THE BIRTH OF A MENTALLY RETARDED CHILD: INFORMING THE PARENTS

By

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ABSTRACT

The purpose of the study was to assess parental satisfaction with the professional help received at the time of the diagnosis of their mentally retarded child. Satisfaction was defined as the parents viewing the help received as appropriate and meeting their needs. Areas of concern were appropriate time of the informing interview, perception of the informant, expressions of caring and understanding; parents' satisfaction with the amount of information presented and the opportunity to express their feelings, and perceptions of adequacy of referrals for follow-up services. The level of research design was that of a descriptive study. The study attempted to answer the research question "How satisfied are parents of a retarded child with professional help received at the time of diagnosis?"

A semi-structured questionnaire was used for data collection. The questionnaire was delivered to the parents which met the criteria for participation in the study by program workers. Data was obtained from 25 families. Results showed that frequently mother was first to be informed and usually in a hospital setting. Informing was almost always done by a single person. Parents were found to be in agreement that the diagnosis was presented in a sympathetic manner, and was presented with clarity using language which was quite understandable. Satisfaction rate was found to be lower on areas of concern around the parents involvement in the interview. These included an attempt to determine parents knowledge

of the child's condition and areas concerned with the expression of feelings being experienced by the parents. Parents express an overall satisfaction rate of 46%. Lower percentages were also found in referrals to community resources. It was concluded that while the present study did obtain the measurement desired, the method would have been more productive if an interview schedule had been used rather than the semi-structured questionnaire. Much research focuses on parents' views of the informant. A possible direction for further study is parental expressions of emotions in this interview, and how informants can best respond to these feelings. Informing the parents of a diagnosis of mental retardation is but a beginning of a process for the family and professionals. There will, to some degree, be a need for ongoing support by the family and the handicapped child.

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THE BIRTH OF A MENTALLY RETARDED CHILD: INFORMING THE PARENTS

The family life-cycle traditionally involves the rearing of children with the parents accepting the responsibility for this process, and enjoying the rewards of these labours. Parents normally assign a status to each of their children in the course of this life-cycle in terms of the child's performance and capability. This status, along with the roles and expectations it encompasses, will normally develop as the child increases in age (Kew, 1975). Where there is a retarded child within the family, this status development is interrupted. The fact that the retarded child may never "grow up" means that the parents' role toward him will remain constant in contrast to an evolving and developing role with a normal child. Where a retarded child is present in the family, the parents are restricted to one stage in the family's life-cycle (Kew, 1975).

Parents look forward to the arrival of their offspring for various reasons. The birth of a child may represent a narcissistic endeavor, a pride in themselves which gives them a desire to produce a child (Howell, 1973). Through their child, parents may hope to produce a life that is more fulfilling and complete than their own. Whatever the parental desires and future expectations at the time of the birth, their mental image will be of a perfect, whole offspring.

With the birth of a handicapped infant, parents may experience varying degrees of emotional conflict.

Throughout the process, the idealization of the whole child which was not born prevails. Most parents experience what may be termed "chronic sorrow" at the birth of a retarded child. The sorrow is due to the realization that their child is handicapped and this sorrow is chronic in that it stays with the parents as long as the child lives. Olshansky (1966) regards this as an understandable non-neurotic response to what has taken place. The actual manifestation of the sorrow will be dependent on such variables as social class, age of the parents, religion, ethnicity, size of the family, ordinal position of the child, and sex of the child (Olshansky, 1966).

The most common and predictable reaction by the parents is depression which can range in severity from disappointment to deep despair. Professional help may be needed for the parent who experiences this extreme despair in some instances. Associated with depression may be shame for having a retarded child and the anticipation of social rejection, pity, or ridicule. Concurrent with depression may be a loss of esteem reflecting parental devaluation through producing a retarded child.

All parents experience some guilt in varying degrees. They may blame themselves and feel that their child's retardation is a result of their past misdeeds. A distorted reaction in parents is the development of a masochistic or self-punishing life-style. When this occurs the parents appear to enjoy suffering, and thus become what may be termed

"willing martyrs". These parents devote all their time and energy to their retarded child. There is no time or energy left for other activities in their life. Their life may be seen as one of the endless sacrifice (Moloney, 1971).

Reactions to the birth can vary in type and intensity. One factor which might influence the degree of reaction by the parents is the amount of support provided from the time they are informed of the defective birth. If there is ongoing support, and an opportunity to express their feelings and anxieties, then it may be less difficult for the parents to work out their emotional upset, and begin to cope with the daily routine of caring for a handicapped child. These processes are essential for a healthy development of both family and child, and need to begin at the time of the informing interview.

The mode in which parents of a retarded child are initially informed of his or her handicap is likely to have considerable import. It has been stated that optimally parents should receive from diagnostic counseling specific, clear, honest information concerning their child transmitted in an understanding and compassionate manner. The counseling should include implications for the child's future and suggest to the parents steps that can be taken to cope with present problems (Matheny and Vernick, 1969). The professional is in a position of having to inform parents awaiting a joyous event, that it has turned into a catastrophe (Pueschel and Murphy, 1975).

It is at this time that the willingness of the parents to seek or accept help may be determined. Alternatively, dissatisfaction could lead to a shopping pattern by the parents, whereby they seek more favourable opinions concerning their child. Anderson (1971,p.3) defines shopping behavior as ".....the retarded child's parents making visits to the same professional or to a number of professionals or clinics in such a manner that one visit follows another without resolution of a resolvable problem."
This pattern of behavior is considered maladaptive in that it can be costly in time, parental energy, and money. It also disrupts family life and takes the focus off constructive efforts to work with the child.

Presentation of diagnostic information is usually carried out singly by a doctor who may be a pediatrician, obstetrician, or a general practitioner. An alternative is a team presentation based on an interactional model.
The hypothesized superiority of this model is based upon three assumptions. The first assumption is that various professionals with specific skills can best be utilized for the interpretation of the various aspects of the diagnosis. Professionals with the ability to provide a simple clear explanation are needed, parents are minimally impressed by professionals who wish to display their expertise (Stephens,1969).

The second assumption is that simple understandable language is best used. Parents gain little understanding from detailed medical reports.

As a guideline, this model suggests that the interview follow the lines suggested by the parents through their questions. It is important to be aware of the emotional state of the parents, and not all information will be recalled at a later time. For this reason, future meetings can be arranged, and the parents be provided with additional opportunities to understand the condition of their child (Stephens,1969).

The third assumption of this model is that several sessions are required to interpret the diagnosis to the parents. Advantages of this approval are realized in terms of information transmitted, and the investment of professional time. At first, it may appear to be more time consuming for the professional involved, but this method may eliminate many of the phone calls and appointments which may ensue if only a single session is used to present the findings to the parents. If further sessions are not planned right from the beginning, parents may continue to return intermittently to seek additional information concerning their child (Stephens, 1969).

A value of the interactional model is that it maintains on-going contact with the parents. Through this, the parents can be introduced to community agencies and organizations, and what they can expect as services from these resources. The addition of agency support may assist parents in adjusting to their new life style with a retarded child in the home.

It may also be that this approach of a team model would reduce the risk of "shopping behavior".

The method by which parents are informed of the birth of a child with mental retardation, the timing and the place of the informing are important aspects of a right beginning. Also of import are characteristics of the informant. The person should be comfortable in presenting the diagnosis in a sympathetic and understanding manner. This will assist the parents with acceptance of their child, and the development of positive feelings toward the future life with their offspring.

Parent told first

A review of literature reveals that the preferential method of informing parents of the birth of a handicapped child is to have both parents together at the time of presentation (ie: Green and Soutter,1977). In most studies of actual practice, however, it is the mother alone who is the first to be informed. Studies indicate that in about 50% of the cases the mother alone is the first to be told (Carr, 1970; Cunningham and Sloper,1977; Edelstein and Strydom, 1981; Gilmore and Oates,1977; Lucas and Lucas,1980; Rubin and Rubin,1980; Shiono and Kadowaki,1979).

Only infrequently is the father told first. The percentage of fathers informed initially generally drops to the 20% area (Carr,1970; Edelstein and Strydom,1981; Shiono and Kadowaki, 1979).

Most literature suggests that parents should be informed of the diagnosis together. Findings reveal that parents were generally told together about 20 - 30% of the time (Carr, 1970; Cunningham and Sloper,1977; Edelstein and Strydom,1981; Gayton and Walker,1974; Gilmore and Oates,1977; Lucas and Lucas,1980; Rubin and Rubin,1980; Shiono and Kadowaki,1979). When the preference of parents is studied, it is found that most parents expressed a preference for being told together. Rates of this preference ranged from 63% - 86% (Cunningham and Sloper,1977; Gayton and Walker,1974; Lucas and Lucas, 1980).

A contrary preference, that of the "stronger" parent being informed first, is reported in a number of studies. Hare, Laurence, Paynes, and Rawnsley (1966) reported that 33 of 96 fathers thought the mother should be told later either by the father, or at the same time as the father was informed. Cunningham and Sloper (1977) reported that six parents (N=51) felt the stronger parent should be told first. A similar view was expressed by the parents of the Gayton and Walker (1974) study with the decision as to the more stable parent being made by the physician. This study also found that nine parents (N=81) preferred the father be informed first.

Most parents felt that being told together was important. Their reason for this feeling was that they would be able to support each other (Cunningham and Sloper,1977).

Carr and Oppe (1971) suggest that if the father is the first to be informed, he should not be left alone to inform the mother. There should be a professional person present at this time. Patterson (1956), a mother of a retarded child, reminds professionals that fathers are parents too, and both parents should be seen together at the informing interview. It is further pointed out that when the mother is first to be told, it is difficult for her to restate, interpret, and answer questions concerning the diagnosis of their infant. The mother may be attempting to explain something which she does not understand, and has placed her in a state of emotional shock.

Jacobs (1962) surveyed 307 medical personnel as to their preference of whom they talked to first. Father alone was the first choice (113), the second choice was parents together (79), and mother alone was indicated 75 times. Twenty-one responded that it would vary with circumstances presented at the time. McDonald, Carson, Palmer, and Slay (1982) through telephone interviews with 69 physicians found that 88% of the time parents were informed together.

Generally literature shows a preference for parents being informed together. This preference is by both professionals and parents. In actual practice in about half of the cases it is the mother alone who is first told, and only in the 25% range are parents told together.

Preference for this method is based upon the support parents can provide each other at this time of emotional stress. A factor which appears to be of import is that one parent does not have to attempt to explain and answer questions which they may not completely understand. When parents are informed together, there is less risk of the information being transmitted to be misinterpreted when told by one parent to the other. By informing parents together there is opportunity for more questions to be asked of the informant, and this may provide a better understanding by the parents of their child's condition.

Who does the informing?

Previous studies have indicated that in the majority of cases a pediatrician was the first informant. The percentage of cases in which it was the pediatrician ranged from 44% - 88% with the majority well above 50% (Cunningham and Sloper, 1977; Edelstein and Strydom, 1981; Gayton and Walker, 1974; Gilmore and Oates, 1977; Lucas and Lucas, 1980; Rubin and Rubin, 1980; Shiono and Kadowaski, 1979; Stone, 1973). The representation of other informants appeared to drop drastically from these percentages. Other professions named as the initial informant included obstetrician, general practitioner, gynecologist, nurse and midwife.

A few studies reported that one parent was the informant for the other parent.

Generally in these studies, the father was the presenter of the information to the mother (Gayton and Walker, 1974; Lucas and Lucas, 1980). Gilmore and Oates (1977) found that no parents were informed by their spouse, but these authors did find one mother who learned of the diagnosis of her child by reading the hospital's medical file.

When physicians were surveyed, in contrast to parents, McDonald et al. (1982) found that in a survey of physicians across the state of Texas, there were 91% who indicated that they were the initial informant.

When parents were asked who should be the informant, Gayton and Walker (1974) found that all but 4 of 170 parents stated that the informer should be a physician. Generally it was accepted that on medical matters a doctor is the one to present the diagnosis. In the case of informing parents of the birth of a handicapped child, the advantages of having a team approach are in terms of on going support for the parents while the mother and child are in the hospital, and when they go home. For example, if a social worker were included in the team, referrals could be made to community resources, and possibly an introduction of the parents to the resources by the social worker.

Time of informing

It is generally accepted that parents need to be informed of the diagnosis as soon as a definite diagnosis can be made (Carr and Oppe,1971; Green and Soutter,1977; Pueschel and Murphy,1975).

An alternative view is if possible within a one week period of the birth time (Lucas and Lucas, 1980), but not all physicians agree with such a short time span. Emery (1974) contends that it should be a few weeks after the birth. A longer time frame is suggested by Lobo and Webb (1970) which ranges from six weeks to three months. Reasons stated for a six weeks to three months include the need for the mother to regain her normal functioning, and to establish a bond with the new-born child. Should symptoms be recognized by the parents, then the informing should take place earlier. Golden and Davis (1974) further suggest delays in informing parents may contribute to misunderstandings of the infant's diagnosis.

Studies have shown a wide range from 7% - 50% of parents informed within a 24 hour time period after the birth of the child (Gilmore and Oates, 1977; Lucas and Lucas, 1980; Stone, 1973). Two studies (Cunningham and Sloper, 1977; Edelstein and Strydom, 1981) reported one-half the parents were informed within 48 hours of the birth of the infant. In most studies it was found close to 50% of parents reported to be informed approximately the first week after the mothers giving birth to the child (Berg, Gilderdale, and Way, 1969; Carr, 1970; Cunningham and Sloper, 1977; Drillien and Wilkinson, 1964; Edelstein and Strydom, 1981; Gayton and Walker, 1974; Gilmore and Oates, 1977; Lucas and Lucas, 1980; Shiono and Kadowaki, 1979).

Studies reviewed showed that only a small number of parents were not told of the diagnosis by the end of a one-year period.

Parents when asked about a preferred time for diagnostic counseling state that they want to be informed as early as possible (Berg et al., 1969; Carr, 1970; Carr and Oppe, 1971; Cunningham and Sloper, 1977; Drillien and Wilkinson, 1964; Edelstein and Strydom, 1981; Gayton and Walker, 1974; Gilmore and Oates, 1977; Hare et al., 1966; Lucas and Lucas, 1980; Shiono and Kadowaki, 1979; Stone, 1973).

Surveys of medical personnel indicate similar preferences to parents. Jacobs (1962) surveyed 307 medical personnel. Results showed about one-quarter preferred informing the parents within a 24-hour period; this increased slightly to one-third for a time period ending at one week. Approximately three-quarters expressed the opinion that parents should be told within a one year time frame. McDonald et al (1982) found that 88% of the doctors surveyed informed the parents right after the birth of the child.

Parents who were informed early generally were found to express satisfaction with the time of the informing (Berg et al., 1969; Cunningham and Sloper, 1977; Drillien and Wilkinson, 1964; Gayton and Walker, 1974; Gilmore and Oates, 1977). It appears that a delay in informing the parents tends to increase their dissatisfaction with when they were told of the diagnosis (Berg et al., 1969; Cunningham and Sloper, 1977;

Gilmore and Oates, 1977). When delays occurred, parents reported feelings of being cheated, information was being hidden from them, and also complained bitterly of having to inform relatives and friends when earlier had been told the infant was fine (Cunningham and Sloper, 1977). This suggests that early informing may be important to parents because of social contacts. Having to redefine their child's health status may be, in some cases, a contributing factor to a loss of esteem and to social isolation experienced by some parents.

Acceptance of the diagnosis and resultant feelings toward the child may also be related to the time of initial diagnostic informing. Edelstein and Strydom (1981) found that mothers who were informed within 48 hours of the birth of the infant tended to be much more accepting and to have more positive feelings toward the child (Roth Mother-Child Evaluation). These results appear to indicate disclosure time is a factor in determining an attitude of acceptance. Carr and Oppe (1971) suggest it is generally accepted that if parents are to accept their responsibilities for their child, they have a right to know the diagnosis of their infant as early as possible. The literature reviewed would suggest that early informing is the preference of most parents and the recommendation of some doctors. It appears that most parents who were told early expressed satisfaction with the time of the presentation of the diagnosis.

Acceptance was also shown to be positively related to mothers learning of the diagnosis early. A further suggestion to aiding mothers in these areas is to have the baby with her at the time of the informing, or shortly after. Mothers expressed this wish in order that they may have the comfort of holding the child (Cunningham and Sloper, 1977; Green and Soutter, 1977).

In some instances, parents were suspicious of something wrong with their infant prior to being informed. Studies reporting this factor found that one-half of the parents reported these suspicions (Carr, 1970; Cunningham and Sloper, 1977; Drillien and Wilkinson, 1960; Gayton and Walker, 1974). Cunningham and Sloper (1977) reported that nearly one-half of the parents reporting suspicions were assured that all was well with their baby, and many complained bitterly when informed otherwise. These authors raise the question whether it is possible to conceal changes in routine by hospital staff. The change in routine by hospital staff inevitably happens with the birth of a handicapped child. These findings suggest that there is an argument for early informing based on a definite diagnosis, and that often early informing can be a factor in a positive start for the parents.

How are parents told

> "The initial telling in the maternity unit is not merely designed to avoid deceit and deal with immediate emotional reactions, but should also be the first step in gaining acceptance for the child and promoting continuing care" (Carr and Oppe, 1971, p.1076).

The informing interview is a traumatic event; it involves shock, reduction of self-confidence, and a state of bewilderment for the parents (Lucas and Lucas, 1980). Parents, consciously or subconsciously, have some desire and/or want for the informant to give them some sense of worth and importance (Zuckerberg and Snow, 1968). A well-conducted interview may set a firm foundation for further contact with the parents (Drayer and Schlesinger, 1960). To be helpful, the informant needs to be more than sympathetic, he must share the parents' attitudes, and ally himself with the difficulties with which the parents are attempting to cope (Zuckerberg and Snow, 1968).

The diagnosis should be presented in a simple honest, and direct manner. Of importance is that parents are provided with the diagnosis in a way which they will understand (Drayer and Schlesinger, 1960). To this end, the language used in the presentation comes into importance. It should be simple and clear; intellectualizing and the use of professional jargon only tend to create a distance between the informant and the parents (Green and Soutter, 1977). Lucas and Lucas (1980) state that language used at this time is related to feelings of satisfaction or dissatisfaction of the parents with help provided. Patterson (1956),a mother of a retarded child, tells professionals to watch the use of words such as "idiot", "feebleminded", and "moron". It is through wisely chosen words the physician must inform the parents, and simultaneously convey confidence that the parents

have the ability to undertake the responsibilities placed upon them (Carr and Oppe, 1971). The presenter should not be a stranger to the parents, but someone who has a knowledge of the family and their background. Should the informant be a specialist not familiar with the family, the particulars can often be provided by the family physician (Carr and Oppe, 1971). Cunningham and Sloper (1977) suggest that parents have a private room where they can go after the information has been given to them, and that there should be no fear of interruption. The informing interview is a time of intense emotional interchange, but it is not usually a time when there is transference of much knowledge (Carr and Oppe, 1971). The goal of the endeavour is to create a non-threatening and non-judgmental climate (Green and Soutter, 1977). Success of the initial interview is not in the amount of information presented, but in the foundation it lays for further contact with the parents.

Parents expressed a need to be told in a sympathetic and understanding manner. Language should be kept simple and within the comprehension of the parents. There should be opportunity to ask questions, and the diagnosis should be presented truthfully without unjustifiable pessimism or unrealistic optimism (D'Arcy, 1968; Edelstein and Strydom, 1981; Gilmore and Oates, 1977). It was suggested that chromosomal information be available, and addressing questions such as a definition of the condition, is it transmittable, risk to future children, and risk for existing childrens'

children (Cunningham and Sloper, 1977).

It was found that some parents recommended their baby be present at the time of the initial interview, this provides some degree of assurance, and that the informing take place in a private room (Cunningham and Sloper, 1977; Owens, 1964). Some parents reported that they were informed in front of an audience of nurses, secretaries, or students (Cunningham and Sloper, 1977). It would appear that some time alone is important to parents at the time of being informed of the diagnosis.

Studies have found a range of 49% - 80% of the parents were satisfied with the informant and how the informing was handled (Abramson, Gravink, Abramson, and Somers, 1977; Berg et al., 1969; Carr, 1970; Edelstein and Strydom, 1981; Gayton and Walker, 1974; Gilmore and Oates, 1977; Hare et al., 1966; Lucas and Lucas, 1980; Rubin and Rubin, 1980; Shiono and Kadowaki, 1979).

Parents expressed dissatisfaction if the informant was viewed as unsympathetic, abrupt, clinical, casual, or uninformative (Berg et al., 1969; Carr, 1970; Cunningham and Sloper, 1977; Edelstein and Strydom, 1981; Lucas and Lucas, 1980; Rubin and Rubin, 1980; Stone, 1973). Some parents complained the informant was unaware of the physical or mental patterns of the condition (Shiono and Kadowaki, 1979).

Other parents reported that the informant was too pessimistic about the diagnosis (Berg et al., 1966; Gayton and Walker, 1974). Golden and Davis (1974) reported that parents were told their infant would reach few milestones if any. A few parents were told that their baby was "subhuman" (Shiono and Kadowaski, 1979), and Koch, Graliker, Sands, and Parmelee (1959) found that some parents were told "there is no hope - put the baby away and forget him," "other children will be affected if you keep him in the home." It is only a small percentage of parents which are informed as such. A more representative prognosis of the child was found in the Lucas and Lucas (1980) study. Almost half the parents were told the child would be slow, about one-third was told the child would be handicapped, and only 5% were informed the child would be no good at all. Of the studies reviewed, definite diagnostic labels were provided in all cases for the infants' condition. Soutter (1972) suggests that where a definite diagnosis is not able to be made, developmental delay is an honest and meaningful diagnosis which may be used without the attachment of a stigma. Once the diagnosis of mental retardation has been given, it is a difficult diagnostic label to revoke.

Lipton and Svarstad (1977) found that the amount and type of information provided to the parents was related to the physicians' perception of the parents emotional stability, and to the severity of the child's disability. Information was provided as the doctor felt parents could cope with and understand what was being presented.

Hare et al. (1966) found most mothers were unable to comprehend what was told to them soon after the delivery of the infant. This suggests that the diagnosis should be presented in general terms, and a more precise explanation be presented later. Carr (1970) found nearly one-quarter of the parents felt that informing of the diagnosis was an inevitable ordeal. It has been suggested that the way parents are informed can have a profound effect on their emotional state and their acceptance of further help (Cunningham and Sloper, 1977).

Reasons for negative experiences were information had been presented in an unkindly manner, it may be due to the informants own anxiety of having to impart distressing news (Green and Soutter, 1977; Hare et al., 1966). Although physicians are regarded as the source of relevant information, they may not do well at presenting the diagnosis (Olshansky, 1966; Pueschel and Murphy, 1975).

The interactional model accommodates stress which may be experienced by some physicians who are in the position of having to inform the parents. Other professionals would be present to assist with answering questions, and to meet the emotional needs of the parents. As stated previously the physician is often viewed as the primary source of relevant information, but parents needs go beyond the initial informing. Parents need an opportunity to vent their feelings and anxieties as well as referrals to community resources. Pueschel and Murphy (1975) suggest that a social worker may be utilized by

a doctor when presenting the diagnosis to the parents. A social worker may be able to assist the parents with their emotional state, and also serve as a link to community resources. Informing the parents is but a beginning process which should lead to involvement with other professionals (Carr and Oppe, 1971).

Self-help groups may assist parents with their emotional needs, acceptance of their child, and learning to cope with the difficulties of having a handicapped child in the home. Parents expressed a wish to meet with parents of children with a similar problem. Over one-third of the parents of the Gilmore and Oates (1977) study recommended such a parent be part of a crisis team which could present the diagnosis. Whether parents are informed by a single individual, or a team approach, one thing seems clear; it is only the beginning of a long process. Miller (1968) suggests that counseling the parents of a mentally retarded child is almost a life long process. The person who tells parents of the birth of their handicapped child should be mindful of the significance of the news he is about to impart. Consideration must be given to the parents as individuals and their needs at that time. Unfortunately, no matter how humanely the information is presented, the parents may not be able to accept it (Carr and Oppe, 1971), but professionals should nevertheless be aware of the need for a sympathetic and understanding approach to the parents at this time.

Initial shock

Lobo and Webb (1970) suggest that the birth of a Down's Syndrome infant has an impact upon the parents for two reasons. First, there is early recognition of the distinctive features, and secondly, the association of this condition with mental retardation is well-known. When reasons such as these are combined with little or no knowledge of the condition, it would be reasonable to expect most parents express some emotional reaction to the birth of a handicapped child. Stone (1973) found that all mothers reported feelings of shock upon being informed of the diagnosis. Other studies reported that 72% - 83% of parents experienced similar feelings of shock (Carr, 1970; Gilmore and Oates, 1977; Shiono and Kadowaki, 1979). Studies report that most mothers felt they were over the initial shock by the end of the first month after the birth (Cunningham and Sloper, 1977; Edelstein and Strydom, 1981); a small percentage of the mothers took as long as the end of the first year to recover (Edelstein and Strydom, 1981).

Various other reactions were expressed by the mothers of the studies reviewed. Stone (1973) found that about two of every five mothers expressed feelings of guilt over the birth of a handicapped child. Studies have also shown that mothers feared a rejection of the infant (Gilmore and Oates, 1977; Lucas and Lucas, 1980; Stone, 1973), and feelings of resentment and anger (Stone, 1973).

More extreme emotional reactions were a wish that the infant would die (Gilmore and Oates, 1977; Lucas and Lucas, 1980). Stone (1973) reported that about one-eighth of the mothers had feelings of infanticide. The studies surveyed reveal the traumatic event of the birth of a retarded child causes various emotional reactions immediately after the informing of the diagnosis.

Second opinion sought

Green and Soutter (1977) suggest that parents need on going support from the time the diagnosis is presented. The lack of support may contribute to a denial of the diagnosis, and to a pattern of "shopping around" for a more favourable view of the child's problem. Of the studies reviewed, only four reported information regarding the seeking of a second opinion. In three studies, the proportion of parents seeking a second opinion was about one in four (Carr, 1970; Edelstein and Strydom, 1981; Gilmore and Oates, 1977). Cunningham and Sloper (1977) found that no parents of their sample actively sought a second opinion.

Reasons given for seeking a second opinion included seeking a more sympathetic view of their situation, seeking a physician who could provide a more complete explanation of Down's Syndrome, and a person who could provide assistance with community referrals.

Some parents sought another opinion after originally being told that the infant was fine, but later informed that the baby was a Down's Syndrome child. Another reason was a hope by the parents that the informant was mistaken in his diagnosis.

Cases of these four studies reporting on parents seeking a second opinion represent the birth of 149 children with mental retardation. Only 24 cases (16%) actively sought a second opinion. Therefore, it appears that while parents may express dissatisfaction with how they are informed, in general they do not actively engage in obtaining a second opinion.

Referrals to community resources

Parents need the reassurance that when the mother and child are discharged from the hospital, there will be further assistance available (Lucas and Lucas, 1980). Referrals can be suggested to the parents at the time of informing of the diagnoses, and this may well provide a measure of reassurance in view of the traumatic event which has just occurred. Owens (1964) recommends a referral to the local public health nurse, and a visit be arranged for soon after the parents have taken the child home.

A few studies reported referrals to community resources. The percentage of parents referred ranged from the low thirties to the mid-sixties (Edelstein and Strydom, 1981; Gilmore and Oates, 1977; Lucas and Lucas, 1980).

Referrals were made to facilities which provided literature, and social work involvement as well as contact with other parents who have a child with a similar condition. Lucas and Lucas (1980) found that the failure to put the parents in touch with other resources led to dissatisfaction with the informing process by the parents. Gilmore and Oates (1977) requested suggestions for better management of the informing from the parents. The two main suggestions were contact with community facilities (64%), and contact with other parents of retarded children. Similar suggestions were found in other studies (Cunningham and Sloper, 1977; Edelstein and Strydom, 1981; Gayton and Walker, 1974). In contrast to this situation, Graliker, Parmelee, and Koch (1959) found that community referrals were largely ignored by the parents. This study differs from the previous studies in that the diagnosis was not made and presented until after the parents had the child at home.

McDonald et al. (1982) reported that 87% of the physicians surveyed made referrals to community resources. Patterson (1956) suggests that it is important for professionals to be aware of resources available in their community. The assistance needed by parents of handicapped children extends far beyond the help provided while mother and child are in the hospital.

In summary, the studies reviewed showed that parents were satisfied with professional help at the time when the diagnosis was presented if certain conditions were met.

Generally satisfaction was expressed by the parents if the information was presented in a clear, honest, and compassionate manner. Parents who were found to be critical of the informant usually viewed the informant as being unsympathetic.

The majority of parents expressed a desire that both parents should be present at the informing, and that the informing take place as early as possible. Early informing of the parents was found to be helpful with parental acceptance of the child, and to an adjustment to a new life style with a handicapped child as a member of the family.

Parents of previous studies expressed a desire for practical assistance prior to mother and child leaving the hospital. Two main areas were identified. Referrals to community resources, and referrals to organizations of parents with children having a similar condition.

It was found that none of the literature reviewed for the present study examined the opportunity for parents to express the feelings being experienced at the time when the diagnosis was presented. Mothers, in some studies, were asked if they experienced shock at learning of the diagnosis, and most studies, which included this aspect, reported that mothers felt they were over this shock by the end of the first month after the birth of the handicapped child. There were no reports of the informant attempting to help parents express their feelings, and no studies reported

an attempt to examine the feelings of the fathers. Only a few studies were found which included responses from fathers. The majority of study populations were made up solely of mothers of a handicapped child. The present study differs from most previous studies on these two aspects. The opportunity for parents to express their feelings was examined, and the responses of the fathers was sought as well as the responses of the mothers. In this present study, the focus was on obtaining the views of both parents on selected areas of the informing process.

Problem statement

The purpose of this study was to evaluate the satisfaction of parents with professional help received at the time of the diagnosis of their mentally retarded child. Satisfaction was defined as the parents viewing the professional help received as appropriate and meeting their needs at the time of diagnosis. The satisfaction of the parents was measured by a questionnaire which evaluated parents perception of the appropriate timing of the informing interview, perception of the informant(s), expressions of caring and understanding, and helpfulness; parents' satisfaction with the amount of information which was provided and the opportunity to express their feelings; and perceptions of the adequacy of referrals for follow-up services.

In all instances it was the parents' perceptions and evaluation of these factors which were sought. The study attempted to answer the question "How satisfied are the parents of a retarded child with professional help received at the time of diagnosis?"

METHOD

This study sought to replicate and expand upon previous studies investigating parental reactions to the diagnosis of mental retardation of their child. An attempt was made to obtain a comprehensive description of this reaction including time and place of informing, characteristics of the informant, and referrals to community resources. In addition to these areas found in previous studies, the opportunity for parents to express the feelings being experienced at the time of the informing was also examined. In all cases, there was an attempt to obtain the views of both parents of the handicapped child's family.

This replication involved a province-wide sample of parents serviced by the Infant Development Program of the Province of British Columbia. It was from these parents that data was obtained in order to gain a description of parental reactions to the diagnosis of a child with mental retardation.

Level of research design

The level of research design for this project was that of a descriptive study. The rationale for this approach was that the study did not attempt to test a hypothesis, but rather sought to answer a research question. The aim of a descriptive study is to gather complete and accurate information regarding a particular situation (Sellitiz, Wrightman, and Cook, 1976). In this investigation, the purpose was to elicit the views of the parents pertaining to characteristics of the informant, time and place of diagnostic counseling, and the opportunity for expression of feelings by the parents.

Sampling design

The population of interest for this study were parents of children between the ages of 0-3 years, who were diagnosed as mentally retarded. The lowest age range recorded by the Ministry of Health is 0-4 years, but no figures were published for 1979, the year of this study. The distribution for years 1978 and 1980 of such children by sex and level of retardation for these years is presented below in Table I.

TABLE I

MENTAL RETARDATION; AGE 0-4 YEARS, 1979, 1980

	YEAR END 1978			YEAR END 1980		
	MALE	FEMALE		MALE	FEMALE	
BORDERLINE	7	5		3	1	
MILD	3	6		1	4	
MODERATE	10	2		1	4	
SEVERE	10	6		8	5	
PROFOUND	1	-		2	2	
UNSPECIFIED	127	112		152	124	
T =	158	131	= 287	167	140	= 307

(Ministry of Health 1980,1981)

Most studies of this area are concerned mainly with Down's Syndrome infants. The number of Down's Syndrome births for 1979 were 51 (SEE TABLE II), and the number of Down's Syndrome children, 0-4 years, residing in the Province of British Columbia were 154 for the year 1978 (SEE TABLE III). These figures represent a minimum population as there were cases which were not reported to the Ministry of Health.

TABLE II

DOWN'S SYNDROME BIRTH; 1978 + 1979

	MALE	FEMALE	TOTAL
1978	27	20	47
1979	32	19	51

(Ministry of Health, 1980, 1981)

TABLE III

DOWN'S SYNDROME - 0-4 YEARS, 1978-80

	MALE	FEMALE	TOTAL
1978	89	65	154
1980	93	78	171

(Ministry of Health, 1980, 1981)

The Infant Development Program of the B.C. Association for the Mentally Retarded provided an accessible population for this research project. This agency provides services throughout the Province of B.C. to parents of mentally handicapped children between the ages of 0-3 years. An occasional family receives services beyond the child's third birthdate. Approximately 700 families constitute the total caseload of the Infant Development Program (Brynelsen, 1983). Many of the children of these families were diagnosed as developmentally delayed. A total of 65 families from the families serviced by the Infant Development Program were found to be eligible for participation because they met the criteria of a definite medical diagnosis of mental retardation was provided for their child's condition. Table IV presents families eligible, families provided with questionnaires by participating Infant Development Programs.

TABLE IV

PARTICIPATING INFANT DEVELOPMENT PROGRAMS

	FAMILIES ELIGIBLE	FAMILIES VIEWED AS INAPPROPRIATE	FAMILIES GIVEN QUESTIONNAIRES	REFUSALS
Burnaby	2	-	2	-
Duncan	5	-	5	-
Kelowna	2	-	2	-
New Westminster	7	-	7	-
North Vancouver	8	-	8	-
Surrey	10	5	4	1
Upper Fraser Valley	6	-	6	-
Vancouver-Richmond	20	10	10	-
Victoria	5	-	5	-
T =	65	15	49	1

In the Province of British Columbia there were 12 Infant Development Programs in operation. One program had just recently come into being, and it was decided not to use this program as the worker would be relatively new to the parents. Approval was obtained from 11 programs for their participation in this study. Approval letters are found in APPENDIX. Subjects for this study therefore came from various locations within the province, but mainly from the Lower Mainland area.

Originally a sample population of 110 cases was intended for the present study. Through random sampling procedures 10 cases were to be selected from each of the 11 participating programs. However, on the basis of information obtained from Infant Development Program workers at a meeting on April 27, 1979 it was determined that only a fraction of families met the criteria of a definite medical diagnosis for their child's condition. Therefore, workers were requested to deliver the questionnaires to as many families in their areas as met this criteria. This method yielded a total of 65 families. Fifteen families were viewed by the workers as inappropriate to participate, and questionnaires were given to 49 families. One family which was presented with a questionnaire declined to participate (SEE TABLE IV). Families were viewed as inappropriate if the Infant Development Program worker felt that it would be upsetting for them to participate in this study. It was recognized that participation in the present study could cause emotional stress for the parents, and as a precaution

to this happening, the decision as to which families were provided with questionnaires was to be that of the program workers.

It is likely that the population of this study represents a selected sample of parents of retarded infants. The parents of this study have had the benefit of a trained professional assist them with coping at the birth of their handicapped child. Their feelings and views may have been modified by this factor. Therefore, views and feelings expressed by parents who have not had the benefit of this service may be considerably different. The parents of this study were located in reasonably well-populated areas which would possibly offer more services than would be available to parents in more rural areas of the province. These factors may have influenced the parents recall and memory of how they view and feel about what took place at the time the child's diagnosis was presented.

The data obtained from this population was not viewed as appropriate for generalization to all parents which gave birth to a child with mental retardation. Therefore, the prime focus was one of direction for better service to parents and further investigation into the informing process as opposed to generalization of the findings to the total population of parents who have experienced the birth of a handicapped child. Cunningham and Sloper (1977) concur with this position. It is suggested that extreme caution is

needed when generalizing from such data as no rules can be given, but only guidelines offered.

Instrumentation

The questionnaire constructed for this study covered three main areas. These were: (1) time and place of the informing, (2) characteristics of the informant, (3) opportunity for the expression of feelings by the parents. Parents were asked to describe where and when they were informed, and by whom. Information about the clarity of presentation, level of language used, and mode of informants referral to community resources was sought. A portion of the questionnaire queried the opportunity for parents to express their feelings during the informing interview as well as to seek clarification of the diagnosis presented. Through these areas, it was sought to obtain a measure of satisfaction of the parents with the manner by which they were informed of the birth of their handicapped child. A general measure of overall satisfaction was also included.

The literature on diagnostic counseling for parents of mentally retarded infants has indicated that the three areas of clarity of presentation, level of language used, and opportunity for expressions of feeling are of importance. The values of the social work profession also affirms the need for clarity of presentation, the opportunity for expression of feelings, the opportunity for client participation in the process, and the need for professional follow-up services.

Professional staff working with parents of mentally retarded children also indicated that these areas were salient to their practice.

The instrument used for data collection was a semi-structured questionnaire. Most questions were fixed responses with a few open-ended questions. The sample population for this study was over a wide geographical area, and the questionnaires were to be delivered by local workers. This format used was,to some degree, dependent upon the motivation of the respondent and the amount of effort required to complete the measuring instrument. This type of questionnaire could be completed within a reasonably short time period, and therefore,it was felt that more parents would be willing to take the time to complete it. Also, this type of instrument can be coded, and the computer utilized in the analysis of the data obtained with relative ease.

A pretest was conducted by having three parents of mentally retarded children each complete a questionnaire. These parents had a handicapped child who was over the age range of the present study, and these families were not serviced by the Infant Development Program. Access to these parents was obtained through the Vancouver-Richmond Association for the Mentally Retarded. The parents expressed no difficulty in completing the questionnaire as to content or wording.

After this was completed, the questionnaire was modified by the addition of three more questions. The original questionnaire asked if professional jargon was used during the informing interview. A question was added to learn if the professional jargon was within the level of understanding of the parents.

Two further questions were added. One asked if the parents had changed doctors since the diagnosis had been presented. The other question asked if so, how did the parents decide on the new physician. These were added to provide a new dimension to the present study.

The present study did not directly replicate any of the other studies found in literature. The areas of focus revealed in the survey of literature such as parent told first, diagnosis presented in a sympathetic manner, and areas of satisfaction with the informing process were made the central theme of the present study. The items of the measuring instrument were designed to elicit the desired information as based on information presented in literature pertaining to the informing of parents at the birth of a handicapped child.

Literature shows that two approaches are taken for the sample population in studies on the informing process. Some studies focus on the responses of mothers only, and others attempt to obtain the views of both parents. Often the father appears to be a forgotten person at the birth of a handicapped child.

The fathers views were considered to be of importance, as their views may differ from that of their spouse regarding the same situation. It was decided that since questionnaires were being delivered to the parents by an Infant Program Development worker, an attempt would be made to obtain the views of both parents. Packages containing two identical questionnaires and one sheet of questions for demographic data were assembled for distribution by the workers.

Permission to carry out this research was granted by the Provincial Coordinating Committee of the Infant Development Program. Further approval was sought and obtained from the local Infant Development Programs. The approval form is to be found in APPENDIX C. The University of British Columbia Behavioral Science Screening Committee granted approval for this project. The certificate from that committee is located in APPENDIX A.

Validity

The validation of the questionnaire used in the present study was based on face validity. The purpose of the study was descriptive and no questionnaire items were designed with underlying meaning or to assess a trait of the respondent. Items of the questionnaire were worded in a simple and straightforward manner. Respondents were asked to provide their agreement or disagreement with the statements presented.

It was fully realized that face validity is the weakest form of validation for a measuring instrument, but for the purpose of the present study, it was considered sufficient as the purpose of the study was straightforward in nature.

Reliability was based on the examples of questions and information provided by studies conducted in the past. Construction of the questionnaire utilized in the present study was based on information concerning areas of focus of previous studies, and examples of questionnaire items of past studies. It was accepted that because previous research has considered the informing process a valid area of research, and has conducted such research, the types of items of the questionnaires would be reliable to some degree. The items of the questionnaire were in simple language, and were meant to gather information of a descriptive nature. Again, this is recognized as a weakness of the present study, but under the circumstances it seemed sufficient as there was no attempt to measure underlying concepts or traits.

Parents recall of their child's development and their own accompanying feelings have consistently demonstrated high levels of inconsistency. Studies have shown that inaccuracy of parental recollection of developmental data was frequent (Pyles, Stolz, and MacFarlane, 1935).

Brekstad and Skard (1960) found that parents' recall of developmental data was more reliable than their recall of previous responses to attitudinal questions. Similarly, Robbins (1963) found responses from both parents concerning developmental data to be inaccurate most of the time. Glidewell, Gildea, Domke, and Kantor (1959) obtained a 70% agreement between information given to mothers, and their latter reports, but only at the end of a one-year period. Graham and Rutter (1968) found that information obtained from mothers pertaining to assessment of childhood behavior was accurate with some degree, but only up to a one-year period.

It has been further suggested that memories become coloured by subsequent events, and by the feeling the parent has toward the child. Memory distortions are less likely to occur when the events being examined are in the recent past (Graham and Rutter, 1968).

This distortion of recall is clearly a factor to be considered in this study. Parents were asked to recall views and feelings which took place up to three years in the past. It was recognized in developing this study that time and events do change a persons thoughts and feelings. Even having experienced a traumatic event as the birth of a handicapped child, most parents have come to live with what has taken place. It would have been desirable to check the

information sought against some type of recording or file completed at the time, however, this was not available. The validity of the present investigation, therefore, rests upon the honesty and truthful recall of the reponses of the parents. In this present study, total reliance is placed upon the memory and the ability of the parents to recall views and feelings at the time of diagnostic informing. This is admittedly a weakness of the study, but under the present circumstances, it was the only alternative available.

RESULTS

A total of 49 families were given questionnaires, but data were obtained from 25 families. From these 25 families, questionnaires were received from all the mothers, but only 15 fathers responded. Two of these families were known to be single parent families with only the mother in the home. Demograhic data were obtained from 24 families. The response rate for mothers was 51%, and the response rate for fathers was 32%. Of the two parent families which responded; there were 35% of the fathers which did not choose to participate in this study.

Each parent was provided with a questionnaire to complete. A separate sheet was provided for the demographic data. The information was sought in this manner so that the responses of the parents could be compared as to the views of mothers with those of the fathers. This method also provided for the combining of the responses of the mothers and fathers for statistical analysis between questionnaire items.

Data obtained from the questionnaires was analyzed by the utilization of the SPSS:9 computer program at the facilities of the U.B.C. Computer Centre.

Demographic data

The handicapped children in this study were predominantly male (67%) with a minority of females (33%). The average age at the time of the study was 1.5 years, ranging from 13 weeks in age to 3.5 years.

The primary diagnosis was Down's Syndrome (52%) with Cerebral Palsy, Infantile Convulsions, Microcephaly, Trisomy Five being the other diagnosis.

Family size ranged from the handicapped child being the only child (6) to a family with four siblings to the mentally retarded child (1). In only two families was the handicapped child the first born with one other sibling. The mentally retarded child was a latter born child in all other families. One handicapped child had an older sibling which was affected similarly. In 12 families of this study there was one sibling to the handicapped child, in two families there were two siblings, in three families there were three siblings, and in only one family there were four siblings.

The mothers age range was found to be 22 - 42 years with a mean of 31 years. Of this, 44% of the mothers were 30 years of age or younger, 75% were found to be 35 years or younger. The educational level for the mothers was found to be that 30% were high school graduates while 35% were post-secondary school graduates. A further 22% had some high school education. The most frequent occupation for mothers was that of a housewife; only 18% were actively employed.

The age range for the fathers was found to be 24 - 41 years with a mean of 32 years. It found that 29% of the fathers were under the age of 30 years, and 76% were under the age of 35 years.

The occupations were found to range from farming to managerial and professional positions. There were no high areas of concentration as was found with mothers. The fathers educational level was found to be that 52% were post-secondary graduates, 24% had some post-secondary education, and 5% were high school graduates.

It was found that 16 of the 24 families had incomes in excess of $20,000 per year, and only two families reported incomes of less than $10,000 per year. Of the 24 families reporting demographic data, 22 were married, one was a divorced family, and one was a single mother family.

Global satisfaction

Mothers and fathers had divergent views on their overall satisfaction with the manner by which they were informed. The rate for mothers was 38%, and for the fathers the rate was 60%; this produced a combined rate for the parents of 46%. Three times as many mothers (21%) were undecided as were fathers (7%) on this question. Overall satisfaction produced some significant results when cross tabulated with other items of the questionnaire.

Presentation of information

In the majority of cases (60%), it was the mother who was informed first. The father was the first informed in only 13% of the cases, and parents were told together 28% of the time.

Parents preferred that both parents should be at the initial informing together (70%), but 24% of the mothers expressed a desire to be the first told as did 20% of the fathers. Exactly half of the parents were in agreement with the parent who was initially told by the informant. Satisfaction with sequence of parental informing was highly associated with overall satisfaction. This relationship reached statistical significance ($x^2 = 8.5$, df=1, $p. > 0.01$).

Parental agreement with which parent was informed first appears to be related to how the parents feel about the appropriateness of the time of the presentation of the diagnosis. As parents were equally divided on the agreement with the parent told first, similarly close to half of the parents were in agreement that the time of presentation of the diagnosis was appropriate ($x^2 = 6.1$, df=1, $p. > 0.01$). It was also found that the parental agreement with which parent was initially informed was significantly related to the appropriateness of the time of presentation in the data obtained from the mothers ($x^2 = 4.4$, df=1, $p. > 0.04$). Parents who were in agreement with which parent told first were similarly in agreement on the time of the presentation of the diagnosis.

Parents were almost equally divided as to the appropriateness of the time of presentation of the diagnoses. It was found that 45% of the parents thought the timing was appropriate and 43% thought it was not.

Mothers were found to be in agreement 40% of the cases and in disagreement 52% of the cases. Almost twice as many fathers were in agreement with the timing (53%) as disagreed (27%). Many more fathers were undecided on this point (20%) as were mothers (8%). A cross tabulation between overall satisfaction and the combined rate for the parents produced highly significant results (x^2 = 14.24, df=1, p.>0.001). These results obtained show that parental satisfaction in both areas were below the midpoint, and demonstrate that appropriateness of the time of presentation is an integral part of overall satisfaction.

One-half (50%) of the parents were informed of their child's diagnosis within the first week after the birth. By the end of a six month period 70% had been informed, and the figure for the end of the first year was 93%. Only two cases went beyond the one year time period, and only one of these cases were not informed until after the child's second birthdate.

Parents overwhelmingly rejected the notion that the information be presented at a later time. Virtually all mothers rejected this notion, as did 72% of the fathers. But, parents were far less sure that the diagnosis should have been presented earlier. Only 35% of the parents were in favour of earlier presentation of the information, but 22% were undecided on this point.

Fathers overwhelmingly rejected this idea as only 14% were in favour, but 22% were undecided. Mothers were much more in favour of an earlier presentation (48%), and 17% were undecided. The low agreement of parents on an earlier presentation of the diagnosis, and similar results on the appropriateness of the time of the presentation of the information produced highly significant results (x^2 = 11, df=1, p.>0.001). Results show that most parents were very unsatisfied in both areas.

Almost all parents (85%) were informed by a single person; 13% of the parents were informed by two persons, and only one mother was informed by three people. A pediatrician was the most frequent informant (55%), and a general practitioner was the informant 25% of the time. In cases where there was a second informant it was a pediatrician (4), neurologist (2), social worker (1), nurse (1), and in the case where there were three professionals present, it was a neurologist.

It was found that a second meeting with the informant was arranged for 65% of the parents. Mothers responded affirmatively (56%) considerably less than did fathers (80%). Most frequently the meeting was arranged by a general practitioner or pediatrician (69%).

Parents recommendations for professions presenting the diagnosis was in favour of a physician (general practitioner, 53%; pediatrician, 34%). Their second choice was even more pronounced than their original choice (pediatrician, 63%;

social worker, 19%). A few parents went as far as recommending a third profession be present. Professions recommended were psychiatrist, social worker, and minister.

The length of time for the interviews ranged from two minutes to an hour and one-half with a mean of one-half hour. Most of the parents were informed in a hospital setting. Almost half the parents were informed on the maternity ward, and one-quarter of the sample were informed on the pediatric ward. Only a few (10%) were informed in a doctor's office, and only one father was informed at home. The most unusual place to be informed was in the board room of the hospital; it was a mother who was informed here.

There was considerable diversity of opinion amongst the parents studied in relation to the novelty of the information presented. Parents were divided on this matter. Most parents (60%) agreed that the diagnosis was a surprise where as one-third did not express this opinion. Examining percentages for parents separate shows a wider divergence. Mothers were more equally divided than fathers were. It was found that 52% of the mothers expressed surprise, and 40% did not agree that it was a surprise. The percentage spread for the fathers was vastly greater; 73% were surprised and only 20% were not.

Three-quarters of the parents were of the opinion that the diagnosis was presented in a sympathetic manner. Fathers (80%) felt that the information was presented with clarity more often than did mothers (64%).

The combined percentage for parents was 70%. Parents (78%) did not feel the language used was technical. The response rate for mothers (88%) was much higher than that of the fathers (60%). Nor did parents feel professional jargon was utilized (80%). Again, the response rate for mothers (88%) was significantly higher than fathers (67%). On this matter one-fifth of the fathers were undecided. If professional jargon was used, then the parents overwhelmingly perceived it to be within their level of understanding (parents, 84%; mothers, 83%, fathers, 87%). Parents vastly disagreed on the ease of understanding the information presented. Fathers (80%) more often agreed that the information was easy to understand than did mothers (52%). The combined rate for the parents was found to be 63%. Significant results were found when a cross tabulation of the parental responses was performed on overall satisfaction and the information presented was not easy to understand ($x^2 = 4.8, df=1, p. > 0.03$). Results show parents who found the information presented easy to understand also expressed satisfaction with the informing process.

The majority of parents (73%) found the information presented was helpful with understanding their child's condition. The responses of the fathers (80%) was somewhat higher than that of the mothers (68%). These percentages dropped when parents were asked if the information was helpful with understanding the future growth and development of their offspring.

Only 38% of the parents felt it was helpful. It appears that this aspect of the information presented is significantly related to the information being easy to understand (x^2 = 5.1, df=1, p.>0.03). It would appear that parents who did feel the information on the prognosis of the child was helpful similarly did feel the information presented was easy to comprehend.

Less than half (45%) of the parents thought the informant made an attempt to determine their knowledge of their child's condition. Again, a significant number of fathers were undecided on this issue (27%). The attempt to determine the knowledge of the parents was significantly related to overall satisfaction with the informing process (x^2 = 7.6, df=1, p.>0.01). Results show that parents who were satisfied with the attempt to determine their knowledge by the informant were also satisfied with the overall satisfaction of initial interview. Furthermore, the attempt to determine the parents knowledge of their child's condition is of importance in relation to the appropriateness of the time of presentation (x^2 = 6.2, df=1, p.>0.02). Parents who felt there was an attempt by the informant to determine their knowledge were in agreement that the time of the presentation of the diagnosis was appropriate.

Most parents (70%) felt that there was no encouragement to ask questions of the informant. In contrast, two-thirds

of the parents felt that they were encouraged to seek clarity of the information presented. It would appear that more fathers (79%) were given encouragement than mothers (60%).

Slightly over half (58%) of the parents did not feel a complete explanation was provided. This factor when a chi-square was performed of overall satisfaction by incomplete explanation given came close to being significant ($x^2 = 3.6$, df=1, $p > 0.06$). It was also found that the same percentage (58%) of parents who felt the informant was certain concerning the facts regarding the child's condition. Of note on this point is that one-fifth of the parents were undecided, but fathers (73%) appeared to be more confident as none were undecided. Mothers were far less confident with a rate of 48% with 32% of the mothers undecided. Parents were asked if the informant was not certain about the prognosis. There was total agreement between parents on this matter. The combined rate was 68% with the same percentage for the mothers and two less for the fathers.

Most parents (70%) were not asked what they were feeling at the time of the initial interview, but it was found that 35% felt they had an opportunity to express their feelings. The opportunity to express their feelings was found to be significantly related to two other aspects of this study.

Cross tabulations of a chance to express feelings by an incomplete explanation given (x^2 = 4.9, df=1, p.>0.04), and overall satisfaction with the informing process by a chance to express feelings (x^2 = 7.6, df=1, p.>0.01) produced significant results. Results show that parents are dissatisfied when an incomplete explanation is provided and they are not given an opportunity to express what they are feeling at the time. It was also found that the lack of opportunity to express their feelings was associated with a high rate of dissatisfaction. Again, it was found that a sizable portion (20%) of the fathers were undecided regarding an opportunity to express their feelings.

In general, fathers were less critical about the way in which the diagnosis was presented to them. One-third of the fathers felt the situation was handled well and nothing could have been done to improve it. Suggestions for improvement from the fathers were: (1) informant should have been more careful about the timing, (2) present the diagnosis with some hope, (3) provide more information on testing procedures, (4) inform both parents together. The most critical complaint was from a father who sat in a small room for one-half hour. The hospital staff kept looking in at him as they passed by, and he would ask questions but was provided with no answers. He felt someone should have been there to inform and assist him.

Mothers were much more critical of the initial interview. Only five mothers felt nothing could be done to improve the presentation of the diagnosis. Some mothers were provided with literature, and one mother had a social worker come and explain support services which were available. Another mother complained that support services should have been made available without her having to search out these services. One mother told of her husband being told the infant was healthy, and that night sharing the good news with friends and relatives. The next day he was informed that the child was mentally handicapped. Two mothers were not happy with the initial interview taking place on a hospital ward, but felt a quieter place would have been more appropriate. A mother perceived the physician as nervous, uncomfortable, and had a lack of knowledge on the child's condition as well as community resources. Another physician was seen as being evasive. The mother felt time should have been spent answering questions, and the diagnosis should be presented as honestly as possible. Two mothers felt that a more optimistic view could have been presented. One mother was critical of the nurse who informed her. This took place while the mother was feeding the infant, and the mother felt that the presentation of the diagnosis should have been left to the doctor. The harshest comment made was to a mother. She was told her child would be a vegetable.

Most parents stated that unanswered questions, which they still have at the present time, centre around the future growth and development of their child. How will he be able to care for himself in the future? A few parents had questions concerning causation and will it occur again. One father questioned how a family is expected to maintain the child in the home without adequate government support, but the majority of parents expressed concern over the child's future.

Parents were requested to state what profession they would choose if they wanted to discuss their child's condition at the present time. Of the parents who responded, their first choice was a pediatrician (53%), and their second choice was a general practitioner (19%). Their second choices were Infant Development Program worker (63%) and social worker (25%).

The study also revealed that few parents reported changing doctors. Only two parents stated that they were unhappy with the first doctor, three stated the new doctor was more informed, and only one parent stated the reason as the new physician was more understanding.

Practical assistance

Just over half of the parents (58%) were given practical suggestions on how to cope with a handicapped child. Practical suggestions made when cross tabulated with the provision of information regarding community resources produced highly significant results ($x^2 = 15.9$, df=1, $p. > 0.001$).

Parents who were provided with practical suggestions for caring for their child were also the parents who were told of community resources. Three parents were referred to the Association for the Mentally Retarded, 16 parents were referred to the Infant Development Program, and two parents were referred to the Variety Treatment Centre. Only two parents reported being referred to a government agency. One was referred to a public health nurse, and the other to the Ministry of Human Resources. Information on community resources was found to be significantly related to the overall satisfaction of the parents with the informing process ($x^2 = 6.96$, df=1, $p. > 0.01$). Parents who were provided with referrals to community resources were also satisfied with the overall manner by which they were informed of the diagnosis.

The vast majority of parents sought help as soon or shortly after being informed of the diagnosis. There were 37 parents who were informed of the diagnosis within the first year of birth, 36 parents reported seeking assistance within the same time period. Therefore, it appears that once parents are informed there is a need felt for immediate further assistance.

DISCUSSION

Prior to 1960 little knowledge was known about the preference of parents regarding the manner by which they were informed of the birth of a handicapped child (Gilmore and Oates, 1977). Since this time, studies have been conducted in various parts of the world such as the British Isles, U.S.A., South Africa, Japan and Australia. Most studies attempt to gain some measure of overall satisfaction with the informant and the initial interview. Previous studies have generally obtained results that indicate parents were satisfied somewhat over 50% of the time. Only two studies (Abramson et al., 1977; Rubin and Rubin, 1980) reported results below this mark. These latter results more closely approximate the results of the present study. The overall satisfaction of the parents of this study was found to be significantly related to the ease of understanding the information presented, an attempt by the informant to determine the parents knowledge of their child's condition, completeness of the explanation provided, appropriateness of the time of the presentation, and the opportunity for the expression of feelings being experienced by the parents at the initial interview. These areas, in the majority, are connected to the internal state of the parents, and not to direct characteristics of the informant such as being sympathetic, using understandable language, and the clarity of the information being presented.

These results of this study indicate that low overall satisfaction related to similarly low evaluations of other areas. It was the experiential aspects of the informing interview which also produced lower percentages of satisfaction of the parents. This would seem to indicate that the parents of the present study associated overall satisfaction more closely with the feeling being experienced at the informing interview, and not with the more concrete aspects of the informant. As no studies were found which reported findings concerning the feelings of the parents, a comparison cannot be made with previous research, but from the results of this study, it would appear to be an area worthy of consideration.

This raises a further question. If parents had not been requested to recall their feelings and areas of participation in the interview, would the overall satisfaction rate have been higher? Maybe so, for if parents were only asked about characteristics of the informant, then it may not have raised as many of the emotional aspects of the presentation of the diagnosis. It is of note that the rate of overall satisfaction of the fathers (60%) was somewhat higher than that of the mothers (38%). Of further interest is why were three times as many mothers (21%) as fathers (7%) undecided when asked about overall satisfaction with the informing interview.

Because of the structure of the measuring instrument, answers to these questions cannot be provided, but these questions may be worth consideration for further research.

The need for a sympathetic approach to informing parents is highly supported in literature. Language and communication skills have been identified as important aspects of the informing interview. Early informing has also been identified with avoidance of misunderstanding by the parents and with parental satisfaction (Cunningham and Sloper, 1977; Drillien and Wilkinson, 1964; Golden and Davis, 1974; Pueschel and Murphy, 1975). The present study revealed that most parents expressed satisfaction in these areas, but as stated previously, not a high rate of satisfaction on an overall rating. This finding tends to further suggest that while parents may be satisfied with how the informant handles himself and presents the information on a technical level, these areas did not influence the global rating of the interview. These results appear to further affirm that more consideration may be needed in the areas of parental participation in the interview.

It is evident that in literature there is a strong preference for early informing of the parents by both professionals and parents. Half the parents of the present study were informed within a one week period after the birth of the child. Only a few studies reported findings of less than 50% (Berg et al., 1969; Carr, 1970; Shiono and Kadowaki, 1979; Stone, 1973).

The finding that nearly all parents were informed of the diagnosis by the end of the first year appears to be consistent with most other studies. Only 35% of the parents thought the diagnosis should have been presented earlier, but one-fifth of the parents were undecided on this point. In contrast nearly all parents were in agreement that the information should not have been presented later. Out of the findings on these aspects of the initial interview, it is of note that a large number of parents were undecided on an earlier presentation of the diagnosis. If this were examined further what would the reason be. The fact that parents were not in favour of a later presentation would not appear to support their feeling that the mother needs time to regain her strength. Since half of the parents were informed within the first week, it may be that for many parents the exact time of presentation was not a salient factor as long as the informing was not delayed. Parents were almost equally divided on the appropriateness of the time of presentation of the diagnosis. An overall view would tend to suggest that the parents of this study were accepting of the time of the informing.

As in all studies reviewed, the mother was most frequently the first to be told of the child's handicap. The finding of 60% is in the general range of most other studies. The finding that only 12% of the fathers were the first to be informed was found to be lower than all the studies reviewed with the exception of the Rubin and Rubin (1980) study.

These authors found that none of the fathers were the first to be informed. In the present study, 70% of the parents were in favour of being informed together; a finding consistent with other studies. Only 28% of the parents of the present study were actually told of the diagnosis together, and only two studies reported findings which were slightly higher than this percentage (Carr, 1970; Cunningham and Sloper, 1977). Most parents were informed by a single person which frequently was a pediatrician; a finding which appears to be similar to many previous studies.

The finding that 85% of the parents of this study were informed by a single person who was a physician is close to the findings of McDonald et al. (1982) that nearly all the time the physician was the initial informant. Parents of the present study overwhelmingly recommended a physician be the one to inform the parents. These findings appear to substantiate the notion that the physician is regarded as the primary source of relevant information. This high recommendation of a doctor as the informant would seem to support that parents want the facts right from anexpert in diagnosing, and not from a professional viewed as part of the support system.

Most other studies used the word "shock" to define the parents initial reaction to the diagnosis.

Research which addressed this factor reported findings of 80% and higher of parents which were shocked at the news presented to them (Carr, 1970; Cunningham and Sloper, 1977; Edelstein and Strydom, 1981; Lucas and Lucas, 1980; Shiono and Kadowaki, 1979; Stone, 1973). The present study used the word "surprise"; this word would seem to be less harsh, but only 60% of the parents agreed that the diagnosis was a surprise. About one-third of the parents did not feel the information was a surprise. Literature suggests that most parents experience shock, and have strong emotional reactions to the birth of a mentally retarded child (Drotar, Basklewica, Irvin, and Klaus, 1975; Olshansky, 1966; Schild, 1976; Solnit and Stark, 1961), but even with a weaker wording the results of the present study was at least 20% less than previous studies.

The finding that one-third of the parents were not surprised with the diagnosis may be an indication that the parents had prior knowledge from a physician regarding the risk of having a mentally retarded child. A possible reason to this response of the parents is the ages of the mothers. At the time of the study 56% were over the age of 30 years and 26% were over the age of 35 years. An alternative explanation for these results may be the terminology used. The word shock has the connotation of something drastic having happened. A surprise can be either sad or happy, and places the respondent in a position of having to make a broader interpretation of the situation. If these reasons were found

to be the reasons for these results, then it would appear that mothers had greater reason for having some suspicions. The rate for mother was that 52% were surprised and 40% were not. The results for fathers were vastly different with 73% surprised and only 20% were not surprised. The greater question is why these results occurred. As only one item on the questionnaire dealt with the element of surprise at the diagnosis, an answer cannot be provided, but this would appear to support the notion that further research on informing parents needs to approach the emotion aspects rather than characteristics of the informant.

As stated previously, it is generally agreed that the diagnosis should be presented to the parents in a sympathetic manner. Three studies were found which reported findings in the 60% range (Berg et al., 1969; Lucas and Lucas, 1980; Rubin and Rubin, 1980). Parents of the present study provided a rate (75%) which was higher than the findings of previous studies. The majority of parents felt that the diagnosis was presented with clarity, the language used was not technical or professional jargon. It was found that 15% of the parents did feel that technical language was used, and this finding is much higher than the 4% reported by Lucas and Lucas (1980).

Most parents felt the information presented was easy to understand, and they were encouraged to seek clarification of the information being provided to them. Slightly more parents (70%) felt that there was no encouragement by the

informant to have them ask questions. The results on the last point are just under those found by Rubin and Rubin (1980). Parents were less in agreement when asked if the informant attempted to determine the extent of their knowledge concerning the child's condition. Just over one-third of the parents thought that an attempt was made by the informant, but of note is that one-fifth of the parents were undecided on this matter.

These results show differences in results between characteristics of the informant, and areas which involved the participation of the parents. In areas concerning how the informant conducted himself in presenting the diagnosis the majority of parents were satisfied, but in areas where the parents would have been an active participant the rate of satisfaction became closer to the level of the overall rate of satisfaction. Again, it may be that the areas of concern to parents are more closely related to their participation in the informing interview. A question which may be salient to the overall satisfaction is that if parents had been asked at the end of the section of the questionnaire on characteristics of the informant would the rate have been higher. It is argued that it probably would have been closer to the percentages obtained on characteristics of the informant.

The questionnaire item on overall satisfaction was placed near the end of the measuring instrument. It was after parents were asked about feelings and referrals to community resources. It was these areas in which results more closely approximated those of overall satisfaction. Possibly the recall of these two areas influenced the parents judgment of their overall satisfaction with the informing interview.

Over half of the parents of study felt an incomplete explanation was provided, and similarly, 58% of the parents thought the informant was sure about the information being presented. A high percentage (20%) of the parents were undecided on this last point. A breakdown of rates for each of the group of parents shows that 73% of the fathers had confidence in the informant, but only 48% of the mothers expressed the same opinion. None of the fathers were undecided where as 32% of the mothers were uncertain. In most cases it was the mother who was the first to be told, and it may well be that her emotional state at the time has influenced her decision on this matter. Also, the informant may have found it easier to present the diagnosis the second time, and to present the information to the father who may have been considered stronger emotionally than the mother. The vast difference found in this area would be an interesting area for future consideration.

Parents were much less certain regarding the prognosis as presented by the informant. Only 25% of the parents felt

that the informant was certain of the future growth and development of the child. Two major concerns of parents at this time are to understand their child's condition, and to understand the future for their offspring. Most parents (73%) felt the information provided helped understand the condition, but far less (38%) felt it was helpful in understanding the future of the child. Two other studies reported findings concerning information regarding the child's future, and both were considerably above the results of the present study (Gayton and Walker, 1974; Lucas and Lucas, 1980). These results seem to be understandable at the time of diagnosis. A physician would probably be far more certain of the diagnosis than of the prognosis of the child. It should be recalled that half of the parents were informed within one week of the child's birth. At such an early time, the only prognosis which could be presented to the parents would be one in very general terms, and a more specific prognosis would have to wait until the child was older. A time when developmental milestones are reached and providing a clearer indication for future growth and development.

Past studies report that some parents had a second interview arranged with the informant (Cunningham and Sloper, 1977; Gayton and Walker, 1974; Gilmore and Oates, 1977; Stone, 1973). The present study found that two-thirds of the parents had a follow-up interview which was frequently

arranged by a physician. Only in 15% of the cases was it arranged by the parent. Gilmore and Oates (1977) reported that 62% of the parents who had a second interview felt that there was a positive interchange between the parents and informant. A subsequent meeting of the parents and informant is to assist the parents in obtaining a clearer understanding of their child's condition and to provide further assistance to the parents in the form of practical help. Many parents may not recall most of what was told to them at the informing interview. This information needs to be reaffirmed, and if community resources were told to the parents at the initial interview, these also need to be restated. It is at this time referrals may be made on behalf of the parents although this may also be accomplished immediately following the presentation of the diagnosis. A further suggestion which may be made to the parents is to seek a second opinion, or special counseling such as from a geneticist.

Cunningham and Sloper (1977) reported that none of the parents of their study sought a second opinion regarding the diagnosis. Other studies report that about two-thirds of the parents did not seek a second opinion (Carr, 1970; Edelstein and Strydom, 1981; Gilmore and Oates, 1977). The present study found that a little less than this rate did not seek a second opinion. The parents who did actively seek a second opinion usually sought it from a pediatrician, geneticist, or neurologist. Over one-half of these parents

were encouraged to do so by a physician and just over a third did so on their own. Further guidance for parents from specialized professionals may be salient if the family is considering having more children. Parents need to be informed of the risk of reoccurrence, and of the risk of their children giving birth to a mentally handicapped child. Often there are other children in the family as well as the handicapped child.

Hare et al. (1966) found that one-third of the fathers and over half of the mothers felt more practical suggestions should have been made to them. Parents of the present study felt that in 58% of the cases practical suggestions were provided, and just over half of the parents were provided with information regarding community resources. The physicians of the McDonald et al. (1982) study reported that nearly all of them made referrals on behalf of the parents. Only a quarter of the parents of the present study were told of the name of an organization of parents with a child who had a similar handicap. More parents were referred to an agency which could provide assistance to them. Most of these parents were referred to the Infant Development Program. Only two parents were referred to a government agency. Ongoing support is necessary if the parents are to adjust to a new lifestyle with a handicapped child in the home.

Informing the parents is but a first step. There may be a need for continual support during the early stages of adjusting to the new life style of the family. Some parents may suffer social isolation, and it may be that early contact with community resources will be important (Gilmore and Oates, 1977). Carr and Oppe (1971) stress the need of the parents for medical, social, and educational resources. Waskowitz (1959) suggests that mental retardation has a serious impact upon parents. This affect is understandable when considered in view of the attitude of society as well as the problems of a intellectually limited child finding a safe and secure place in our culture. Education is a salient factor in our society despite recurrent expressions of anti-intellectualism (Condell, 1967). Parents of a retarded child also have needs in the area of special education for their handicapped child. These may include workshops, daycare centres, and special education classes for their child. These may be seen as substitutes for normal education, but in these areas, parents may need help with understanding what is provided and the realities of the programs (Condell, 1967). In some instances, parents may join together to use their collective strength for better programs, facilities, and research into the needs of a special child. Furthermore, parents may be an effective political force in convincing legislatures of the needs of families with an exceptional child (Mandelbaum, 1967).

More important, community resources provide a stability for the parents from the beginning of a lifetime of caring for a handicapped child. Birenbaum (1971, p.56) states:

> "Community-based programs, through the orderliness and predictability they proffer, allow the family to accept the burden of care more readily than if there were no specialized services. Presence of these services means the child can be more readily kept in the community. More importantly they enable the members of the family to confirm their own conventionality despite the presence of an atypical member; for the child's activities, and, concomitantly, the mother's activities, approximate those of a normal child and his parents."

Community-based programs can provide much needed assistance to both parents and child in terms of assisting with caring for and the educational needs of the handicapped child. Parents may also need the support of contact with other parents of a mentally retarded child. This may help to relieve the feeling of being alone in their situation of having and caring for an atypical child (Gayton and Walker, 1974; Gilmore and Oates, 1977; Golden and Davis, 1974).

Practical needs of the parents are important, but there are emotional needs at the informing interview as well as after mother and child have returned home. Parents need an opportunity to express their feelings. The present study found that parents were largely in agreement that they were not asked what they were feeling at the time of presentation of the diagnosis. Just over a third of the parents did feel there was an opportunity of express what was being felt at the time. The birth of a mentally defective child represents a

narcissistic blow to the parents (Solnit and Stark, 1961), and some parents will experience varying degrees of mourning for the loss of the expected normal healthy infant (Olshansky, 1966). Cummings (1976) points out that it should be remembered that fathers will have these experiences and should not be viewed as a means of support for mothers. Parents may feel totally overwhelmed if there is not an opportunity to discuss their child's diagnosis (Solnit and Stark, 1961), and an opportunity to vocalize their internal feelings may be of similar import. Initial counseling, although it may be brief, has implications for the future of the family and the child. Solnit and Stark (1961) views interpretation as a continuing process which includes many clarifications. These successive communications are to facilitate the reorganization of the parents' views, and to promote their adaptation to the reality of the situation.

Initially, the parents ability to copy may be related to the communication skills of the informant (Matheny and Vernick, 1969). D'Arcy (1968) suggests that initial counseling makes a lasting impression. In some instances, counseling parents of a retarded child may be viewed as a life long process (Miller, 1968), and may involve counseling parents in giving birth to more children. Morgan (1973) suggests that genetic counseling is essential for parents who give birth to a Down's Syndrome child. Shiono and Kadowaki (1979) studied mothers of Down's Syndrome children, and found that

one-fifth of the mothers had induced abortions on subsequent pregnancies. Future help to parents goes beyond the presentation of the diagnosis. It may take a variety of roles and expectations as the focus changes from an acceptance of the diagnosis and child to future family considerations as well as the development and growth of the child.

The method of informing parents of the diagnosis is probably of more significance than who is informed first or when the parents are told (Gilmore and Oates, 1977; Zwerling, 1954). Similarly, there is no way of knowing how much information and at what pace it should be given to the parents. Some parents are capable of absorbing much information while other parents must progress at a slower rate (Blodgett, 1957). What is important is that the physician be prepared to accept a continuing role focusing on the care of the child, development of the child, and the adjustment of the family (Shiono and Kadowaki, 1979). Professional involvement with these families is to help the parents accept and adjust to the presence of a mentally retarded child within the family. This is a desirable goal, but some parents may continue to wish that their child could be normal (Condell, 1967). It is unlikely that the totality of parent-child interaction will be uncovered or resolved shortly after the diagnostic informing. It may be possible to identify some

of the complex feelings of the parents, and to assist them with an understanding of their interrelationships (Mendelbaum and Wheeler, 1960). Most often success with informing the parents can be expected when it is done with sympathy in an honest and factual manner. This should include repeated contact with the parents and an element of gradual planning for their child (Blodgett, 1957).

McDonald et al. (1982) suggests that their findings show that physicians are aware of the needs of parents, and doctors are making an effort to work with parents. It should be recognized that even if the diagnosis is presented in a sensitive and supportive manner, some parents may still view the informant as non-supportive of themselves and their child. For some parents, this may be a time when there are many questions as to why this happened to them, and questions concerning their personal worth (Valente, 1972). For the parents the time of informing may be one of conflict of emotions, and an adjustment to what has taken place, but for the professional it is a time when patience and understanding are needed in order to assist the parents. Professionals may have personal attitudes toward intellectual handicaps which are obliquely transmitted to parents by means of over objectivity in order to maintain a distance, or alternatively, an excessive empathy which reveals a personal discomfort (MacKinnon and Frederick, 1970).

Authors suggest that training in human relations as well as interviewing needs to begin at the educational level of training for doctors who serve parents of a mentally retarded child (Jacobs, 1962; Woodmansey, 1971). Even with sufficient training, it takes time and experience to become sensitive to the needs of parents, and how to present a diagnosis of mental retardation. As one father aptly stated "There is no optimal time to be told your child has Down's Syndrome, ... but, more important, there is an optimal way in which parents can be informed" (Erickson, 1974, p.23). Professionals should be aware that parents did not choose their role, but professionals did (Doernberg, 1982).

Conclusions

The present study attempted to assess the views of parents regarding the informing process. An attempt was made to obtain the views of both parents, but as found in previous studies (Gilmore and Oates, 1977; Lucas and Lucas, 1977) less fathers participated. Data obtained from this sample population revealed a major shortcoming of the measuring instrument used. The semi-structured questionnaire provided mainly dichotomous responses. On the items presented to parents, they agreed or disagreed, but this did not provide for reasons of this position by the parents. Nor did the questionnaire provide any insight into the feelings or views of the parents on the subject matter of this study.

While this does not take away from the satisfaction or dissatisfaction of the parents on questions asked, it does not provide insight into better methods of informing, or much direction for further research. In light of these happenings, it appears that a well designed interview schedule would better serve the purpose of this type of research by allowing more expression of views by the parents. A weakness of questionnaires is that few will respond if it is lengthy or requires much writing. A well constructed interview schedule can consist of less questions, but if open-ended, may obtain the amount of data desired, and could still be coded as agree or disagree for the purposes of analysis. Even with these shortcomings there may be suggestions for further research.

The data obtained shows that the majority of parents were satisfied with the method of informing such as clarity of presentation, comprehendible language used, and the information was presented in a sympathetic manner. Areas of less satisfaction, and closer to the level of overall satisfaction of the parents were areas concerning the feelings being experienced at the time when the diagnosis was presented. Possibly further investigation of this area could reveal findings which could be of assistance with improving the initial interview. Good mechancis of an interview are essential, but the emotional upset of the parents must also be taken into account.

It is felt that a beginning to deal with these emotions should commence with the initial interview. Further study in this direction would clarify whether overall satisfaction is affected by characteristics of the informant, or with the emotional state of the parents. It is also possible, and more likely, it is a combination of both, but the larger question is to what degree.

The results of the present study were obtained from parents who were serviced by an organization of professionally trained workers. The sample population of this study may not be truly representative of all parents of a young retarded child. This study population constitutes a selected sample population. For an adequate descriptive study, it is required that the study population be representative of the larger population under consideration. If this requirement is met, then implications for service can be made from the results obtained. The results of the present study has provided questions for further inquiry, and possibly through further investigation services to parents can be improved.

SUMMARY

A study was conducted to assess the satisfaction of parents with professional help at the time of the diagnosis of their mentally retarded child. Satisfaction was defined as the parents viewing the help received as appropriate and meeting their needs. Areas of concern were appropriate timing of the informing interview, perception of the informant, expressions of caring and understanding, helpfulness; parents' satisfaction with the amount of information presented and the opportunity to express their feelings, and perceptions of the adequacy of referrals for follow-up services.

The level of research design was that of a descriptive study. The study did not attempt to test a hypothesis, but to obtain a measure of the views of a sample population regarding the presentation of the diagnosis of mental retardation. The central focus was a research question. "How satisfied are the parents of a retarded child with professional help received at the time of diagnosis?"

Data were obtained from 25 families via a semi-structural questionnaire. Questionnaires were delivered by workers to families serviced by the Infant Development Programs of British Columbia. Only families which met the criteria of having a child diagnosed as mentally retarded, and were viewed as appropriate for participation in this study were provided with questionnaires. Parents viewed as not appropriate were those for whom there may have been

too much stress by participating. Parents were requested to complete the questionnaire and return it by mail. Results were analyzed through the SPSS:9 computer program.

Results showed that frequently it was the mother who was first to be informed. This usually took place in either a maternity or a pediatric ward of the hospital. In almost all cases the informing was done by a single person, and the profession of the informant was a physician. The majority of parents were satisfied with characteristics of the informant. Parents were in high agreement that the diagnosis was presented in a sympathetic manner, and was presented with clarity using language which was quite understandable. There was less satisfaction shown when parents were asked about the personal interaction of the informant with them. Lower rates were found for an attempt by the informant to determine their knowledge of the child's condition, and being asked by the informant or an opportunity to express their feelings being experienced at that time. These lower findings were closer to a measure of the overall satisfaction of the parents with the informing process. A rate of 46% was obtained for parents as a combined group. The percentage for fathers was 22% above that of the mothers. About half of the parents were provided with information concerning community resources of which almost all were referred to the Infant Development Program.

It was concluded that while the present study did obtain the measurement desired, the method would have been more productive if an interview schedule had been used rather than the semi-structured questionnaire. The instrument used provided only dichotomous answers, agree and disagree, and did not provide insight into the reasoning or desires of the parents. A direction for further research was suggested. Much research focuses on parents views of the characteristics of the informant. A possible other direction is on the feelings being experienced by the parents and how would it be best for the informant to deal with these feelings. Parents need to commence from the initial interview to express and come to terms with their emotions over the traumatic event as the birth of a mentally retarded child. The informing of parents at the time of diagnosis is but a beginning process for the family and for professionals. Parents, to some degree, will need ongoing support for themselves and for their handicapped child.

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APPENDIX A

APPENDIX B

Generalization from other countries is possible, but is not the equivalent of research which examines services provided in British Columbia.

The results of this project may identify areas in which parents are satisfied. This could exemplify areas which could further be utilized by workers in the field of mental retardation. Conversely, the study could bring forth areas in which there exists much dissatisfaction. Ultimately, this could lead to changes and improved services to parents of children with mental retardation.

The findings will be forwarded to your agency, and it is hoped that the results will be of benefit in your seeking changes for future parent who will receive diagnostic counseling. Also, the parents of the Infant Development can share in the information gained from this research by your workers sharing the findings with them.

It is felt that many can benefit from this type of research, and hopefully, it will contribute to the provision of improved services to parents. I would ask that you consider participation in this project. Should you give your approval, then I would ask that you forward a letter of approval as soon as possible.

This is needed to meet the requirements of the University of British Columbia Research Committee who have given approval to the study.

Thank you for your consideration.

Yours truly

Kenneth J. Mair
M.S.W. Student, U.B.C.
School of Social Work

PROVINCIAL ADVISOR - INFANT DEVELOPMENT PROGRAMME
2979 WEST 41st. AVENUE, VANCOUVER, B.C. V6N 3C8

Funded by:
Ministry of Human Resources

April 11, 1979

Dear People:

Enclosed is a package relating to a Master of Social Work Thesis developed by Ken Mair. Your participation, your committee approval and parent participation is strictly voluntary. I know your workloads. I think the questionnaire and proposed thesis have the potential for providing some very interesting information which, when collated and published will provide us with some statistics and more importantly recommendations to improve parent/professional relationships. A significant number of families are not receiving adequate initial diagnostic/counselling services. With some families our initial energies are directed to undoing or re-channeling the frustration and anger experienced by families when information from professionals in the past has been misleading, inaccurate or non-productive. Parents on the Provincial Steering Committee and myself have reviewed the questionnaire and have made suggestions to clarify ambiguities.

If you agree to participate in this, the following outlines what is expected of us.

(1) Give package to chair of Local Advisory Committee to approve or not to approve distribution to families. The package contains a letter to the committee - brief research proposal and questionnaire.

(2) If the chair and or committee approve - a letter to Ken Mair indicating approval should be sent to him by chair.

(3) Staff write list of families who:

. have infant aged 0 - 3 with medical diagnosis of mental retardation that have been informed of this.

. if 10 or less - all families should be asked to participate.

. if more than 10 meet above criteria - random selection (names from hat be used.)

(4) Staff during home visit discuss questionnaire with family. If they agree to participate leave package with them.

(5) Both mothers and fathers are asked to separately fill in and enclose both questionnaires in one sealed, stamped, addressed envelope.

(6) Parents will be requested not to discuss the questionnaires with staff.

Ken will discuss this with us at noon, Friday, April 27, 1979 at in-service. If you wish to participate you could bring the letter from the chair at that time. Ken hopes to have 120 families to participate in this which means 10 families/programmes.

Thank you

Dana

APPENDIX C

SURREY

ASSOCIATION

for the MENTALLY RETARDED

P.O. Box 1204, Station "A"

Surrey, B.C. V3S 2B3

October 3, 1979

Mr. Ken Mair
School of Social Work
University of B.C.
VANCOUVER, B.C.

Dear Mr. Mair:

The Surrey Association for the Mentally Retarded is pleased to inform you that they have approved your study to be used with parents of retarded children who are currently taking part in the Surrey Infant Development Programme.

We would be most interested in receiving information from you as to the results of your study.

Yours truly,

Marvis Holm
Supervisor
Surrey Infant Development

MH/pk

INFANT DEVELOPMENT PROGRAMME

RUTLAND HEALTH CENTRE

155 GRAY ROAD

KELOWNA, B.C.

V1X 1W6

May 18, 1979

Mr. Ken Mair
U.B.C. - M.S.W. Student
c/o The Provincial Advisor
Infant Development Programme
2979 West 41st Avenue
Vancouver, B.C. V6N 3C8

Re: Your M.S.W. Research Project

Dear Ken:

Our Committee approved participation in your M.S.W. research proposal.

Georgie, our staff person, will distribute your questionnaire to those families of the Kelowna Programme who meet your criteria. At best there may only be 5.

It is our hope that you have built in some feedback process into your research project. We would love to know your conclusions.

There was considerable interest in your research expressed at the Kelowna and District Society for the Mentally Retarded. Hope we will hear from you soon.

Sincerely,

Betty Lou Mowery, Chairman
Kelowna Infant Development
Management Committee

BLM/adm

Duncan and District

ASSOCIATION FOR THE MENTALLY HANDICAPPED

Incorporated under the Societies Act 1957

COWICHAN OPPORTUNITY ACHIEVEMENT CENTRE
5856 Clements Street

CHILDREN'S PLACE
Integrated Day Care
Infant Development Programme
5814 Banks Road

Please address
All Correspondence To:
P.O. Box 204,
Duncan, B.C. V9L 3X3

AFFILIATED WITH THE BRITISH COLUMBIA ASSOCIATION
FOR THE MENTALLY RETARDED

May 14, 1979

Mr. Ken Mair
School of Social Work
University of B.C.
2075 Wesbrook Place
Vancouver, B.C. V6T 1W5

Dear Mr. Mair:

At the meeting of the Infant Development Advisory Committee for the Duncan programme, the decision was made to give out five of your questionnaires to our parents. Hopefully you will receive them in time to use them in your study.

We would like to extend our best wishes for you in your study and will look forward to hearing of your findings.

Yours sincerely,

(Mrs.)Kathleen L. Maxwell,
Chairperson.
Infant Development
Advisory Committee.

KLM/dn

NEW WESTMINSTER INFANT DEVELOPMENT PROGRAM

2266 Wilson Avenue

Port Coquitlam, B.C.

V3C 1Z5

May 8th, 1979

Mr. K. Mair
School of Social Work
2075 Wesbrook Place
University of British Columbia
Vancouver, B.C.
V6T 1W5

Dear Mr. Mair:

I have reviewed your research proposal and sample questionnaire. It is agreeable to me, on behalf of this committee, that the questionnaire be given to certain parents involved in the Infant Development Programme.

Yours sincerely,

J. Sellers, Chairman,
Infant Development Programme
Advisory Committee

JS/rg.

APPENDIX D

April, 1979

Dear Parents:

Services for the parents of a handicapped child are a concern of various groups within the community. Professionals, organizations, and parents have an interest in the services which are provided. As parents of a handicapped child, your experiences are a valuable sourve of knowledge relating to the area of services. Through a research project, the views of parents are being sought concerning the services which were received at the time they were first told that their child was handicapped. To this end, a questionnaire has been enclosed, and you are requested to complete the questionnaire.

You are requested to think back to the first time that you were informed that your child was handicapped. This may have been in a hospital, doctor's office, or a clinic. You may have been informed by one person or a group of persons. It is this initial interview which is the focus of the study. The areas under consideration in the questionnaire are how you viewed the services rendered to you, and how you felt about the manner in which the information was presented to you.

Your views on these subjects will provide some assessment of the services rendered to parents. It is hoped that through this study, an examination of services can be completed which will be of benefit to parents like yourself. The findings of this project, upon completion, will be made available to the Infant Development Program. Should you wish to know the results of the study, these may be obtained from your Infant Worker.

Your participation in this research project is, of course, voluntary. To ensure confidentiality, you are asked not to write your name, address, or telephone number on the questionnaire. As your reply will be anonymous, participation will have no effect on the services rendered by the Infant Development Program.

I would ask that you consider lending your support to this task by completing the enclosed questionnaires, and returning them at your earliest convenience.

Yours truly,

Kenneth J. Mair
M.S.W. Student,
U.B.C.
School of Social Work

Mary Russell, M.A.,
M.S.W.
Professor of Social
Work, U.B.C.
School of Social Work

APPENDIX E

INSTRUCTIONS

This questionnaire contains a series of statements and questions. For the statements, you are asked to place a check mark (✓) next to the statement which most closely represents your point of view.

Please do not write your name, address or telephone number on this questionnaire.

PLEASE NOTE: An interview shall be defined as a situation where a professional person(s) is in your presence, and discusses your child with you. A telephone conversation should not be considered an interview.

This questionnaire was completed by:

1) Mother ____

2) Father ____

QUESTIONNAIRE

Please think back to the time when you were first told of your child's condition, where the informing took place, and which parent was told first or were you told together.

1) Which parent was first told of your child's condition or were you informed together?

____(1) Mother told first
____(2) Father told first
____(3) Told together

2) Do you agree that the answer to question #1 was the best way of presenting the information?

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

3) Which of the alternatives of question #1 do you feel is the best?

____(1) Mother told first
____(2) Father told first
____(3) Told together

4) The time when the information was presented was the appropriate time.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

5) The information should have been presented earlier

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

6) The information should have been presented later

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

7) What was the age of your child at the time you were told of your child's condition? ____months or ____ weeks.

8) How old was your child when you first sought help? ____months or ____ weeks.

9) Were you informed by:

____(1) One person
____(2) Two persons
____(3) Three persons
____(4) Four persons
____(5) Five persons

10) Which of the following professions were present when you were informed of your child's condition? (Check (✓) all professions present.)

____(1) General practitioner
____(2) Pediatrician
____(3) Psychiatrist
____(4) Psychologist
____(5) Social Worker
____(6) Other (please specify)_____

11) As you look back on your experience, which professions would you recommend be present when parents are informed of their child's handicap?

____(1) General practitioner
____(2) Pediatrician
____(3) Psychiatrist
____(4) Psychologist
____(5) Social worker
____(6) Other (please specify)_____

12) What was the length of the time of the interview?
_____

13) Were you informed at:

____(1) Doctor's office
____(2) Maternity ward
____(3) Pediatric ward
____(4) Diagnostic or outpatient clinic
____(5) Other (please specify)_____

14) The information came as a complete surprise.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

Next, think back to the manner by which the information was presented to you in this first interview. This section will examine the type of language used, the type of information given, and your involvement in the interview.

15) The language was very technical.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

16) There was much professional jargon used.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

17) The professional jargon used was within my level of understanding.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

18) The information presented was clear.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

19) The information was presented in a sympathetic and understanding manner.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

20) The information was helpful in understanding your child's condition.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

21) The information provided helped to understand the future growth and development of your child.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

22) The information given concerning our child was not easy to understand.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

23) There was encouragement to ask questions concerning our child's condition.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

24) There was no encouragement to seek clarification of the information that was presented

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

25) An attempt was made to determine the extent of knowledge I had regarding our child's condition.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

26) Could anything have been done to improve the presentation of the information? Please explain.

_____

_____

_____

_____

_____

27) The person(s) who presented the information asked what feelings were being experienced during the time when the information was being presented.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

28) There was an opportunity for me to express what we were feeling at this time.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

29) What were you told regarding your child's condition? (diagnosis) _____

_____

30) There was not a complete explanation of your child's condition provided.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

31) The person(s) was certain about the facts regarding the child's condition.

_____(1) Strongly agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

32) The person(s) was not certain about the future growth and development (prognosis) of our child

_____(1) Strong agree
_____(2) Agree
_____(3) Undecided
_____(4) Disagree
_____(5) Strongly disagree

33) Was a second meeting arranged with the person(s) who first told you of your child's condition?

_____(1) Yes
_____(2) No

34) By whom was this meeting arranged? _____

_____

35) To assist in the acceptance of our child's condition, practical suggestions were made. (i.e.: a worker to visit the home)

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

36) Information concerning community resources was provided during the interview.

____(1) Strongly agree
____(2) Agree
____(3) Undecided
____(4) Disagree
____(5) Strongly disagree

37) Were you told of an organization of parents who have a child with a similar handicap?

____(1) Yes
____(2) No

38) If yes, what was the name of the organization?

_____

39) Were you referred to an agency (government or private) which would provide you with help?

____(1) Yes
____(2) No

40) If yes, what was the name of the agency?

_____

41) Were you satisfied with the way in which the information was presented at this first interview?

____(1) Very satisfied
____(2) Satisfied
____(3) Undecided
____(4) Unsatisfied
____(5) Very unsatisfied

In this section please recall some of the events that may have taken place since the first interview in which you were told of your child's condition.

42) Did you seek a second opinion?

____(1) Yes
____(2) No

43) From whom did you seek a second opinion?

____(1) General practitioner
____(2) Pediatrician
____(3) Psychiatrist
____(4) Psychologist
____(5) Other (please specify) _____
_____

44) Were you encouraged to seek a second opinion by any of the following means:

____(1) A friend
____(2) Doctor
____(3) Other professional (psychologist, social worker, etc.)
____(4) Other (please specify) _____
____(5) Sought a second opinion without an outside suggestion.

45) Have you changed your doctor since your child was originally diagnosed?

____(1) Yes
____(2) No

46) If yes, how did you decide on the new doctor?

_____
_____
_____
_____
_____

47) If you wished to discuss your child's condition at the present time, which profession would you contact?

____(1) General practitioner
____(2) Pediatrician
____(3) Psychiatrist
____(4) Social worker
____(5) Other (please specify) _____

48) What is your biggest unanswered question concerning your child?

_____

_____

In this section, I need to know some characteristics of you and your family. This is for the purpose of analysis.

49) How many other children are in your family? _____

50) What is the age and sex of the other children?

	Sex	Age		Sex	Age		Sex	Age
1	____	____	4	____	____	7	____	____
2	____	____	5	____	____	8	____	____
3	____	____	6	____	____	9	____	____

51) What is the present age of your handicapped child?____ months Is the child male ____ or female ____?

52) Which of the following categories would represent your educational level:

Father	Mother	
_____	_____	(1) Elementary school education
_____	_____	(2) Some high school education
_____	_____	(3) High school graduate
_____	_____	(4) Some post-secondary education
_____	_____	(5) Post-secondary school graduate

53) Of the following ranges, where would your family income fall:

____ Under $10,000.00
____ $10,000.00 - $12,500.00
____ $12,500.00 - $15,000.00
____ $15,000.00 - $17,500.00
____ $17,500.00 - $20,000.00
____ $20,000.00 - $22,500.00
____ $22,500.00 - $25,000.00
____ Over $25,000.00

54) What is your age?

Mother: _____ years
Father: _____years

55) What is your occupation:

Mother: _____
Father: _____

56) What is your marital status?

____ (1) married
____ (2) separated
____ (3) divorced
____ (4) other (please specify) _____

APPENDIX F

1) Which parent was first told of your child's condition or were you informed together?

	Father	Mother
Mother told first	9	15
Father told first	2	3
Told together	4	7
Total	15	25

2) Do you agree that the answer to question #1 was the best way of presenting the information?

	Father	Mother
Strongly agree	3	8
Agree	3	6
Undecided	2	2
Disagree	3	2
Strongly disagree	4	7
Total	15	25

3) Which of the alternatives of question #1 do you feel is the best?

	Father	Mother
Mother told first	1	6
Father told first	3	2
Told together	11	17
Total	15	25

4) The time when the information was presented was the appropriate time.

	Father	Mother
Strongly agree	2	5
Agree	6	5
Undecided	3	2
Disagree	1	6
Strongly disagree	3	7
Total	15	25

5) The information should have been presented earlier.

	Father	Mother
Strongly agree	2	8
Agree	-	3
Undecided	4	4
Disagree	8	6
Strongly disagree	-	2
Missing	1	2
Total	15	25

6) The information should have been presented later.

	Father	Mother
Strongly agree	-	-
Agree	1	1
Undecided	3	-
Disagree	5	7
Strongly disagree	5	15
Missing	1	2
Total	15	25

7) What was the age of your child at the time you were told of your child's condition?____months or ____weeks.

Weeks	Fathers	Weeks	Mothers
1	8	1	12
13	1	2	1
22	1	6	1
30	1	13	3
34	1	22	1
43	1	30	1
49	1	34	1
64	1	43	2
		49	1
Total	15	64	1
		112	1
		Total	25

8) How old was your child when you first sought help?
____months or ____ weeks

Weeks	Fathers	Weeks	Mothers
1	6	1	9
2	1	2	2
13	2	4	1
17	1	5	2
26	1	13	3
30	1	17	2
49	1	30	2
64	1	43	1
0	1	49	1
		64	1
Total	15	0	1
		Total	25

9) Were you informed by:

	Fathers	Mothers
One Person	12	22
Two Persons	3	2
Three Persons	0	1
Four Persons	0	0
Five Persons	0	0
Total	15	25

10) Which of the following professions were present when you were informed of your child's condition? (Check (✓) all professions present.)

	Fathers	Mothers
General practitioner	2	8
Pediatrician	9	13
Psychiatrist	0	0
Psychologist	0	0
Social Worker	0	0
Nurse	1	1
Neurologist	2	2
Eye Specialist	0	1
Missing	1	0
Total	15	25

11) As you look back on your experience, which professions would you recommend be present when parents are informed of their child's handicap?

	Father	Mother
General Practitioner		
Pediatrician	3	1
Psychiatrist		
Psychologist		
Social Worker		1
Neurologist	1	1
Nurse		1
Missing	11	21
Total	15	25

12) What was the length of time of the interview?

Minutes	Father	Minutes	Mother
2	1	5	4
5	3	10	3
15	1	15	3
30	3	20	2
60	2	30	3
90	1	45	2
missing	4	60	4
		70	1
Total	15	102	1
		missing	2
		Total	25

13) Were you informed at

	Father	Mother
Doctor's office	1	3
Maternity Ward	7	12
Pediatric Ward	5	5
Diagnostic or outpatient clinic	0	2
Hospital	1	1
Home	1	0
Boardroom of hospital	0	1
Missing	0	1
Total	15	25

14) The information came as a complete surprise

	Father	Mother
Strongly agree	7	8
Agree	4	5
Undecided	1	2
Disagree	3	7
Strongly disagree	0	3
Total	15	25

15) The language was very technical

	Father	Mother
Strongly agree	1	1
Agree	3	1
Undecided	2	1
Disagree	7	16
Strongly disagree	2	6
Total	15	25

16) There was much professional jargon used

	Father	Mother
Strongly agree	1	0
Agree	1	3
Undecided	3	16
Disagree	7	6
Strongly disagree	3	0
Total	15	25

17) The professional jargon used was within my level of understanding

	Father	Mother
Strongly agree	2	3
Agree	11	16
Undecided	1	1
Disagree	0	1
Strongly disagree	1	2
Missing	0	2
Total	15	25

18) The information presented was clear

	Father	Mother
Strongly agree	3	2
Agree	9	14
Undecided	1	2
Disagree	1	3
Strongly disagree	1	4
Total	15	25

19) The information was presented in a sympathetic and understanding manner

	Father	Mother
Strongly agree	2	5
Agree	9	14
Undecided	1	1
Disagree	0	4
Strongly disagree	3	1
Total	15	25

20) The information was helpful in understanding your child's condition

	Father	Mother
Strongly agree	4	3
Agree	8	14
Undecided	0	1
Disagree	1	4
Strongly disagree	2	3
Total	15	25

21) The information provided helped to understand the future growth and development of your child

	Father	Mother
Strongly agree	3	2
Agree	4	6
Undecided	2	4
Disagree	3	7
Strongly disagree	3	6
Total	15	25

22) The information given concerning our child was not easy to understand

	Father	Mother
Strongly agree	1	1
Agree	1	8
Undecided	1	3
Disagree	9	10
Strongly disagree	3	3
Total	15	25

23) There was encouragement to ask questions concerning our child's condition.

	Father	Mother
Strongly agree	2	4
Agree	9	13
Undecided	2	0
Disagree	0	4
Strongly disagree	2	4
Total	15	25

24) There was no encouragement to seek clarification of the information that was presented.

	Father	Mother
Strongly agree	1	5
Agree	1	3
Undecided	1	2
Disagree	9	10
Strongly disagree	2	5
Missing	1	0
Total	15	25

25) An attempt was made to determine the extent of knowledge I had regarding our child's condition.

	Father	Mother
Strongly agree	2	4
Agree	5	7
Undecided	4	4
Disagree	3	8
Strongly disagree	1	2
Total	15	25

27) The person(s) who presented the information asked what feelings were being experienced during the time when the information was being presented.

	Father	Mother
Strongly agree	1	1
Agree	3	3
Undecided	1	3
Disagree	7	8
Strongly disagree	3	10
Total	15	25

28) There was an opportunity for me to express what we were feeling at this time.

	Father	Mother
Strongly agree	2	3
Agree	2	7
Undecided	4	1
Disagree	4	9
Strongly disagree	3	5
Total	15	25

29) What were you told regarding your child's condition? (diagnosis) _____

	Father	Mother
Mongoloid	8	11
Tuberous Sclerosis	1	0
Cerebral Palsy	1	2
Infantile Convulsion	1	4
Microcephaly	1	1
Retarded	2	2
Trisomy Five	0	1
Missing	1	4
Total	15	25

30) There was not a complete explanation of your child's condition provided.

	Father	Mother
Strongly agree	2	7
Agree	6	8
Undecided	1	2
Disagree	4	5
Strongly disagree	2	3
Total	15	25

31) The person(s) was certain about the facts regarding the child's condition

	Father	Mother
Strongly agree	2	3
Agree	9	9
Undecided	0	8
Disagree	3	4
Strongly disagree	1	1
Total	15	25

32) The person(s) was not certain about the future growth and development (prognosis) of our child.

	Father	Mother
Strongly agree	3	7
Agree	7	10
Undecided	2	1
Disagree	2	5
Strongly disagree	1	2
Total	15	25

33) Was a second meeting arranged with the person(s) who first told you of your child's condition?

	Father	Mother
Yes	12	14
No	3	11
Total	15	25

34) By whom was this meeting arranged? _____

	Father	Mother
Doctor	5	5
Pediatrician	3	5
Neurologist	1	1
Parents	2	2
Parents and doctor	1	0
Nurse	0	1
Missing	3	11
Total	15	25

35) To assist in the acceptance of our child's condition, practical suggestions were made (i.e.: a worker to visit the home).

	Father	Mother
Strongly agree	2	6
Agree	8	7
Undecided	0	1
Disagree	3	7
Strongly disagree	2	4
Total	15	25

36) Information concerning community resources was provided during the interview.

	Father	Mother
Strongly agree	1	2
Agree	9	9
Undecided	0	0
Disagree	2	9
Strongly disagree	3	5
Total	15	25

37) Were you told of an organization of parents who have a child with a similar handicap?

	Father	Mother
Yes	4	6
No	11	18
Missing	0	1
Total	15	25

38) If yes, what was the name of the organization?____

Organization	Father	Mother
Association for Mentally Retarded	1	2
Infant Program	2	2
Missing	12	21
Total	15	25

39) Were you referred to an agency (government or private) which would provide you with help?

	Father	Mother
Yes	9	13
No	6	11
Missing	0	1
Total	15	25

40) If yes, what was the name of the agency?

	Father	Mother
Infant Program	6	10
Variety Treatment Centre	1	1
Ministry of Human Resources	0	1
Public Health Nurse	0	1
Missing	8	12
Total	15	25

41) Were you satisfied with the way in which the information was presented at this first interview?

	Father	Mother
Very satisfied	1	3
Satisfied	8	6
Undecided	1	5
Unsatisfied	0	3
Very unsatisfied	5	7
Missing	0	1
Total	15	25

42) Did you seek a second opinion?

	Father	Mother
Yes	4	12
No	11	13
Total	15	25

43) From whom did you seek a second opinion

	Father	Mother
General practitioner	1	1
Pediatrician	1	3
Psychiatrist	0	0
Psychologist	0	1
Geneticist	1	3
Neurologist	2	3
Infant Worker	0	1
Missing	10	13
Total	15	25

44) Were you encouraged to seek a second opinion by any of the following means?

	Father	Mother
A friend	1	0
Doctor	1	8
Other professional (psychologist, social worker, etc.)	0	0
Sought a second opinion without an outside suggestion	3	3
Missing	10	14
Total	15	25

45) Have you changed your doctor since your child was originally diagnosed?

	Father	Mother
Yes	3	8
No	11	15
Missing	1	2
Total	15	25

47) If you wished to discuss your child's condition at the present time, which profession would you contact?

	Father	Mother
General practitioner	1	6
Pediatrician	9	10
Psychiatrist	0	0
Social Worker	0	0
Infant Worker	1	3
Neurologist	2	3
Other	1	0
Missing	1	3
Total	15	25