TYPE OF INTERACTION WITH CHILD:												
As if child is developmentally delayed		X	X			X					2	.28
As if child is sickly							X	X		X	3	.05
As if child is unable to learn	X				M						2	.28
As if child is developing normally					F				X		2	.56
As if child is stubborn				X							1	.56
ACTIVITY IN TRAINING CHILD:												
Child enrolled in program			X			X			X		2	.56
Child trained under supervision of professional		X					X				2	.56
Read books about retardation		X									1	.56

*p compares attending and nonattending families on each variable and indicates probability of obtaining this distribution as computed by a Fisher's Exact Test. Analysis excluded Family 6 who attended only one of the educational group sessions.

X = parents in agreement; M = mother only; F = father only.

the parents used biological concepts when describing the cause of the child's defect. Instead, eight of the ten families stated that the child's condition was a reflection of Divine will. One mother believed that the child "had been marked" by an envious relative during pregnancy. Another mother stated that she had previously believed that the child's retardation was Divine punishment for having attempted to abort the child early in pregnancy, but that she no longer accepted this belief since the child was no longer a burden on her. Thus, technical information seemed largely irrelevant to parents' development of an explanation of the child's condition that was satisfying to them.

The appropriateness of parents' manner of interacting with the retarded child was also assessed. These results are presented in Table 11. Only six of twenty parents appropriately treated the child as if he were developmentally delayed. These parents modified their expectations to the child's developmental level and provided additional stimulation to help the child's development. Of the remaining fourteen parents, five treated the child as if he were developmentally normal, four treated the child as if he were sickly, three treated the child as if he were incapable of learning, and two treated the child as if he stubbornly refused to learn. Parents who treated the child as if he were developmentally normal made no attempt to provide additional training or stimulation for the child. Parents who treated the child as if he were sickly emphasized his physical illnesses and did not supplement appropriate health precautions with activities that would stimulate his development. Parents who treated the child as if he were incapable of learning stated that the child was incapable of enjoying any activity or

developing skills beyond the infant level. Parents who treated the child as if he were stubbornly refusing to learn attempted to force skills appropriate to the child's chronological rather than developmental age. For example, these parents refused to allow the child to support himself against a piece of furniture when learning to sit, because they believed he could "really" do it on his own but that he was refusing to demonstrate this skill.

Parental Activity with the Child with Down's Syndrome

Parental activity is defined here as either enrollment of the retarded child in a training program or training the child in the home under the supervision of a professional, and reading of books about retardation by the parents. Table 11 shows that few of the parents were active in training their retarded child at the time of the first home visit. Only three of ten children were enrolled in a training program. Two other children were being trained by their parents in the home under the supervision of the child's pediatrician. The remaining five children were not receiving any specific training, nor were their parents attempting to locate a training program. Only one family reported having read a book about mental retardation.

Parents' Accommodations to the Retarded Child

Eight of ten families reported that the presence of the retarded child had significantly changed their lives in ways that they thought would not have occurred if the child had been normal. The two remaining families reported that the retarded child had caused few enduring changes in their lives. Parents identified three major areas of accommodation:

(1) restriction of the parents' ordinary activities due to the child's prolonged immaturity, (2) changes in the family's finances to meet the expenses of the child's special needs, and (3) changes in plans for subsequent children. These findings are presented in Table 12.

Five of ten couples reported that the child's prolonged immaturity had resulted in restriction of the parents' ordinary social activities. Four of five couples reported that the child's susceptibility to lung infections interfered with taking the child into public or visiting in the homes of friends. Two of five couples reported that the child's developmental delay interfered with shopping. These parents reported that they had previously enjoyed shopping together. However, their large, but developmentally immature child, was difficult to manage in a shopping cart. Consequently, these parents reported that they could rarely shop together. One other couple reported that the combination of the child's developmental immaturity and the parents' depression about the child's prognosis interfered with pursuit of previously enjoyed activities. The mother stated:

> We were going so much, the children and I. We were going fishing, we were doing everything. And all of a sudden, when (the retarded child) came, there was no more. It really did do things to them for a while. Because they would ask me to go to a football game with them and I would have to turn them down. I didn't feel like going. I couldn't go because she was sick. And after she got up to the point that she was walking, I couldn't take her. She was too restless.

Although parents were displeased with restrictions in their social lives, they had found few solutions. Parents would have been able to resume most of their ordinary activities if they had been able to find qualified babysitters to tend the retarded child. However, parents were

Table 12

Parents' Reports of Accommodations to Their Child with Down's Syndrome at the Time of the First Home Visit

Variable	Attending Families						Nonattending				Sum	*p
	1	2	3	4	5	6	7	8	9	10		
EXTENT OF CHANGE:												
Major change	X	X		X	X	X	X	X		X	7	.06
Little change			X						X		2	.56
TYPES OF CHANGES:												
Adjustment to child's prolonged immaturity	X				X	X	X	X	X		5	.40
Adjustment to child's special expenses		X			X				X		3	.56
Delaying plans for another child due to retarded child			X					X		X	3	
Parents sterilized after birth of child with Down's Syndrome	X				X	X					3	.28
Parents sterilized after birth of additional child due to retarded child							X				1	.44

*p compares attending and nonattending families on each variable and indicates probability of obtaining this distribution as computed by a Fisher's Exact Test. Analysis excluded Family 6 who attended only one of the educational group sessions.

afraid that a babysitter would be unaware of precautions required by a retarded child. Parents occasionally did leave the retarded child with a relative who was familiar with the child's special needs. However, parents were unwilling to rely on relatives on a frequent basis.

Thus parents were often forced to restrict their social activities due to the child's condition. No couple reported an enhancement in social activities due to the retarded child during the first home visit.

Meeting the expenses of the child's special needs was identified by three families as another difficulty. One couple reported that the wife had left her job so that the family's income would be sufficiently reduced that the child would be eligible for a training program for retarded children from low income families. The loss of the wife's income was a significant financial sacrifice for all members of this family. One father transferred to a better paying, but less desirable, job so that he could better meet his child's medical expenses. Another father reported that he substantially increased his life insurance coverage to assure that the child's needs would be met in the event of the father's death.

Alteration in plans for subsequent children was the third area of change. Despite the youth of the parents and the small size of many of their families, five of ten couples stated that they did not intend to have additional children. Three of these couples had requested and received sterilization after the birth of the child with Down's Syndrome. Although parents reported that the decision about sterilization was reached prior to the birth of the retarded child, the actual timing of the decision could not be assessed. The couples were sterilized prior to

receiving information about amnioscentesis, a test which assesses the presence of genetic defects early in pregnancy and allows for elective abortion of defective offspring. This information was presented in the genetic counseling session, three months after the retarded child's birth.

Five other couples reported that they wanted to have at least one more child. However, by the time of the first interview only one couple had given birth to a child after the birth of the child with Down's Syndrome. In this case, the mother requested to be sterilized after the birth of a normal child following the Down's Syndrome child, and this was done. She requested the operation because she was reluctant to undergo amnioscentesis with each pregnancy. Her reluctance apparently resulted from apprehensions of the risks involved in the procedure. Of the remaining four couples who wanted children, three reported that they were delaying the birth of another child due to the risk of having another child with Down's Syndrome, the retarded child's need for extra attention, and the expenses associated with the child's special needs. The one remaining couple reported that the birth of the child with Down's Syndrome had not altered their plans for other children. However, they stated that they were delaying having another child due to financial problems unrelated to the retarded child.

Quality of Interpersonal Interactions

Parents were asked to assess changes in a variety of interpersonal relationships. They reported on changes in relations between the spouses, between the retarded child and his siblings, between the parents and their

relatives, and between the family and the community. Results at the time of the first home visit are presented in Table 13.

Interactions between spouses. Eight of ten couples reported that there had been no change in the quality of relationship between the spouses. One couple reported an increase in closeness. Another couple reported a decrease in closeness. The father described interactions with his wife:

> We can't talk about (our son), really. I have accepted it (the child's condition). If my wife could do this, too. But as far as accepting it and the ability to accept it, it only comes from Him (God). I know this wouldn't happen but it was God's will. She wouldn't have near the problem if she didn't let it get to her so much. We don't talk about it at all. The good things about him we can share. But to talk about it, we disagree quite often.

Parents reported little overall impact of the retarded child on the quality of their interactions.

Interactions between the retarded child and his siblings. Of seven families in which the retarded child had siblings, six couples reported that the siblings had a positive relationship to the retarded child. In the remaining case, the retarded child's two siblings reportedly considered the retarded child to be a nuisance. The siblings appeared to model their mother's discomfort about the retarded child. Two families reported that experiences with the retarded child had encouraged older siblings to choose a career in the field of mental retardation.

Parents indicated that they had little difficulty explaining the child's retardation, even to young siblings. For example, one mother described her explanation to her four-year old:

Table 13

Interpersonal Changes Resulting from the Birth of a Child with Down's Syndrome Reported by Parents at the First Home Visit

Variable	Attending Families					Nonattending					Sum	p*
	1	2	3	4	5	6	7	8	9	10		
Increased closeness to spouse		X									1	.56
Decreased closeness to spouse					X						1	.56
Siblings like child	X	X				X			X	X	4	.48
Siblings dislike child					X						1	.56
Grandparents positive toward child		M	MP	M		M			M		5	
Grandparents normal	M			P	P		MP	M		MP	8	
Grandparents somewhat negative	P	P			M						3	
Grandparents reject child						P		P			2	
Extended family positive toward child		X	X								2	.28
Extended family does not understand child's condition	X		X		X						3	
Strangers positive toward child												
Strangers neutral	X	X	X	X	X		X	X	X	X		.44
Strangers reject child						X						

*p compares attending and nonattending families on each variable and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excluded Family 6 who attended only one session of the educational group.

X = both sets of grandparents; M = maternal grandparents; P = paternal grandparents.

> She (the four-year old) asked me one day—we have a friend that had a baby that's (the retarded child's) age. And my daughter asked me why didn't (the retarded child) do something that this little girl was doing. And I just tried to explain to her that her sister was going to be a baby a lot longer than the other little girl. Because she couldn't understand the big words and details. And if she mentions anything like that, I try to explain that we are going to have to help her a lot more, that she would need more help than the other little girl would need.

Thus, in all but one case, parents reported that siblings had a positive relationship with the retarded child. In no instance did parents report that the retarded child had had a negative impact on normal siblings' personality or interactions with their friends.

Interactions with grandparents. No parent had been given professional assistance in presenting the child's diagnosis to the child's grandparents. The difficulties inherent in presenting the diagnosis to the grandparents are reflected in one father's descriptions of his attempts to inform his mother of the child's condition:

> I called her right after he was born and told her everything was all right. And then after they told me, I called her back. And I told her, "there's something wrong." And I had never actually come out and used the word "retarded" to her. But I thought that I had explained it to her where she knew. But really she didn't. See, I had said—I told her something was wrong. And she asked me what it was and I said, "The doctor said that he's going to be (pause) slow. Real slow." And things like that. And she said, "well, I'm sorry. But we'll love him just as much as we do (your daughter)." If I had told her that he was a Down's Syndrome, she wouldn't have known anyway. I doubt if she would know what a mongoloid is. But she does know what retarded means. And if I had come out and said that—but I didn't.

Parents reported variable quality interaction between grandparents and the child with Down's Syndrome. Seven of the nineteen sets of grandparents were reported to have normal, accepting interactions with

the retarded child. Seven other sets of grandparents were reported to have exceptionally positive interactions with the child. In these instances, the child was a favorite of the grandparents. Five of nineteen sets of grandparents reportedly had a somewhat negative reaction to the retarded child. Grandparents were reportedly unsure about interacting with a child who had developmental delays and chronic physical illnesses. Two other sets of grandparents reportedly rejected the child and avoided contact with him due to his retardation. One father described the response of the child's grandparents:

> She (the grandmother) doesn't want to go out with him (the retarded child), like shopping, because she doesn't want them to look at her. . . . As a matter of fact, we don't go up there anymore. I'll give you a perfect example of her. We've been up there some months ago, this is at breakfast time, nine o'clock, Sunday morning. And she says, "have you all thought about what you're going to do to curb his sex drive when he gets older?" Okay? That's enough, right? She don't know—she goes off the deep end. I haven't been up there in three months and I'm not going to. You know, a question like that on nine o'clock Sunday morning.

Another mother describes the reaction to her husband's mother:

> My husband's mother didn't accept her (the retarded child). Couldn't stand the sight of her. When she got to know (the child), she accepted her. She saw (the child) and would look at her. Now she did not learn to love her. Because she made comments to my husband, "we don't like you being in this situation. Walk away. There's no need for you to be in this situation and let it drag you down."

In the seven instances where grandparents had somewhat negative or rejecting responses to the retarded child, parents decreased or terminated contacts with their parents. Strained relationships to relatives caused tension within these families.

Interactions with other members of the extended family. Five families reported that members of the extended family typically had normal, accepting interactions with the child. Two couples reported that the extended family had a highly positive response to the child with Down's Syndrome. For example, one mother stated:

> I have some brothers and they're kinda rough on the highways and they do some things that I'm not proud of, but they— She (the retarded child) has really made them turn an about face in a lot of ways. If she is sick of anything, they are always calling and just so concerned about her. I don't know, she has just won them all. There is just something about her. She has just won them all over with her loving ways.

Three couples reported that the extended family did not understand the child's condition. Relatives consequently compared the retarded child to severely handicapped or mentally ill people. Parents reported that they had decreased contact with family members who persisted in making inappropriate predictions about the retarded child's future.

Interactions with the community. Nine of ten families reported that the retarded child did not cause problems between the parents and their neighbors. The remaining family reported that neighbors did not allow their children to play with the retarded child because of its retardation. The mother reported:

> Now her best little friend that was two doors down, she just moved away. For two years now (the retarded child) was her pride and joy. They were together every day. Until Patty started to school. And Patty's mother told her that (the child) was retarded and that she could not do what Patty could do. So ever since then, every time that (the child) would go out to play, they would run away from her.

The mother who made this statement was sensitive to any slights concerning the retarded child and appeared, at times, to misinterpret the cause of other people's behavior.

Six of ten couples reported that strangers recognized that the child with Down's Syndrome was abnormal but stated that the child was usually treated in a neutral manner by strangers. Nevertheless, parents reported feeling embarrassed when strangers noticed that the child was abnormal. For example, one mother stated:

> And if people know how old he (the retarded child) is, they know something is wrong. That gets you all the time. He'll be sitting in the doctor's office and people say, "Oh, he's cute. How old is he, seven months?" And we say, "no, eighteen." I don't know what to say. I don't know. I don't want to be telling his whole personal life history, you know.

Another mother stated:

> Well, there has been some that have stared and there has been a couple that has asked me about her tongue, when she sticks her tongue out. (Children with Down's Syndrome have small mouths relative to the size of their tongue.) I mentioned it to the doctor one day and he said just to tell them that she's just one of the more beautiful babies. But other than to say that, I don't know. I see people look at her and stare at times. But those two have been the only strangers that have actually said anything about it.

Parents appeared to have few ways to handle this discrimination and reported that they typically withdrew from strangers and felt embarrassed about the child's condition.

Thus, parents reported that there were few changes in the quality of interpersonal interactions due to the retarded child. Within the family, there are few difficulties between spouses or between the retarded child and his siblings. Grandparents and other relatives were generally reported to accept the retarded child. In some cases, the retarded child

was a special favorite, although in other instances the grandparents rejected the retarded child. Parents judged that strangers often saw the child as abnormal, although most strangers were neutral in their reaction to the child. Most parents reported that they were embarrassed by discrimination against the child and did not know how to cope with it.

Future Expectations

At the time of the first home interview, all but six of the twenty parents were fairly realistic about the child's future. These parents expected that the retarded child would attend school, receive simple vocational training, and would work in a sheltered setting rather than in competitive employment. They also understood that the child with Down's Syndrome would not marry or reproduce.

Three of twenty parents had unrealistically high expectations for the retarded child. One couple's erroneous beliefs resulted from their apparent inability to generalize from one statement about the child's future limitations to other probable limitations. In this case, a physician had informed the couple that the child would be unable to marry and they had accepted this information. However, the couple apparently had not been informed of the child's limited educational potential, and they assumed that the retarded child would attend high school and college. They evidently had little appreciation of the intellectual skills required for such activities. One father insisted that his retarded child had the same potential as a normal child, despite counseling to the contrary. This insistence appeared to be a reaction to his wife's equally unrealistic, low expectations for the child. The wife accurately reported

the retarded child's expected limitations, but extended these limitations to exclude even the possibility that the retarded child would respond to affection.

This mother shared with two other parents unrealistically low expectations for the retarded child. For example, one father stated:

> He (the retarded child) won't have playmates that (his sibling) did and he won't have the enjoyment of going (out). That's the main thing to me. I mean, he's going to have a good home and he's going to be fed good, but he's not going to have enjoyment.

Although the majority of the parents had an accurate knowledge of the child's probable limitations, no parent could discuss the child's probable future accomplishments at the time of the first home visit.

Table 14 reflects the variety of parental concerns reported during the first home visit. The data indicate that parents were especially concerned about their future with the retarded child. Except for one family who had regular contact with their pediatrician, the remaining families did not have regular contact with a professional who could respond to these concerns.

Summary of Parents' Functioning at the Time of the First Home Visit

At the time of the first home visit, the majority of participating parents had limited understanding of the retarded child's condition. They knew little about Down's Syndrome or of available training resources for the child. The majority of parents' interactions with the retarded child were inappropriate to the child's needs, although there were no instances of flagrantly inappropriate interactions. Parents rarely

Table 14

Impact of an Educational Group on Parents' Knowledge of Down's Syndrome and Activity in Training the Retarded Child

Variable	Attending Families						Nonattending				Sum	*p
	1	2	3	4	5	6	7	8	9	10		
SCORE ON 40-ITEM TEST ON DOWN'S SYNDROME:												
Prior to group sessions	11	11	9	6	6	10	9	14	7	7		
After group sessions	36	39	38	34	39	21	9	14	6	7		
CHILD ENROLLED IN TRAINING PROGRAM:												
Prior to group sessions			X			X			X		2	.56
After group sessions	X		X	X	X	X			X		5	.16
CHILD TRAINED IN HOME UNDER SUPERVISION:												
Prior to group sessions		X					X				2	.56
After group sessions		X									1	.16
READ BOOKS ON RETARDATION:												
Prior to group sessions		X									1	.56
After group sessions	X	X	X	X							4	.04
OTHER REPORTED IMPACT:												
Met other parents with similar child	X	X	X	X	X						5	
Gained support	X	X		X							3	
Gained information	X	X	X								3	
Positive impact on normal sibling	X										1	.56

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one session of the educational group meetings.

understood that their child was developmentally delayed and consequently would profit from intensive, physical and intellectual stimulation. Only half of the children were receiving training at the time of the first home visit. Parents frequently reported that the retarded child had caused them to restrict their usual social activities and that the child's special needs had led the parents to change their plans for subsequent children. Most parents reported that the retarded child did not change social relationships within or outside of the family. Most parents were realistic about the retarded child's expected limitations, although they had little knowledge of the child's potential accomplishments.

Differences between Attending and Nonattending Parents at the Time of the First Home Visit

The overall pattern of attending and nonattending parents' responses indicated that attending parents were more aware of both positive and negative aspects of their environments than were nonattending parents. For example, attending parents were more likely to report having seen a retarded person prior to the birth of their child with Down's Syndrome. Attending parents also recalled more facts mentioned by the physician counselor during the diagnosing interview. Parents in the current study generally showed a negative reaction to retardates they had seen and had been presented with pessimistic information during the diagnosing interview. Consequently, attending parents, who were more sensitive to these experiences, were more likely to have had early negative experiences that would interfere with adjustment to the child with

Down's Syndrome than were nonattending parents. Attending parents' more negative response to their retarded child is reflected in their reports of a greater number and variety of emotional responses to the retarded child during the initial adjustment period. Attending parents' increased distress about the retarded child may have led them to attend the educational group sessions.

In contrast, parents who did not attend the group sessions were more accepting and less active in attempting to change events. During the home interview, nonattending parents spontaneously related fewer experiences about life with their retarded child and relied more heavily on the interviewer's questions than did the parents who attended the group sessions. Nonattending parents also reported a more restricted range of concerns about life with a retarded child. Nonattending parents may have been less aware of potential problems, have had fewer resources for expressing their concerns or have been less willing to share them with the interviewer. Nonattending parents seemed to accept the child's limited functioning to a degree greater than the attending parents.

The Parents' Educational Group

The investigator organized an educational group to respond to needs expressed during the first home interview. The group sessions were organized with three major goals. First, sessions were designed to introduce parents to other families with a Down's Syndrome child so that parents would have a knowledgeable audience with whom they could share the pleasures and difficulties of rearing a developmentally delayed child. Second, group meetings provided opportunities for parents to raise,

questions and to discuss concerns with a professional. Third, group sessions provided information about resources available in the community for young, retarded children.

The educational group met for five weekly sessions. The meetings were held during an evening hour so that both mothers and fathers could attend. Each session lasted about one and one-half hours. Parents were encouraged to bring their retarded child to the group sessions so that parents could meet each other's children. In two instances, normal siblings were also brought to the group meetings. Free babysitting services were provided during the meetings.

Five of the ten couples consistently attended the educational group sessions. One couple who attended consistently had initially been reluctant to attend. The mother feared that she would meet only mothers of her own, advanced age, and that their age would add to her belief that the child's retardation was caused by her advanced age at the time of conception. One family discontinued after the first session and offered no explanation for their behavior. Four remaining families did not attend any sessions, despite a weekly reminder note which encouraged attendance.

The first of the five sessions was devoted to informal discussion of the parents' children and presentation of information about Down's Syndrome. The session was begun by asking parents to discuss their child's most recent accomplishment. Initially, parents were reluctant to mention the retarded child's skills and, instead, discussed only delays in the child's development. The investigator was able to encourage discussion of the child's skills since the investigator had observed the

child's skills during the home visit. Parents then began to compare spontaneously their children's accomplishments. This discussion had several important consequences. First, parents who were previously discouraged by their child's slow progress were relieved to learn that their child was progressing at an expected rate. Second, the parents whose children with Down's Syndrome were older were treated as better informed experts who were able to provide support and encouragement to the less experienced parents. At the conclusion of this first session, important facts about Down's Syndrome were reviewed.

The second session emphasized the importance of training the retarded child. Parents who had normal children were encouraged to discuss their role in helping their normal children develop skills. They discussed their use of praise, modeling, reward and scolding. Parents were informed by the instructor that these techniques could be applied to the training of retarded children. Parents had assumed that completely different skills were required for the rearing of a retarded child; they were pleased by this information.

The third session presented more detailed information about teaching self-help skills. Parents with older retarded children contributed suggestions for teaching independent feeding, dressing and toileting. Parents were shown a copy of Training Your Retarded Child in Your Home, which explained the importance of breaking complex tasks into simpler components that could be taught to the child before the entire skill was taught.

At the beginning of the fourth session, one parent asked about the nature of psychological evaluations. The first part of the session was

devoted to a discussion of intelligence testing and the nature of IQ. Parents were informed of both the limitations and accomplishments to be expected at various mental ages. The second part of the session was devoted to a discussion of discrimination against the mentally retarded. Parents provided support to each other as they discussed instances of prejudice to which they had been exposed and expressed their concerns about other people's reactions to their child. Some parents discussed means of coping with discrimination. At the conclusion of this session, the investigator described briefly the accomplishments of two individuals with Down's Syndrome, a local girl who was an accomplished swimmer and a youth with nonmosaic Down's Syndrome who had written a book about his life.[1] Insofar as the instructor could tell, the instructor did not lead parents to expect that their own children would accomplish similar exceptional feats. However, knowledge of these accomplishments did give parents confidence in their children's futures.

The final session was devoted to information about services available to children with Down's Syndrome. Eligibility requirements of local agencies were also described and explained.

Parents' Status After the Educational Group

One month after the conclusion of the educational group, all ten couples were again interviewed in their homes. The interview assessed changes in attending and nonattending families since the first home

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[1]Nigel Hunt, The World of Nigel Hunt. New York: Sarritt Publications, 1967.

interview. Parents' reports of these changes are presented in Table 14 (page 72).

There were several objective indicators of the effect of the educational group sessions. Attending parents were significantly more knowledgeable about Down's Syndrome, as measured by their responses to the 40-item test on the condition. Parents were also significantly more active in training their retarded child. Prior to the group sessions, children from two attending and two nonattending families were receiving training. At the conclusion of the group sessions, all five of the children of attending parents were receiving training, but only one of the children from a nonattending family was receiving training. Thus, three children whose parents attended the educational group enrolled their child in a training program for the first time. No nonattending family had enrolled their child in a training program. In fact, one nonattending family had discontinued professionally supervised training of the retarded child in the home.

Three of the five attending couples reported that the group sessions had provided a valuable source of support. For example, one mother stated:

> It takes someone who knows to make it all right. It hurts my feelings, but you don't want to admit it, maybe, to your next door neighbor, who wouldn't really understand. But if you can develop a friendship with another mother of a handicapped child, it is just so important. Because not even your own family really understands.

One mother had initially been reluctant to attend the group sessions because she feared that the other mothers would be old and that their advanced age would add to her belief that the child's retardation was

due to her advanced age when the child was conceived. The mother reported that she was surprised to discover that the majority of mothers were younger than herself and reported a resulting decline in worry about her age as the cause of the child's condition.

Two of five attending couples reported that the group sessions had provided valuable information. One family stated:

> Well, I really think that the biggest thing (that helped us accept the child) was the classes that you conducted. I really learned more about Down's there. Because I was really uptight about it and then when I seen how everybody else's child was doing and that they grow up and do things, although they are much, much slower. And the couples that were down there, talking between each couple, it really helped. I think the biggest thing was talking to people that already had a Down's—that's had the actual experience.

Each of the five attending families reported that the educational group sessions had allowed them to meet other couples with a retarded child. Four of five couples continued social contact with other members after the conclusion of the group sessions. None of the nonattending families had met a new family with a retarded child.

One attending couple reported that the educational group sessions had benefited the normal sibling in their family. The normal sibling had previously been kept out of contact with individuals with Down's Syndrome because the parents feared that the normal child would show an adverse reaction that, in turn, would influence his interactions with the retarded child. In fact, the normal sibling enjoyed the contact with the children with Down's Syndrome and the parents reported that the normal sibling began to anticipate a time when the retarded child was older so that the two could play together.

Final Home Visit

At third and final home interview was conducted two years after the first home interview. The interview assessed parents' adjustment to their older, retarded child and the long-term effects of participation in the educational group sessions.

Parents' Understanding of the Child's Condition at the Time of the Final Home Interview

At the time of the first home visit, the majority of parents had misconceptions about the nature of the child's condition. Only three couples were judged to correctly understand that their child was developmentally delayed. In contrast, by the final home interview, nine of ten couples recognized that the child's defect primarily involved developmental delay and a limitation on his eventual intellectual accomplishments. One remaining family continued to believe that their retarded child was developing at a normal rate. This belief was apparently based on three factors: (1) the parents' initial limited expectations for a retardate, (2) the child's actual level of ability which had been developed at a training center he had attended since birth, and (3) the relatively small differences between the abilities of the retarded child and the other slow-to-develop children in this family. Thus, in all but one case, continuing experience was sufficient for parents to develop a more realistic understanding of the child's condition and to eliminate misconceptions. Data on the appropriateness of parents' interaction with the retarded child are presented in Table 15.

Table 15

Parents' Interactions with Their Child with Down's Syndrome
at the First and Final Home Visits

Variable	Attending Families						Nonattending				Sum	*p
	1	2	3	4	5	6	7	8	9	10		
AT FIRST HOME VISIT:												
Child is developmentally delayed		X	X			X					2	.28
Child is sickly							X	X		X	3	.05
Child is unable to learn	X				M						2	.28
Child is developmentally normal					F				X		2	.56
Child is stubborn				X							1	.56
AT FINAL HOME VISIT:												
Child is developmentally delayed	X	X	X	X	X	X	X	X		X	8	.44
Child is sickly												
Child is unable to learn												
Child is developmentally normal									X		1	.44
Child is stubborn												

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution of events as computed by a Fisher's Exact Test. Analysis excluded Family 6 who attended only one of the education group sessions.

M = mother; F = father.

Attending and nonattending parents reacted differently to their more realistic understanding of the retarded child's condition. Three of five attending couples' more realistic understanding of the child increased their overall satisfaction with the child. For example, one couple who had previously believed that the child was stubborn reported a greater understanding of the child's delayed development after reading books about mental retardation which had been recommended at the educational group. These parents currently participated in activities, such as swimming, which the child enjoyed and which were suited to his developmental level. One mother who had previously been so pessimistic that that she would not attempt to train her child now reported that the child's continuing development of skills had helped her become more confident in the child's future. This mother's improved attitude was reflected in increased closeness to her husband, with whom she had frequently argued about the child's potential. As this mother became more appropriately hopeful, the father abandoned some of his unrealistic optimism, and the couple were able to reach a realistic agreement about the child's potential. The Down's child's siblings correspondingly reported a greater liking of the retarded child, whom they had previously seen as a nuisance.

In contrast, nonparticipating parents' increased experience with the retarded child resulted in decreased satisfaction with the child. Nonattending parents had previously believed that the child's major problem was physical illness. When they eventually realized that an improvement in the child's health would not result in normal development and that limitations would continue to be present, they showed a passive

resignation to the child's future limitations and took no steps to extend them.

Attending parents were also more satisfied with their retarded child's level of functioning than were nonattending parents. Each of the five attending parents reported satisfaction with the child's level of functioning. Satisfaction appeared, to some extent, to depend on the extent to which the retarded child exceeded the parents' initial low expectations, rather than on the child's actual abilities. For example, one mother of a three-year old stated:

> Tonight, he was standing up there by one of the chairs playing and I said, "When he was born, who would have thought that he would have gotten to the stage where he would be doing this." I made that very statement tonight.

In contrast, nonattending parents, who had not expected that serious problems would arise as the child developed, became discouraged by the child's slow development. Three of the four nonattending couples reported dissatisfaction with the child's development.

Another indication of attending parents' adjustment was that four of five attending couples referred to their retarded child as a "normal" child. As the investigator understood them, the parents who used this term were aware that their child was developmentally delayed and did not deny his disability. Rather, they used the term "normal" to indicate that the retarded child was like normal children in both his ability to continue to develop new skills and to contribute to an enjoyable family life. For example, one parent who had attended the educational group stated:

> Like I said, I've just accepted her (the child) as being a normal child. . . . We include [the child] in everything we

> do; everything. I can't think of anything that we don't. Like at Christmas time we wrap gifts together and she helps with wrapping gifts. And at Eastertime, and just everything. She's included in everything we do. I'm not going to say, "Well, [she] is retarded, she can't do this, we won't let her do it." We say, "c'mon, you can do this, too." She has trouble making circles and stuff, but she can do some things.

No nonattending parents referred to their retarded child as "normal."

Parental Activity

At the time of the final home interview, enrollment of the retarded child in a training program was no longer a valid measure of parental activity, since all children had been enrolled in a state-funded training program on the child's third birthday. It is notable, however, that no nonattending parent had enrolled their child in a training program between the conclusion of the educational group and the child's third birthday.

Attending parents reported that they were less active in training their retarded child as the child had grown older. Three of these couples complained that they did not know how to proceed with the child's training once the child had mastered self-care skills. For example, one mother stated:

> We (the mother and father) did want to get her (the child) into something, because I was getting to a point there where I was feeling like I wasn't doing anything for her. . . . I really didn't know what to teach her next, you know, just being at home and not being a trained person. There is just so much you can do. But the things that she learns over there (at her training program), she comes in talking about them.

No nonattending parent complained about their inability to continue to train their retarded child.

Accommodations to the Child's Special Needs

During the first home visit, eight of ten families had reported that the retarded child had significantly changed their lives. Changes primarily involved restriction of the parents' usual activities due to the child's prolonged immaturity. In contrast, during the final home visit, each of the ten couples reported that the retarded child had significantly changed their lives. Changes involved both restriction and enhancement of the parents' lives. Parents identified two major areas of accommodation: (1) adjustment to the retarded child's continued dependence on the parents, and (2) changes in plans for subsequent children. Parents' reports of their accommodations are presented in Table 16.

During the first home interview, five of ten couples had reported a restriction of social activitues due to the retarded child. In contrast, during the final home visit, only one couple reported a restriction in usual activities and this couple had one of the youngest children in the current study. By the final home interview, parental accommodations primarily involved more extensive supervision of the retarded child than would ordinarily be required of a child its age. Accommodation also involved planning based on expectations that the retarded child would continue to depend on the parents throughout the parents' lives. It is striking that parents in the current study were pleased by the idea of the retarded child's continued reliance. This observation is congruent with other findings on family relationships in Appalachian communities, of which these parents are a set. For example, Weller (1961) reported that continuing interdependency between family

Table 16

Parents' Reports of Accommodations to Their Child with Down's Syndrome at the Time of the Final Home Visit

Variable	Attending Families						Nonattending				Sum	p*
	1	2	3	4	5	6	7	8	9	10		
EXTENT OF CHANGE:												
Major change	X	X	X	X	X	X	X	X	X	X	9	--
Little change												
TYPE OF CHANGES:												
Adjustment to child's continued dependence	X										1	.56
No plans for subsequent children	X	X	X		X	X	X		X		6	.17
Delaying having other children due to retarded child								X		X	2	.17

*p compares attending and nonattending families on each variable and indicates the probability of obtaining this distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one session of the educational group sessions.

members is a cultural ideal for many families in Appalachia. He further stated that many family conflicts arise when adult children attempt to leave the parents' home. Consequently, parents in the current study showed a relationship to the retarded child which was consistent with regional ideals. One couple clearly expressed this idea:

> We'll have problems, but not like parents with normal children. We won't have the type of problems they will, you know. Like, what's she (the child) doing out on this date? Really, we're the luckiest parents there is. Because we get to enjoy our child from now on. Whereas they only get to enjoy their child for, say, twenty years, and then they're gone.

A second area of accommodation was changes in plans for subsequent children. At the first home visit, only one couple had delivered a child after the birth of the Down's child. Only four of ten couples wanted to have another child and each was acting to prevent another pregnancy. During the two years between the first and final interview, only one couple had had another child and no other couple was expecting a child. This mother had an amnioscentesis during her pregnancy and subsequently delivered a normal child. After this delivery, the couple decided to have no more children due to the needs of the retarded child. Thus, in the years following the birth of a child with Down's Syndrome, only two of ten couples had delivered another child, and both couples declined to have another pregnancy after the delivery of a normal child. Thus, the presence of the retarded child appeared to have a significant effect on couples' willingness to have another child. However, there was a discrepancy between parents' behavior and statements about their willingness to rear a second child with Down's Syndrome. During the final interview, three couples, each of whom had attended the educational

group, spontaneously stated that they would be willing to rear a second child with Down's Syndrome if an unplanned pregnancy resulted in its conception. These statements were made by one of the couples who had been sterilized immediately after the birth of the child with Down's Syndrome, by one of the couples who stated that they did not want another child, and by one of the couples who had utilized amnioscentesis before continuing the pregnancy to term. The mother who had undergone amnioscentesis stated:

> They all asked me, when I was carrying (the normal child) what would I do, if it were another one. I'd tell them I didn't know, that I'd wait and see. Now, if I could have a guarantee that we could have another one that is as good as (the retarded child)—Now, we have had our troubles with sickness with her. But we just couldn't ask for a better baby than her.

Quality of Interpersonal Relationships

During the final home interview, parents were asked to report on changes in interpersonal relationships resulting from the presence of the retarded child. Assessment was made on relationships between the spouses, between the retarded child and his siblings, between the retarded child and members of the extended family, and between the retarded child and the community. Data on quality of these interpersonal relationships are presented in Table 17.

Interactions between spouses. During the first home interview, parents reported that the presence of the retarded child had had little impact on interactions between the spouses. In contrast, during the final home interview, four of ten couples reported an increase in closeness between the spouse due to the retarded child. Three of these

Table 17

Interpersonal Changes Resulting from the Birth of a Child with Down's Syndrome Reported by Parents at the First and Final Home Visits

Variable	Attending Families						Nonattending				Sum	*p
	1	2	3	4	5	6	7	8	9	10		
AT FIRST HOME VISIT:												
Increased closeness to spouse		X			X						1	.56
Decreased closeness to spouse					X						1	.56
Siblings like child	X	X				X			X	X	4	.48
Siblings dislike child					X						1	.56
Strangers positive toward child											0	
Strangers neutral	X	X	X	X	X		X	X	X	X	9	--
Strangers reject child						X					0	--
AT FINAL HOME VISIT:												
Increased closeness to spouse	X	X	X		X				X		4	.16
Decreased closeness to spouse						X					0	--
Siblings like child	X	X	X		X	X	X		X	X	7	.44
Siblings dislike child											0	
Strangers positive toward child	X	X	X	X	X				X		6	.16
Strangers neutral							X	X		X	3	.05
Strangers reject child						X						

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one of the educational group sessions.

four couples had attended the educational group sessions. For example, one father stated:

> I think it's just brought us a little bit closer together, really. It's made us a little more open and we discuss a lot of things that we never discussed before, you know, her (the child's) possibilities and our future and so on.

One other couple reported that the presence of the retarded child had caused a decrease in parental closeness. The wife in this family reported that her husband stayed away from home and attributed his behavior to his discomfort with the child's retardation. However, she also reported that the husband frequently took the child out in public when he was home. It appeared that the mother blamed the child's presence for difficulties in the marriage which probably had additional, if not different, causes.

Interactions between siblings and the retarded child. During the first home interview, all but two siblings were reported to enjoy the retarded child. During the final home interview, all siblings were reported to have a good relationship with the retarded child. No parent reported that the presence of the retarded child had handicapped or raised difficulties for the siblings. Parents also reported that siblings had little difficulty explaining the child's retardation to their friends.

Interactions with grandparents. Parents reported that there had been no significant change in grandparents' attitudes and behavior toward the retarded child since the first home interview. Most grandparents continued to be at least accepting of the retarded child. A minority of grandparents still avoided contact with the child.

Interactions with the community. During the first interview, parents had reported that both neighbors and strangers were tolerant of the retarded child and responded to him in a neutral manner. In contrast, during the final home interview, all but one couple reported that the retarded child was well received by neighbors and strangers. For example, one mother who had previously reported that the retarded child was treated in a neutral manner stated during the final interview:

> Oh, they (the neighbors) love him; they just pick at (playfully tease) him. They don't, you know, turn their nose up at him or anything like that. They'll just speak to him. He's one of them there kind that loves to be looked at and he'll holler at them or wave at them or something or the other. He likes the attention. Some people don't notice the difference in him. Some pays attention to it (his condition), if they knows their babies. If they don't know their babies, they don't know he's Down's Syndrome. Honey, there's never been nobody that has said anything to me about it. These neighbors around here, they are so sweet to him. They ask every day about him. They take up with him.

It is impossible to assess the exact cause of the reports of improved relationships between the child and the community. Changes may be attributable to changes in the behavior of others or changes in parents' observations. Three couples attributed this change to the child's friendly, outgoing personality, which was more evident as the child was older.

Several parents reported that they and their children were occasionally exposed to prejudice against the retarded. However, these parents no longer reported embarrassment and withdrawal from these situations as they had during the first interview. Instead, they reported that they responded directly to these events. For example, parents reported that they asked whispering strangers why they were gossiping

about the retarded child or explained the child's condition to teasing children. One mother proudly volunteered her more active response to a television program in which a child with Down's Syndrome was reportedly "cured" through prayer:

> What really bugged me was when Pat Roberts (a religious personality on television) says, "Well, I know the mongoloid child, they are the ugliest little things that evern walked. Ugliest children there ever was." And I thought, "You're supposed to be a man of God and here you are talking about ugly children, and they're supposed to be the creatures of God. And supposed to be, in His eyes they're perfect. What are you saying?" I'm going to send him a picture (of the retarded child) and ask him if he thinks that this is ugly. And if it is, I want to know where.

Parents reported a change in the social interactions of their older, retarded children. Nine of ten children lived in neighborhoods without easy access to playmates other than siblings. The normal siblings had established friendships at church or with children living on the same school bus line. Parents often arranged transportation so that their children could continue to play together after school hours. However, the child with Down's Syndrome attended a centralized school which provided schooling for retarded children from all parts of the country. Distances between their homes made it difficult for the retarded children to continue friendships with schoolmates after school hours. Most parents were worried by the lack of opportunities for the retarded child to meet playmates.

One mother attempted to resolve this problem by enrolling the retarded child in a kindergarten with normal children. The teachers in this school were reportedly unwilling to accept the retarded child who was then transferred to the centralized school. The mother complained:

> You can't find other children unless you go to school, unless you see them day after day. When (the child) was going to the elementary school, the other mothers were asking if (the child) could come over to the house to play. Or come to a birthday party. We'd see them in the grocery store and every one went up to her and hug her and kiss her and play with her in the grocery store. . . . We don't have that now. Because she doesn't know the other children.

One notable aspect of families' social relationships was that attending parents had continued to have contact with other group participants during the two years after the conclusion of the group sessions. Parents reported that other group members continue to be a source of support and information. No nonattending parents had met a new family with a Down's Syndrome child.

Future Expectations

By the time of the final home interview, the vast majority of parents had maintained or increased the accuracy of their understanding of the retarded child's probable limitations. One father who had previously insisted that the retarded child had the potential of a normal child was more realistic about the child's potential.

All parents who had attended the educational group had continued their realistic view of the child's limitations. At the same time, these parents expressed their beliefs that their children had more potential for accomplishment than the parents had previously believed. The retarded child's response to training encouraged parents to believe that the child would exceed the accomplishments of retardates who had not received intensive training. These parents, nevertheless, recognized that their child's accomplishments would be less than those of a normal child. One mother stated:

> Well, she (the child) keeps showing improvement and keeps learning like she is now, hopefully, it would be a workshop or some kind of sheltered place, where she could be independent. Do things for herself, you know, and be paid for doing little jobs. I think of things, like she loves music. I think a thing that she might be able to do is to play the organ, because she does seem to have a true talent for music. Some of them, even, you know, work in restaurants and that type of thing.

Parents also reported a decline in worries about the child's future. In fact, no parent mentioned a serious concern about the retarded child's future, although worries about the future had frequently been mentioned for the first home interview (Table 14, page 72). Only four areas of concern were mentioned during the final interview and all related to the retarded child's current functioning.

Summary of Parents' Functioning at Time of the Final Interview

At the time of the final home interview, attending parents showed improved adjustment to the retarded child compared to their adjustment during the first home interview and compared to the adjustment of non-attending families (see Table 18). By the time of the final interview, all parents were more aware that the child was developmentally limited and would not "outgrow" his condition. The improved adjustment of attending parents was reflected in their greater satisfaction with their child's level of functioning and their greater concern about providing training opportunities. Most parents reported that there was little need for special accommodations to the retarded child. Most parents reported that there were few difficulties in interpersonal relationships due to the retarded child and attending parents frequently reported an enhancement of interpersonal relationships. Almost all parents continued to be

Table 18

Parents' Reports of Concerns About Their Child with Down's Syndrome Mentioned During the Final Home Interview

Variable	Attending Families						Nonattending				Sum	*p
	1	2	3	4	5	6	7	8	9	10		
CONCERNS ABOUT THE PRESENT:												
Child's speech	X		X	X		X					3	.14
Child is distractable			X	X							2	.56
Child's poor vision						X					0	
CONCERNS ABOUT THE FUTURE:												
No serious concerns	X				X		X	X	X	X	6	.12

*p compares attending and nonattending families on each variable and indicates the probability of the obtained distribution of events as computed by a Fisher's Exact Test. Analysis excludes Family 6 who attended only one session of the educational group sessions.

realistic about the child's probable limitations and reported few worries about their future with the retarded child.

Parents' Evaluation of Professional Services They Had Received

Parents identified four sources of professional services with their retarded child: (1) the diagnosing interview during which they were first informed of the child's diagnosis, (2) the Birth Defects Evaluation Center, (3) the parents' educational group, and (4) the child's pediatrician.

Physician counseling during the diagnosing interview was identified by all ten families as a source of information. However, only two of ten families were satisfied with the quality of their physician counseling. The remaining eight couples stated that they would have preferred counseling that was more compassionate, which presented more accurate information and which discussed the child's potential accomplishments. Parents' recommendations for improvement of initial counseling are discussed in a following section.

The Birth Defects Evaluation Center was identified as an important source of help by four of the ten couples. These four families were satisfied with the quality of service they had received. However, one couple stated that they would have benefited from additional, specific information about training programs suitable for their child.

Three of five attending couples identified the educational group as an important source of help. These couples reported that they were pleased with the information provided and with an opportunity to meet

other parents rearing a retarded child. However, one father of one of the older children stated that he would have preferred for an educational group to include parents of older children with Down's Syndrome.

One family identified contacts with their pediatrician as an important source of help. The couple was highly satisfied with these contacts, which provided information about the child's condition and encouragement to the parents.

Parents' Advice to Counselors of Families with a Newly Diagnosed Child with Down's Syndrome

Parents who participated in the current study made several suggestions to counselors who would be contacting families with a newly diagnosed child. Parents stressed the importance of counselors' sensitivity to parents' needs for support, for accurate information and for encouragement. One father eloquently called for compassion from counselors:

> No matter how good your doctor was and how much education he had and how many degrees he had and no matter how great a surgeon he might be, if he wasn't a human being, he wasn't enough doctor for me. And I think so many times doctors, they kind of get on a pedestal or a plateau and speak from a medical standpoint, rather than a human one. They speak cold, hard facts that are like words from a book to them, while they're breaking a parent's heart.

This recommendation for compassion was supplemented by specific suggestions by other parents. One mother recommended that parents be given privacy during the initial interview so that parents could openly discuss their questions and concerns with the counselor. She stated:

> I really think they should have a private room. Because, with the other mother there, you're embarrassed. The things you

> want to know, they sound so silly. And there she sits, with a perfect baby. So you don't ask.

Another mother suggested that the counselor distribute a handout on Down's Syndrome. This handout would allow parents to review information that could easily be forgotten during the stressful initial counseling session. The mother stated:

> I think it (a handout) would be really good in teaching things. Because you're not going to comprehend everything they say. And you're going to say, "he said something about that, but I can't rightly remember." And then you could go and make a bad mistake with your own kid. . . . But I think it would stick with you and then when they have time and by themselves and then you go through it and it wouldn't be so bad.

Yet another family recognized the isolation experienced by families with a newly diagnosed retarded child and urged the sensitive counselor to introduce parents to families who were already rearing a child with Down's Syndrome. The father in this family stated:

> Say a couple has a mongoloid child, that they've found out it's mongoloid. Then have a couple come into their home. Now this couple has taken a bit of education into what a mongoloid is and all, to answer some of the questions. And just let them sit down and tell people what to expect. Because you can see the doctor and all this and they can answer some of your questions, but I think parents need to know from someone that's been through it and to tell them what to expect. Because if we had had someone to do that to us, I think we would have been a lot better off in the beginning.

Parents also emphasized the need for appropriate information. Two couples criticized their physician for presenting information about the child's condition that later proved inaccurate. One family was reportedly informed that the retarded child would die in his teens, an event that was common prior to the introduction of antibiotics. Another couple's physician apparently failed to recognize the child's condition, despite the mother's frequently expressed concerns about the child's slow

development. The mother learned of the child's diagnosis only when she took the child to another physician who immediately recognized that the child had Down's Syndrome. Two couples criticized their physician because he reportedly withheld information about the seriousness of the child's condition and prognosis. One other family was critical of their physician because he did not provide detailed information about the child's condition and about available services. Indeed, the father stated that information about the retarded child's daily functioning and about training resources was the most important service the counselor could provide to a family. He stated:

> Whether it's in the fifteenth chromosome or the twentieth or whatever, it doesn't matter. He's retarded and you need help with him. And nobody gives you any or tells you anything. And the only way we found out, like I said, was when we talked to you (the investigator) and them other people (at the parents' group). . . . Maybe they thought that because we are middle class and were fairly educated, that we knew everything. But you don't. . . . Like they (Down's children) have a constipation problem; we didn't know that. And like they have a lot of respiratory troubles and their teeth don't come in so soon. You know, things like that.

Finally, many parents strongly urged counselors to inform parents of the child's abilities as well as his probable limitations. Counselors who emphasize only the child's limitations discourage parents and lead them to concentrate only on the negative aspects of the future. Many parents suggested that parents be reassured that the retarded child would and could develop self-care skills and that the child would not be an enduring management problem.

Additional Recommendations for Counselors of Parents with a Newly Diagnosed Child with Down's Syndrome

Interviews with parents indicated that modification of several counseling procefures would avoid negative experiences to which parents reported that they were exposed.

First, counselors should make every effort to provide for positive, early experiences between parents and the retarded child. Parents should be permitted to see and hold the retarded child prior to disclosure of the diagnosis. This examination probably would decrease parents' tendency to imagine grave visible deformities in response to counselors' statements that the child had an "atypical appearance." Counselors have sometimes been reluctant to allow parents to see their child prior to diagnosis because they fear that parents may recognize that the child is abnormal and be unprepared for this shock. However, this possibility could be avoided if the counselor were present during the parents' introduction to the child and if he then answered questions which arose. The presence of a counselor would be especially important if the parents were sophisticated and likely to recognize the child's diagnosis from his appearance. In the current study, no parent who saw the child prior to diagnosis suspected the child's diagnosis by his appearance and, hence, none were upset by physicians' statements about the child's appearance. In contrast, parents who had not seen their child prior to diagnosis were distressed by the counselors' statements and, in several cases, delayed seeing the newborn infant for several days due to fears of its appearance. These needless fears contributed to parents' distress about the child.

Support should be provided by counseling the parents together. In the current study, none of the couples were counseled together and, in two cases, fathers of the retarded child were never informed of the child's diagnosis by a physician and the job was left to the mother. Consequently, parents were deprived of each other's support during the difficult period following the time when they were first informed of the child's condition.

Second, counseling practices should be modified so that counseling is presented at a time when parents are most able to understand the counselor's information. Recent literature on counseling procedures recommends that counseling be initiated as soon as the child's defect is suspected (Berg, Gilderdale & Way, 1969; Carr, 1970). However, this commendable desire for early transmission of information should not prevent a day or two delay in counseling if delay would facilitate parental receptivity. Certainly the child's diagnosis should not be presented before the mother has fully recovered from the anesthesia of childbirth. In the current study, four mothers were informed of the child's diagnosis prior to recovery from childbirth, a time at which they are unlikely to be able to understand the complex information which was presented.

Assimilation of information would be increased if full counseling were spread through several counseling sessions on the days following the initial diagnosis. Repeated sessions would allow parents to raise new questions and permit the counselor to clarify misconceptions of previously presented material. Assmiilation would be further enhanced if the couple received regular, supportive contacts with the counselor after discharge

from the hospital. Ideally, the couple would also be introduced to another, experienced couple with a Down's Syndrome child, who could also contribute to the new parents' knowledge.

A third modification in counseling would present information to parents not usually discussed. Parents require information about the nature of mental retardation if unnecessarily low expectations are to be avoided. Parents should also be informed of the impact of physical stimulation of the retarded child's functioning. Parents also need direction in locating training centers and reading materials about the child's condition. In the current study, no counselor discussed the meaning of mental retardation, informed parents of the importance of stimulation, or directed parents to resources. Consequently, parents were needlessly discouraged about the child's prognosis. Parents also require information about their risk of reoccurrence of Down's Syndrome and the availability of amniocentesis, a test which detects genetic defects during pregnancy. In the current study, three couples were sterilized after the birth of the retarded child, but before they were presented with such information. Awareness of the availability of this test might have influenced parents' decisions about sterilization. Two mothers in the current study did make use of amniocentesis, but both declined to use the procedure again after the birth of a normal child. Counselors must be willing to listen attentively to parents' concerns and questions if parental misconceptions are to be clarified and if parents are to appropriately use the information and procedures that counselors offer.

Counselors should offer assistance to parents as they inform other family members of the child's prognosis. Parents may want the counselor to answer questions or provide appropriate assurances to members of the extended family. A counseling session which includes all concerned relatives may reduce relatives' tendency to reject the child's diagnosis or to expect a sudden cure. Counseling may also encourage relatives to support a decision to enroll the retarded child in a training program.

Finally, the timing of counseling contacts should be altered. In the current study, parents were given no professional support during the distressing three months prior to confirmation of the child's diagnosis, and were given only rare contact after the diagnosis was confirmed. Presumably, counseling was not provided because a definitive diagnosis had not been established. However, even prior to confirmation, parents were interacting with the child as if he were retarded. Since physician counselors in the current study presented parents with a conclusive diagnosis in nine of ten cases prior to confirmation, there seems to be little reason to avoid providing professional services prior to confirmation. The counselor may wish to inform parents that some of his statements will require modification in the unlikely event that the child's diagnosis is not confirmed or if another condition is diagnosed. Professional support and accurate information might have decreased some of the parents' distress during the months prior to confirmation.

The current study indicates that educational group sessions can have a significant impact on parents of retarded children who are motivated to attend. However, four families in the current study did not attend these group meetings and one other family attended only the first session.

Apparently, another format is required to present information to parents who are passively accepting of the retarded child's condition. These families may require more specific guidance in enrolling their child in a training program and instruction in their homes about the nature of the child's defect.

CHAPTER V

CONCLUSIONS

The majority of articles published about parents with mentally retarded children reflect two beliefs: (1) that parents are unable to adjust to their retarded child, and (2) that parents primarily need to centilate their depression and hostility about the retarded child in order to become more adjusted. These viewpoints are expressed by psychiatrists and psychologists who share intrapsychic theoretical points of view and who may have had some contact with such families. There is almost no empirical data published on parents of the mentally retarded and there is no evidence to support these assumptions.

The current study sought to provide data on how families can and do behave when a retardate is born into it. The current study presents a detailed description of the adjustments of ten families (an exhaustive sample) to their young child with Down's Syndrome over a two-year period. Data indicate that the parents described in the current study differ from parents discussed in the professional literature in at least two major ways. First, although the literature emphasizes parental psychopathology, repeated contacts with these parents over several years showed no "psychopathological" characteristics. Extensive interviews show that they are generous, concerned individuals, who were at least as well adjusted as any demographically correspondent set of adults in the general population. These parents willingly discussed their lives with their retarded child and described both the positive and negative aspects of

their experiences. Observation of them at home and of their interactions with the retarded child sharply contradict the theoretical speculations presented in many professional articles. Second, although parents did report that they had strong emotional reactions to their child's diagnosis of retardation, neither the parents nor the investigator's data indicate that ventilation of these feelings was the parents' primary need. They seemed to resolve within a few months. The reports of those parents who had the most emotional experiences indicated that they would have been spared some of these unnecessary experiences which contributed to their emotional responses by more skilled, better informed and sensitive behavior of the physicians who counseled them. Some of the parents' emotional responses apparently arose from misinformation presented by the physician counselor during the diagnosing interview, such as informing parents that their child would require institutionalization or that the child had an "atypical appearance." Other emotional responses apparently resulted from parents' misconceptions about life with a retarded child into which the physician counselors did not inquire at diagnosis and failed to correct. For example, parents frequently assumed that the retarded child's behavior could not be improved and they consequently felt helpless. Accurate information about the effect of physical and intellectual stimulation on the development of retardates would probably have alleviated parents' feelings of futility and encouraged them to undertake training of their child at an earlier time and to better effect. In sum, these results indicate that rather than ventilation of feelings, parents with a retarded child need accurate, compassionately conveyed information about the child's condition and about

training resources. Further indication of the validity of this finding is the fact that parents in the current study who were presented with information during the educational group sessions readily used this information to benefit the child. They enrolled the child in training programs and read books about retardation so that they could better understand the child's condition.

The results of the study indicate that parents can and do accommodate to a child with Down's Syndrome, even without professional assistance. In this study, four couples who did not attend the educational group sessions reported that they had few or no contacts with professionals after the child's diagnosis was confirmed. Nevertheless, continued experiences with the retarded child allowed these couples to develop an adequate understanding of the nature of the child's probable limitations. Even without professional services and support, there were no instances of severely disturbed relationships between these parents and their retarded child.

The study also clearly indicates that professionals can make a significant contribution to parents' adjustment to their retarded child. Parents who attended an educational group used this experience to gain information about their child's condition and resources available to them, and utilized this information to locate suitable training centers. They also used the group meetings to establish friendships with other parents with a retarded child, and maintained these contacts over several years. Parents who had received these services demonstrated their superior adjustment to their retarded child in their greater satisfaction

with the child and his progress, and their statements that they were willing to rear a second child with Down's Syndrome.

The results of this study indicate the need to improve services provided to parents of a mentally retarded child. Parents' reports of their experiences indicate particular inadequacies in the diagnosing interview, during which parents were first informed of their child's condition. They reported that counselors' practices were insensitive, that they were given information that later proved to be inaccurate, and that they were not given important information that would have been reassuring to them. Pediatricians of most of the couples were poorly equipped to counsel parents with a retarded child. If physicians are to continue to do such counseling, as they must and will, they require fuller education in the nature of retardation and on appropriate ways to present information to parents. Alternatively, counseling practices could be changed so that physicians' personal advising of the child's diagnosis is simultaneously complemented by advice from others more skilled in parent counseling. Such professionals might include not only physicians who are specialists in birth defects, but also social workers, psychologists, appropriately trained psychiatric nurses and ministers. Parents in the current study reported that they did not have any contacts with professionals in the three months between the birth of the retarded child and confirmation of his diagnosis. Parents' many questions and anxieties about the child were ignored. Parents' reports of their lives during this distressing period clearly indicate the need for information and reassurance so that they can develop a more realistic picture of the life to which they would need to adjust. Finally, only one of the ten

couples reported that they had continuing contacts with a professional as their child matured. The remaining families lacked contacts that might encourage them, answer questions about the developing child and direct parents to appropriate resources. The parents, the retarded child, and its brothers and sisters would surely benefit from such contacts.

This study deals only with children with Down's Syndrome. The results can be extrapolated to other classes of retardates who can be diagnosed in early infancy. Further research on exhaustive or randomly selected samples of families must be done before statements can and should be made about families where the child is diagnosed to have other forms of retardation.

BIBLIOGRAPHY

BIBLIOGRAPHY

Auerback, A. B. Group education for parents of the handicapped. Children, 1956, 8, 515-524.

Beck, H. L. Counseling parents of retarded children. Children, 1959, 6, 225-230.

Berg, J. M., Gilderdale, S., & Way, J. On telling parents of a diagnosis of mongolism. British Journal of Psychiatry, 1969, 115, 1195-1196.

Bitter, J. A. Attitude change by parents of trainable mentally retarded children as a result of group discussion. Exceptional Child, 1963, 30, 173-177.

Blatt, A. Group therapy with parents of severely retarded children. Group Psychotherapy, 1957, 10, 133-140.

Boyd, D. Three stages in the growth of parents of a mentally retarded child. American Journal of Mental Deficiency, 1951, 55, 608-611.

Bryant, K. N. & Jirschberg, J. C. Helping the parents of a retarded child: The role of the physician. American Journal of Diseases of Children, 1961, 102, 52-96.

Buck, P. S. The Child Who Never Grew. New York: John Day Company, 1950.

Caldwell, B. & Guze, S. A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. American Journal of Mental Deficiency, 1960, 64, 845-861.

Carr, J. Handicapped children—counseling the parents. Developmental Medicine and Child Neurology, 1970, 12, 230-231.

Caudill, H. M. Night Comes to the Cumberlands. Boston: Little, Brown, 1963.

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

Coleman, J. C. Group therapy with parents of mentally defective children. American Journal of Mental Deficiency, 1953, 57, 700-704.

Condell, J. F. Parental attitudes toward mental retardation. American Journal of Mental Deficiency, 1966, 71, 85-92.

Cummings, S. T. & Stock, D. Brief group therapy of mothers of retarded children outside of the specialty clinic setting. American Journal of Mental Deficiency, 1962, 66, 739-748.

Dalton, J. & Epstein, H. Counseling parents of mildly retarded children. Social Casework, 1963, 44, 523-530.

Denhoff, E. The impact of parents on the growth of exceptional children. Exceptional Children, 1960, 26, 271-274.

Drayer, C. & Schlesinger, E. G. The informing interview. American Journal of Mental Deficiency, 1961, 65, 363-370.

Drillen, D. C. H. & Wilkerson, E. M. Mongolism: When should the parents be told? British Medical Journal, 1964, 2, 1306-1307.

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

Ehlers, W. H. Mothers of Retarded Children—How They Feel, Where They Find Help. Springfield, Ill: Charles C. Thomas, 1966.

Farber, B. Effects of a severely mentally retarded child on family integration. Monograph of the Society for Research in Child Development, 1959, 24, no. 2.

Farber, B. Family organization in crisis: Maintenance of integration in families with a severely mentally retarded child. Monographs of the Society for Research in Child Development, 1960, 25, no. 1.

Frank, J. P. My Son's Story. New York: Alfred A. Knopf, 1952.

Giannini, M. J. & Goodman L. Counseling families during the crisis reaction to mongolism. American Journal of Mental Deficiency, 1963, 67, 740-747.

Goodman, L. & Rothman, R. The development of a group counseling program in a clinic for retarded children. American Journal of Mental Deficiency, 1961, 65, 789-795.

Gordon, N. Parent counseling. Developmental Medicine and Child Neurology, 1972, 14, 657-667.

Goshen, C. E. Mental retardation and neurotic maternal attitudes. Archives of General Psychiatry, 1963, 9, 168-174.

Hersch, A. Casework with parents of retarded children. Social Work, 1961, 6, 61-66.

Holt, K. S. Home care of severely retarded children. Pediatrics, 1958, 22, 744-755.

Hunt, N. The World of Nigel Hunt. New York: Sarritt Publications, 1967.

Hunter, M. H., Schuchman, H., & Friedlander, G. The Retarded Child from Birth to Five: A Multidisciplinary Program for the Child and Family. New York: John Day Co., 1972.

Jordan, T. E. The Mentally Retarded. Columbus, Ohio: Charles E. Merrill Books, Inc., 1966.

Kanner, L. Parents' feelings about retarded children. American Journal of Mental Deficiency, 1953, 57, 375.

Kramm, F. R. Families of Mongoloid Children. U.S. Children's Bureau, Publication no. 401, U.S. Government Printing Office, 1963.

Lewis, J. Effects of group procedures with parents of mentally retarded children. Mental Retardation, 1972, 10, 14-15.

Linder, R. Mothers of disabled children—the value of weekly group meetings. Developmental Medicine and Child Neurology, 1970, 12, 202-206.

Mandlebaum, A. & Wheeler, M. E. The meaning of a defective child to parents. Social Casework, 1960, 41, 360-367.

Marmol, J. G., Scriggins, A. L., & Vollman, R. L. Mothers of mongoloid infants in the collaborative project. American Journal of Obstetrics and Gynecology, 1965, 104, 533-543.

Martin, H. P. Parental responses to handicapped children. Developmental Medicine and Child Neurology, 1975, 17, 251-252.

Mathney, A. P. & Vernick, J. Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived? Journal of Pediatrics, 1969, 74, 953-958.

Menolascino, F. J. Parents of the mentally retarded. Journal of the American Academy of Child Psychology, 1968, 7, 589-602.

Michaels, J. & Schuchman, H. Observations on the psychodynamics of parents of retarded children. American Journal of Mental Deficiency, 1962, 66, 568-573.

Murray, M. Needs of parents of mentally retarded children. American Journal of Mental Deficiency, 1959, 63, 1078-1089.

Nadal, R. M. A counseling program for parents of severely retarded preschool children. Social Casework, 1961, 42, 78-83.

Oberman, J. W. The physician and parents of the retarded child. Children, 1963, 10, 109-113.

Olshansky, S. Chronic sorrow: A response to having a mentally defective child. Social Casework, 1962, 43, 191-194.

O'Neill, J. Siblings of the retarded: Individual counseling. Children, 1956, 3, 13-17.

Patterson, L. Some pointers for professionals. Children, 1956, 3, 13-17.

Pinkerton, P. Pitfalls in interpreting procedure within the diagnostic clinic. Developmental Medicine and Child Neurology, 1970, 12, 516-517.

Popp, C., Ingram, V., & Jordan, P. H. Helping parents understand the mentally handicapped child. American Journal of Mental Deficiency, 1954, 58, 530-534.

Rankin, J. E. A group therapy experiment with mothers of mentally deficient children. American Journal of Mental Deficiency, 1957, 62, 49-55.

Rogers, D. E. Angel Unaware. Westwood, N.J.: Fleming H. Revell, 1953.

Roith, A. I. The parents of subnormal children. In Gunzburg, H. C. (ed.), Advances in the Care of the Mentally Handicapped. Baltimore: Williams and Wilkins Co., 1973.

Roos, P. Parents and families of the mentally retarded. In Kaufman, J. M. and Payne, J. S. (eds.), Mental Retardation: Introduction and Personal Perspectives. New York: Charles E. Merrill Publishing Co., 1975.

Rosen, L. Selected aspects in the development of the mother's understanding of her mentally retarded child. American Journal of Mental Deficiency, 1955, 59, 522-528.

Rychman, D. B. & Henderson, R. A. The meaning of a retarded child for his parents: A focus for counselors. Mental Retardation, 1965, 3, 4-6.

Sarason, S. G. Psychological Problems in Mental Deficiency. New York: Harper and Row, 1953.

Schripper, M. T. The child with mongolism in the home. Pediatrics, 1959, 24, 132-144.

Schreiber, M. & Feeley, M. Siblings of the retarded: A guided group experience. Children, 1965, 12, 221-225.

Schonell, F. J. & Rorke, M. A second survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1960, 64, 862-868.

Schonell, F. J. & Watts, B. H. A first survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1960, 64, 862-868.

Schuchman, J. Further observations of the psychodynamics of parents of retarded children. Training School Bulletin, 1963, 60, 70-74.

Sheimo, S. L. Problems in helping parents of mentally defective and handicapped children. American Journal of Mental Deficiency, 1951, 56, 42-47.

Smith, E. M. Emotional factors as revealed in the intake process with parents of defective children. American Journal of Mental Deficiency, 1952, 56, 806-811.

Solnit, A. J. & Stark, M. H. Mourning and the birth of a defective child. Psychoanalytic Study of the Child, 1961, 16, 523-537.

Solomons, G. What do you tell the parents of a retarded child? Some personal experiences and reflections. Clinical Pediatrics, 1965, 4, 227-232.

Stubblefield, H. W. Religion, parents and mental retardation. Mental Retardation, 1965, 3, 8-11.

Tavormina, J. B., Hampson, R. B., & Luscomb, R. L. Participant evaluation of the effectiveness of their parents' counseling groups. Mental Retardation, 1976, 8-9.

Thurston, J. R. Counseling the parents of the severely handicapped. Exceptional Children, 1960, 26, 351-354.

Weingold, J. T. Parents' groups and the problem of mental retardation. Journal of Clinical Psychology, 1953, 9, 118-124.

Weller, J. E. Yesterday's People: Life in Contemporary Appalachia. Lexington, KY: University of Kentucky Press, 1965.

Wolfensberger, W. Counseling the parents of the retarded. In Baumeister, A. A. (ed.), Mental Retardation: Appraisal, Education and Rehabilitation. Chicago: Aldine Publication Co., 1967.

Woodmansey, A. C. Parent guidance. Developmental Medicine and Child Neurology, 1971, 13, 243-244.

Worchell, T. L. & Worchell, P. The parental concept of the mentally retarded child. American Journal of Mental Deficiency, 1961, 65, 782-788.

Yates, J. L. & Lederer, R. Small, short-term group meetings with parents of children with mongolism. American Journal of Mental Deficiency, 1961, 65, 467-472.

Zook, L. & Unikov, C. Areas of concern for the counselor in a diagnostic clinic for mentally retarded children. Mental Retardation, 1968, 19-24.

Zwerling, I. Initial counseling of parents with mentally retarded children. Journal of Pediatrics, 1954, 44, 469-479.

APPENDIXES

APPENDIX A

APPENDIX A

TOPICS COVERED IN FIRST HOME INTERVIEW

1. Tell me about your pregnancy with _____.
   A. Mother's health
   B. Any unusual events which occurred
   C. Worries and concerns during pregnancy
   D. Expectations for the child

2. When did you first see the child? What was your reaction?

3. When were you first told that _____ would need to come to a place like the evaluation center?

4. What were you told about the child's condition at that time?
   A. Who presented the information?
   B. What were you told?
   C. What did the label mean?
   D. What were you told to expect?
   E. What were you told about the child's limitations?
   F. What were you told about his medical problems?
   G. What were you told about services for the child?

5. What was your reaction? What were your concerns?

6. Before you were told about _____, had you ever seen a child like him?
   A. Had you ever seen a mentally retarded child? What was the child like?
   B. Had you seen a child with Down's Syndrome? What was the child like?

7. What caused your child to have this condition? Why do you think it happened to you?

8. What are the things that _____ likes to do?

9. What are the things _____ can do for himself?

10. What do you think he will be able to do for himself when he is older? When he is an adult?

11. Tell me about the ways that your lives together have changed since you have _____ that would not have changed if you had not had a special child.

A. Changes in being a couple?
B. Changes in going out?
C. Changes in daily living arrangements—shopping, sleeping, eating?
D. Plans for other children?
E. Other changes?

12. Tell me about the things that please you most about _____. What are the things that are hardest to accept?

13. Tell me about how other people get along with _____.
    A. How do his siblings treat him? Do they realize that he is different? What sorts of problems do they have because of him?
    B. How do your own parents treat him? What have you told them about _____? What is their reaction?
    C. How do your neighbors treat him? What sorts of problems do you have because of the child?
    D. How do strangers react to him? Do they notice that he is different? What sorts of problems do you have because of him?

14. What sorts of help are you getting with _____?
    A. Name of agency? What sorts of things are they helping you with?

15. What other agencies have given you help with _____ in the past?
    A. Name of agency? What sorts of help did they give?

16. What sorts of help would you like to have?

17. What questions do you have about _____?

18. What advice would you give to other parents who are just finding out that they have a child like yours?

19. What advice would you give to professional people who were going to be talking to parents who were just finding out that they have a child like yours?

APPENDIX B

APPENDIX B

TOPICS COVERED IN SECOND HOME VISIT

1. Since last seen, how has _____ been?
   A. Any major changes
   B. Any health problems
   C. Any professional contacts

2. What sorts of things is he/she learning now?
   A. What sorts of things are helping him learn this skill?
   B. Who is helping him learn this?

3. Is he/she in a program now?
   A. What is the program like?
   B. How did you learn about it?
   C. Do you like the program?
   D. Does the child like it?
   E. Any problems with the program?

4. Have you read anything new about children like yours?

5. Have there been any other changes in your family recently?
   A. Between parents
   B. Between parents and child
   C. Between sibs and child

6. Have you met any other families with a child like yours?

TOPICS COVERED ONLY WITH PARENTS WHO ATTENDED THE GROUP

7. What is your opinion of the parents' group?
   A. What was helpful to you?
   B. What else would you have like to hear about?
   C. What could have made the group better?
   D. (If applicable) What did your normal children think of the group?

8. Have you talked to the other parents in the group since the group has finished?

APPENDIX C

APPENDIX C

TOPICS COVERED IN FINAL HOME INTERVIEW

1. Since last seen, how has _____ been?
   A. Any major changes that have occurred?
   B. How has his health been?

2. Now that he is older, what does he do most of the time?
   A. What sorts of things does he especially like to do?
   B. What is a typical day like?
   C. Does he have friends of his own; what do they do together?
   D. Does he have pets; in what ways does he interact with them?

3. What sorts of things can he do for himself now?
   A. Dressing
   B. Feeding
   C. Talking
   D. Toileting
   E. How does he get along with his sibs?

4. How does he compare with your other children at his/her age?

5. Are the things that he can do now what you expected him to do by this age?

6. How has _____ effected your family, now that he is bigger?
   A. How has he effected your relation to each other?
   B. How has he effected your relationship to your own parents?
   C. How has he influenced your relationship to your other relatives?
   D. How has he effected his sibs?
   E. What do his sibs tell his friends about him?
   F. How do his sibs' friends react to him?
   G. What sort of reaction do your neighbors have to him?
   H. How do strangers react to him? What places does he go to with you?

7. What sorts of changes have you made in the family that you wouldn't have needed to make for another child?
   A. Have you changed how your household runs?
   B. What your family does for recreation?
   C. Plans for other children?

8. What sorts of things does he do that you like and make you proud of him?

9. What does he do that you wish he didn't do?

10. What kinds of help are you receiving now?
    A. What sort of program is the child in, if any?
    B. What is this program like; what do you think of it?

11. What kinds of additional help would you like?

12. What things have happened that were most helpful in adjusting to your child?

13. What sorts of things were most helpful in adjusting to your child?

14. Have you met other families with children like your child?

15. What sorts of concerns do you have about your child?

16. What do you expect the future will be like with your child?
    A. When do you expect him to enter school?
    B. How do you think that he will get along with the other kids?
    C. How do you expect he will get along with the teachers?
    D. What do you expect he will be like when he is older? When he is an adult?

17. What advice would you give to other parents with a child like yours?

18. What advice would you give to the professionals helping them?

APPENDIX D

APPENDIX D

MEDICAL KNOWLEDGE OF DOWN'S SYNDROME

1. What is the name of the child's condition?
2. What is a synonym for this name?
3. Does the condition the child has run in families?
4. Is it more common in younger or older mothers?
5. What is it about the child's cells that causes the condition?
6. How many chromosomes does the child have?
7. What are the chances of having another Down's child?
8. What is amnioscentesis?
9. If the mother conceives another Down's child, what happens?
10. How do doctors do amnioscentesis?
11. How long can you expect your child to live?
12. Do Down's children have more lung infections than other children?
13. What do Down's children look like?
14. What is their personality like?
15. What is their intelligence like?
16. What is mental retardation?
17. Does mental retardation influence how fast the child learns to walk and talk?
18. Are all retarded people at the same level of functioning?
19. What is intelligence testing like:
20. When will it first be given to the child?
21. Does retardation mean the child will suddenly stop learning?

22. Will training help the child?

23. When do you expect the child will sit up, walk, talk (whichever is the next milestone for the child?

24. Who pays for the child's schooling?

25. Do Down's children attend regular schools?

26. Will the child learn grammar school material?

27. Will the child attend high school?

28. Will the child receive vocational training during high school?

29. Will the child attend college?

30. Will he marry?

31. Will he have children?

32. Do Down's ever support themselves?

33. What do most Down's do for money as adults?

34. What are sheltered-workshops?

35. What are group homes?

36. Can they learn to drive or do they use public transportation?

37. What are some important accomplishments of a Down's person?

38. Name one helping agency.

39. What are its admission policies?

40. Name a second, alternative helping agency.

APPENDIX E

APPENDIX E

A LIST OF EMPIRICAL AND NONEMPIRICAL ARTICLES ON PARENTS WITH MENTALLY RETARDED CHILDREN

Aldrich, C. A. Preventive medicine and mongolism. American Journal of Mental Deficiency, 1947, 52, 127-129.

Baum, M. N. Some dynamic factors affecting family adjustment to the handicapped child. Exceptional Children, 1962, 28, 387-392.

Bawkin, H. Informing the parents of the mentally retarded child. Journal of Pediatrics, 1956, 49, 486-498.

Beck. H. L. Counseling parents of retarded children. Children, 1959, 6, 225-230.

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

Begab, M. J. Counseling parents of retarded children. Canada's Mental Health, 1964, 12, 2-5.

*Berg, J. M., Gilderdale, S., & Way, J. On telling parents of a diagnosis of mongolism. British Journal of Psychiatry, 1969, 1195-1196.

Boyd, D. Three stages in the growth of a parent of a mentally retarded child. American Journal of Mental Deficiency, 1951, 55, 608-611.

Bryant, K. N. & Hirschberg, J. C. Helping the parents of a retarded child: The role of the physician. American Journal of Diseases of Children, 1961, 102, 52-96.

*Caldwell, B. and Guze, S. A study of the adjustment of parents and siblings of institutionalized and noninstitutionalized retarded children. American Journal of Mental Deficiency, 1960, 64, 845-861.

Carr, J. Handicapped children—counseling the parents. Developmental Medicine and Child Neurology, 1970, 12, 230-231.

Casse, R. M. The professional's responsibility in aiding parental adjustment. Mental Retardation, 1968, 49-50.

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

*Condell, J. F. Parental attitudes toward mental retardation. American Journal of Mental Deficiency, 1966, 71, 85-92.

*Cummings, S. T., Bayley, H. C., & Rie, H. E. Effects of the child's deficiency on the mother: A study of mothers of mentally retarded, chronically ill and neurotic children.

Dalton, J. & Epstein, H. Counseling parents of mildly retarded children. Social Casework, 1963, 44, 523-530.

Denhoff, E. The impact of parents on the growth of exceptional children. Exceptional Children, 1960, 26, 271-274.

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

Drayer, C. & Schlesinger, E. G. The informing interview. American Journal of Mental Deficiency, 1961, 65, 363-370.

*Drillien, D. H. C. & Wilkerson, E. M. Mongolism: When should the parents be told? British Medical Journal, 1964, 2, 1306-1307.

*Farber, B. Effects of a severely mentally retarded child on family integration. Monograph of the Society for Research in Child Development, 1959, 24, no. 2.

*Farber, B. Family organization in crisis: Maintenance of integration in families with a severely mentally retarded child. Monograph of the Society for Research in Child Development, 1960, 25, no. 1.

Grebler, B. V. Parental attitudes toward mentally retarded children. American Journal of Mental Deficiency, 1952, 56, 475-483.

Giannini, M. J. & Goodman, L. Counseling families during the crisis reaction to mongolism. American Journal of Mental Deficiency, 1963, 67, 740-747.

Goodman, L. Continuing treatment of parents of congenitally defective infants. Social Work, 1964, 9, 92-97.

Gordon, N. Parent counseling. Developmental Medicine and Child Neurology, 1972, 14, 657-667.

Gordon, E. W. & Ullman, M. Reaction of parents to problems of mental retardation in children. American Journal of Mental Deficiency, 1956, 61, 158-163.

Goshen, C. E. Mental retardation and neurotic maternal attitudes. Archives of General Psychiatry, 1963, 9, 168-174.

*Graliker, B. V., Parmalee, A. H., & Koch, R. Attitude study of parents of mentally retarded children. Pediatrics, 1959, 24, 819-821.

Hersch, A. Casework with parents of retarded children. Social Work, 1961, 6, 61-66.

*Holt, K. S. Home care of severely retarded children. Pediatrics, 1958, 22, 744-755.

*Jackson, M. S. Reaction of some Australian mothers to the birth of their mentally handicapped child. Slow Learning Child, 1969, 16, 37-43.

*Justice, R. S., O'Conner, G., & Warren, N. Problems reported by parents of mentally handicapped children—who helps? American Journal of Mental Deficiency, 1971, 75, 685-691.

Kanner, L. Parents' feelings about retarded children. American Journal of Mental Deficiency, 1953, 57, 375.

Kelman, H. R. Parent guidance in a clinic for mentally retarded children.

*Koch, R., Graliker, B. V., Sands, R., & Parmaless, A. H. Evaluation of parental satisfaction with the medical care of a retarded child. Pediatrics, 1959, 23, 582-584.

Mahoney, S. C. Observations concerning counseling with parents of mentally retarded children. American Journal of Mental Deficiency, 1958, 63, 81-86.

Mandlebaum, A. & Wheeler, M. E. The meaning of a defective child to parents. Social Casework, 1960, 41, 360-367.

Martin, H. P. Parental response to handicapped children. Medicine and Child Neurology, 1975, 17, 251-252.

*Mathney, A. P. & Vernick, J. Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived: Journal of Pediatrics, 1969, 74, 953-958.

Michaels, J. & Schuchman, H. Observations on the psychodynamics of parents of retarded children. American Journal of Mental Deficiency, 1962, 66, 568-573.

Menolascino, F. J. Parents of the mentally retarded. Journal of the American Academy of Child Psychology, 1968, 7, 589-602.

Murray, M. Needs of parents of parents of mentally retarded children. American Journal of Mental Deficiency, 1959, 63, 1078-1089.

Nadal, R. M. A counseling program for parents of severely retarded preschool children. Social Casework, 1961, 42, 78-83.

Oberman, J. W. The physician and parents of the retarded child. Children, 1963, 10, 109-113.

Olshansky, S. Chronic sorrow: A response to having a mentally defective child. Social Casework, 1962, 43, 191-194.

Olshansky, S. Parental responses to a mentally defective child. Mental Retardation, 1966, 21-23.

O'Neill, J. Siblings of the retarded: Individual counseling. Children, 1965m, 12, 226-229.

Patterson, L. Some pointers for professionals. Children, 1956, 3, 13-17.

Pinkerton, P. Parental acceptance of the handicapped child. Developmental Medicine and Child Neurology, 1970, 12, 207-211.

Roos, P. Psychological counseling with parents of retarded children. Mental Retardation, 1963, 344-350.

Rosen, L. Selected aspects in the development of the mothers' understanding of her mentally retarded child. American Journal of Mental Deficiency, 1955, 59, 522-528.

Ryckman, D. B. & Henderson, R. A. The meaning of a retarded child for his parents: A focus for counselors. Mental Retardation, 1965, 3, 4-6.

Scher, B. Help to parents: An integral part of service to the retarded child.

*Schipper, M. T. The child with mongolism in the home. Pediatrics, 1959, 24, 132-144.

*Schonell, F. J. & Rorke, M. A. A second survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1960, 64, 862-868.

*Schonell, F. J. & Watts, B. H. A first survey of the effects of a subnormal child on the family unit. American Journal of Mental Deficiency, 1956, 61, 210-219.

Schuchman, H. Further observations on the psychodynamics of parents of retarded children. Training School Bulletin, 1963, 60, 70-74.

Sheimo, S. L. Problems in helping parents of mentally defective and handicapped children. American Journal of Mental Deficiency, 1951, 56, 42-47.

Smith, E. M. Emotional factors as revealed in the intake process with parents of defective children. American Journal of Mental Deficiency, 1952, 56, 806-811.

Solnit, A. J. & Stark, M. H. Mourning and the birth of a defective child. Psychoanalytic Study of the Child, 1961, 16, 523-537.

Solomons, G. What do you tell the parents of a retarded child? Some personal experiences and reflections. Clinical Pediatrics, 1965, 4, 227-232.

Stone, M. M. Parental attitudes to retardation. American Journal of Mental Deficiency, 1948, 53, 363-372.

Stubblefield, J. W. Religion, parents and mental retardation. Mental Retardation, 1965, 3, 8-11.

Thurston, J. R. Counseling the parents of the severely handicapped. Exceptional Children, 1960, 26, 351-354.

Tretakoff, M. Counseling parents of handicapped children. Mental Retardation, 1969, 31-34.

Wardell, W. Case work with parents of mentally deficient children. American Journal of Mental Deficiency, 1947, 52, 91-97.

Waskowitz, C. H. The parents of retarded children speak for themselves. Journal of Pediatrics, 1959, 54, 319-329.

Wolf, S. & Lourie, R. S. The impact of the mentally defective child on the family unit. Journal of Pediatrics, 1953, 42, 521-525.

Wolfensberger, W. Embarrassments in the diagnostic process. Mental Retardation, 1965, 29-31.

*Worchel, T. L. & Worchel, P. The parental concept of the mentally retarded child. American Journal of Mental Deficiency, 1961, 65, 782-788.

Zook, L. & Unkovic, C. Areas of concern for the counselor in a diagnostic clinic for mentally retarded children. Mental Retardation, 1961, 65, 467-472.

*Zuk, G. H. Autistic distortion in parents of retarded children. Journal of Consulting Psychology, 1959, 23, 171-176.

*Zuk, G. H., Miller, R. L., Bartram, J. B., & Kling, F. Maternal acceptance of retarded children: A questionnaire study of attitudes and religious background. Child Development, 1961, 32, 525-540.

(*Denotes Empirical Articles)

VITA

Susan Parker was born in Cleveland, Ohio, metropolitan area in November 1950, and was educated in that city. During her high school years, she developed an interest in the mentally retarded, and worked as a tutor for adolescent, retarded youths. After earning her high school degree in 1968, she worked for several years as a teacher for young, low-income children. In 1970, she was admitted to the University of Illinois at Chicago Circle. While earning her undergraduate degree, she continued to tutor young children and to become involved in community development work in low-income neighborhoods. In 1973, she received a Bachelor of Science degree in psychology, cum laude and with departmental distinction. After graduation, she worked in Hackney Hospital, London, England, a nationally supported, residental mental institution. In September 1974, she was admitted to the Clinical Psychology program of The University of Tennessee, Knoxville. During her education, she worked in a variety of settings, including work as an evaluator-counselor for the Birth Defects Evaluation Center.

Susan Parker has accepted a clinical internship for 1979-1980 and will receive her Doctor of Philosophy degree in clinical psychology upon completion of her internship.