PARENTS OF INTELLECTUALLY HANDICAPPED CHILDREN — HOW THEY ARE TOLD

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INTRODUCTION

Parents invariably experience great emotional distress when they are informed that their child is intellectually handicapped. From working with parents of intellectually handicapped children, it appears that they experience more anxiety with their child than do parents of normal children, and often have special needs. These needs may vary from requiring assistance to adjust to their child's condition, to advice and guidance about how to manage their child. It is apparent from talking with parents about their experiences with their intellectually handicapped child, that often their needs have not or have only superficially been met by professionals. Some cases have been adequately dealt with, however, in general there appear to be discrepancies in the availability of assistance for parents of intellectually handicapped children. There is a need to bring into focus the situation as it now exists for parents when they are told of their child's handicap. The time when parents are told of their child's handicap is a crucial one for parents, and perhaps not enough is being done to help parents at this time.

Parents suffer great emotional distress when they are told that their child is intellectually handicapped. A review of the literature has shown that how the situation is handled with parents initially may determine how parents subsequently adjust to their situation. A study of parents' experiences with their intellectually handicapped children, and the valued placed by professionals on the types of assistance available to parents was also undertaken in order to determine what procedures are most beneficial for parents of intellectually handicapped children. On the basis of this, recommendations were made as to the most desirable types of assistance which should be offered by professionals working with parents of the intellectually handicapped.

PARENTAL REACTIONS TO MENTAL RETARDATION

The literature pertaining to parental reactions to mental retardation has been well-documented. Molony (1971), Evans (1976), Mackeith (1973), Olshansky (1962) and Robertson (1951), have all written about the extreme emotional distress of parents when they are told that their child is intellectually handicapped.

Part of the psychological preparation of a mother during her pregnancy is her wish that she will have a "perfect child", and her fear of having a damaged one. Throughout her pregnancy she adjusts her fantasy to the newborn child and its growth and development. The birth of a defective child shatters this fantasy (Molony, 1971). It is as if her normal child has "died".

Evans (1976) in an article describing the grief reactions of parents of the retarded presents a comprehensive view of the grief suffered by many parents with intellectually handicapped children. He notes that the process of grief may be divided into five main stages — shock, protest, despair, detachment and acceptance.

Shock is seen to be a time when there is usually confusion, bewilderment and questions, and a feeling of not knowing which way to turn.

The next stage of protest is one where "shopping around" for a cure occurs where parents express denial of their child's condition, repudiate the family doctor and embark upon countless visits to specialists and therapists to prove their doctor wrong.

Despair follows the stage of protest. This is the stage where parents begin to realise that their child is handicapped. Parents may feel guilt, suffer depression and self-recrimination and have a sense of being different from others. At this time parents begin to search for the causes and reasons for their child's handicap. They are hoping to find an explanation that can release them from their guilt. It is at this time that parents tend to withdraw from social contacts and social interactions. Parents have begun to partially accept at this stage, their child's condition, however they still tend to blame their child's symptoms on causes rather than the retardation.

The next stage of detachment shows that there is an apparent acceptance of the child's limitations, however, there are still present, unresolved emotional conflicts between family members, where in the family there may be rigid role delineation where each parent has their own specific responsibilities and does these with minimal sharing of either functions or feelings.

The final stage of acceptance is characterised by a realistic acknowledgement of the child's limitations. The parents can now state that their child is retarded. Parents tend to start planning for their child's care and training. Acceptance, according to Evans, is not necessarily the final stage of grief. Parents must continually adjust to the situation in order to maintain stability throughout their lives. Evans also suggests that most parents who have an intellectually handicapped child suffer chronic grief throughout their lives. Olshansky (1962), has similarly suggested that parents may suffer chronic sorrow upon giving birth to an

intellectually handicapped child. This sorrow may be expressed in different ways and may remain with the parents up to and beyond the death of their child.

PARENTS' EXPERIENCES WITH THEIR HANDICAPPED CHILD

In addition to articles written by professionals on the subject of parental reactions to mental retardation, parents of intellectually handicapped children have written about their own personal experiences [Robertson (1951), Patterson (1956)]. Patterson (1956) in an article which has drawn upon her experiences with parents of intellectually handicapped children as well as her own experiences as a parent of an intellectually handicapped child, has proposed a list of "pointers for professionals", including the following items:

1. Tell us the nature of our problem as soon as possible.
2. Always see both parents together.
3. Watch your language (referring to the terminology used in telling parents of their child's condition).
4. Help us to see that it is our problem.
5. Help us to understand the nature of our problem.
6. Know your resources.
7. Never put us on the defensive.
8. Remember that parents of retarded children are just people.
9. Remember that we are parents and that you are professionals.
10. Remember the importance of your attitudes toward us.

Pueschel and Murphy (1976) in a study of parents' reactions to having a Down's Syndrome child also put forward recommendations which show agreement with Patterson *op. cit.* They recommend that parents be told of their child's condition as soon as possible; tell both parents at the same time, and when telling parents, use as kind and as sensitive a manner as possible.

At this point it should be noted that what is good for some parents is not necessarily good for all parents in this situation. This is evident in practice, from working with parents of intellectually handicapped children. It is important for professionals to individualise each case.

PARENTAL COUNSELLING

The role of the professional is perhaps of most importance at the time when parents are told they have an intellectually handicapped child. The support given at this time by professionals is crucial for long-term acceptance of the child by the parents. [Olshansky (1962), Mackeith (1973)]. Mackeith *op. cit.* has suggested that a medical practitioner should tell parents the child's diagnosis, and that parents should then be able to have access to other professionals who may be able to offer help, in the form of advice, guidance and counselling when parents may require it.

Much has been written in the literature on counselling procedures and techniques which should be undertaken when counselling parents of intellectually handicapped children. Evans (1976), Kanner (1956) and Soddy (1972) in discussing clinical aspects of mental retardation, state that the essence of counselling is to build up with the families of subnormal children, an ongoing relationship where the counsellor should be able to work through problems with the parents, and aim to help parents understand the nature of their problem and to come to an understanding of their own reactions to the situation. Evans (1976) points out that during all stages of grief, which parents in such a situation invariably experience, the parents are prone to suffer many crises, and for this reason, the counsellor should be readily available to assist in such situations.

Mackeith (1973) also expresses this view, as well as emphasising the need to be aware of crisis periods such parents may experience. These crisis periods, according to Mackeith, include decisions about the child's education, questions about the child's future, and what will become of the child when his parents are no longer able to take care of him.

Parents of intellectually handicapped children are also often perplexed by many questions relating to their child's condition. (Kanner, 1953). Many parents often need a satisfactory explanation as to the cause of their child's condition, and one function of the counsellor may be to try and discover a satisfactory cause (Soddy, 1972). Parents invariably are concerned about the future of their child — his potential, his prospects of being able to function in the community, and who will look after him when his parents are no longer able to do so. (Kanner, 1956). An important point emerging here, is again the need for each situation to be individually assessed by professionals. Parents' questions may in fact offer the best offer for counselling by professionals.

Although a considerable amount of literature has been written on parental reactions to mental retardation, and counselling techniques and other forms of assistance that should be available to parents of intellectually handicapped children have been well documented, it could not be said in practice that these suggestions have been universally accepted and followed. Also, it is the opinion of some people working in the field of mental retardation that often not enough is being done to help parents cope with their situation. The situation is hopefully changing. The present study has focussed more directly on parents' experiences and needs when they are told that their child is intellectually handicapped. This study may serve to offer feedback for professionals as to the most appropriate ways to assist parents with intellectually handicapped children.

THE PRESENT STUDY:

This study was an exploratory one. It had four aims:

1. To investigate help in the form of counselling and other types of assistance given to parents of intellectually handicapped children.

2. To investigate the value placed on the types of assistance given by professionals (specifically in this study, social workers) at the time of the diagnosis.

3. To investigate what help parents with intellectually handicapped children would like to receive.

4. To present a list of recommendations for practice by professionals working with parents of intellectually handicapped children.

METHOD:

Sample:

A non-random sample of sixteen parents, some of whom were single parents, was used for this study. Their children either attended or had attended a Day Training Centre of the Helping Hand Association. The particular centre used in this study is situated in one of Melbourne's northern suburbs. The ages of the parents' children ranged from five years to forty-six years. Six of the group of parents interviewed were aware of their child's handicap from birth, whilst ten of the sample of parents were informed of their child's condition at varying periods of time after birth. In order to investigate the third aim of the study the Social Work Departments of two of Melbourne's larger maternity hospitals were consulted.

THE UNSTRUCTURED INTERVIEWS

As this study was exploratory in nature, the unstructured interview schedule was designed in order to obtain the maximum amount of information on both specific and more general areas under investigation. Separate interview schedules were devised for parents, depending upon whether or not their child's handicap was evident at birth or at some period of time after birth. The interview questions were formulated after those used in a study by Pueschel and Murphy (1976). The function of the parent interview schedule was to identify and examine crisis points in the life of an intellectually handicapped child and his family, specifically at the time of diagnosis and during the child's development, and also to examine what procedures undertaken by professionals were/would be of most benefit to them.

The function of the social worker interview schedule was firstly to investigate what procedures other than direct medical treatment, are undertaken when an intellectually handicapped child is born in their hospital, and secondly to investigate what procedures are undertaken and what procedures are seen to be desirable in order to provide assistance and support to parents when they are told that their child is intellectually handicapped.

RESULTS:

Parent Interviews

For the purposes of analysis the data was pooled together for both groups and appears in tabulated form.

TABLE 1

Person(s) who notified mother/father of the child's diagnosis.

Person notifying	No.	%
Family Doctor	3	(19)
Doctor/Specialist at hospital	*12	(75)
Social Worker	*1	
Other	1	(6)

* In one case both a Doctor and Social Worker notified parents of their child's condition.

Table 1 looks at who told parents of their child's condition. Fifteen out of the sixteen parents interviewed said that either their family doctor or a hospital doctor/specialist told them of their child's condition. In one case both a doctor and a social worker notified the parents, and in another case a kindergarten teacher told the parents. One case was unusual in that although the doctor eventually told the parents of their child's condition (Down's Syndrome), it was not until nine months after the child's birth. The mother knew her child had Down's syndrome at birth, as did the doctor, however, according to the mother, the doctor concerned had a policy of not telling parents if their child was handicapped.

TABLE 2

Parents' Perceptions of how the diagnosis was presented to them.

Presentation	No.	%
Sensitive and factual	2	(13)
Sympathetic and factual	5	(32)
Told frankly	7	(43)
Abrupt dismissal	1	(6)
Other	1	(6)

Table 2 looks at parents' perceptions of how the diagnosis was presented to them.

Seven out of the sixteen parents were told frankly of their child's condition, and an equal number were told in a generally sympathetic way.

Table 3 below shows the degree of understanding by parents, of their child's condition when told of their child's diagnosis.

TABLE 3

Degree of Understanding of Child's Condition at time of Diagnosis

Type of Retardation	Understood	
	Yes	No
	No.%	No.%
Down's syndrome	3(19)	3(19)
Birth trauma	1(6)	
Unspecified	5(31)	4(25)

Seven out of the sixteen parents did not understand what the doctor said, whilst nine out of the sixteen parents understood to varying degrees.

Parents' feelings at the time of diagnosis varied from ones of devastation, disbelief, shock, disgust, and being very upset, to relief in some cases, where parents' uneasy feelings that all was not well with their child were confirmed.

Table 4 shows the person(s) first notified by professionals of the child's diagnosis.

TABLE 4

Person(s) First Notified by Professionals of the Child's Diagnosis

Person Notified	No.	%
Both parents	3	(19)
Mother alone	11	(69)
Father alone	2	(12)
Other	0	

In only three cases were both parents told together. Out of the thirteen cases where one or other spouse was told, twelve would have preferred to have been told together, and one said it didn't make any difference.

Table 5 shows the types of assistance offered to parents at the time of their child's diagnosis.

TABLE 5

Assistance Offered by Professional Who Told Parents of their Child's Condition

Type of Assistance	No.	%
Information	6	(38)
Counselling	1	(6)
Told to institutionalise child	1	(6)
Nothing	8	(50)
Other	0	

Eight of the sixteen parents were offered nothing, whilst six of the parents were given information, one couple was offered counselling and one couple was given the option of institutionalising their child. Some of the parents commented that they would have liked to have been given help to understand the nature of their child's condition better than they did at the time of diagnosis.

Response to the question about what parents perceived as being crisis times during their child's development varied. This can be seen from Table 6 below.

TABLE 6

What Parents Perceive as being Crisis Times During their Child's Development

Crisis Time	No.	%
Management of child, e.g. Toilet training	7	(44)
Decision about institutionalisation	1	(6)
Decision about schooling	3	(19)
Adolescence — puberty, relationships	1	(6)
None	4	(25)
Other	0	

Percentages in parentheses

Seven out of the sixteen parents expressed concern about various management aspects, including toilet training and eating. Concern about schooling was another anxious time for some parents, while four out of the sixteen parents expressed that they felt that there were no times which caused anxiety for them with their child.

Table 7 shows the types of assistance sought during the crisis times as outlined in Table 6.

TABLE 7

Assistance Sought During Crisis Times

Source of Assistance	No.	%
Doctor	3	(19)
Day Training Centre	5	(31)
None	8	(50)
Other	0	

Parents were also interviewed in an attempt to gain from them, their ideas about what would be helpful procedures to be undertaken by professionals working with parents of the intellectually handicapped.

A majority of parents interviewed expressed concern that no good reason was given for the cause of their child's condition. This was expressed by eleven out of the sixteen parents interviewed. Half of the parents expressed the need for honesty from professionals in telling parents of their child's condition. Some parents brought up the point that practitioners were reluctant to talk to parents about the child's retardation. In some cases the practitioners were not constructive about the child. They more or less just praised the parents for the good job they were doing with the child. Some parents felt that this was an obstacle preventing them from undertaking adequate planning for their child's future training and management. All parents commented on the necessity for such advice as information about how to manage their child, Day Training Centres and home help. Many parents felt that their lack of knowledge of specialised information prevented them from doing the most that they could for their child. Parents also expressed the desire for professionals to be accessible, just so they knew there was somewhere to go to for advice. Self-help was another important aspect stressed by parents. Many parents felt that by getting together with other parents in a similar situation, they could help each other cope with the situation more easily. Finally, perhaps the most strongly emphasised issue by parents was the question of the future for their child when they, the parents were no longer able to cope with their child.

INTERVIEWS WITH SOCIAL WORKERS

Due to time limitations, contact with Social Workers in only two of

Melbourne's larger maternity hospitals was possible. It should also be pointed out at this stage that most of what was discussed at these interviews related to the parents whose child's handicap was present from birth.

Both social workers interviewed showed a considerable amount of agreement on most areas covered. It was agreed that it was the function of doctors to tell parents of their child's condition, and depending on the situation and the doctor, sometimes a social worker was called in at this time.

When asked how often parents should be seen, it was expressed that it depended very much on each individual situation, and how often the parents came to see the social worker. It was stated that it was important for parents to have time to adjust to their situation, and that they needed time to be able to "absorb" what was going on, so the practice was not to "bombard" the parents with too much too soon. Time for a relationship to form between the social worker and the parents was also seen to be important.

When asked whether or not both parents should be told together of their child's condition, the social workers agreed that both parents should be present, however it was expressed that often this was not possible because of the husband's work commitments. A further point was also made that depending on the state of the marital relationship, one parent may be told and then left to tell their spouse of their child's condition.

When asked about the time when parents should be told of their child's condition, both social workers expressed the need for some form of bonding and attachment to occur between the parents and child. The time to tell parents was seen to be peculiar to each specific case, and professionals should be perceptive enough to be on the alert for the "question that hasn't been asked".

Crisis times for parents were seen by the social workers to be varied. For example, delayed milestones, toilet training and whether or not the child would be able to go to a normal kindergarten. It was also stressed by the social workers, the need for parents not to become isolated from the community.

SUMMARY

It will be recalled that the function of the parent interviews was to investigate the help given to parents of intellectually handicapped children and also to investigate what help parents would like to be given by professionals. The function of the social worker interviews was to investigate the value placed by them, on the types of assistance given to such parents.

A majority of parents indicated that a medical practitioner told them of their child's condition. The social workers interviewed indicated that a medical practitioner should be the person to tell parents about their child as he/she hopefully has the knowledge of the medical implications of the retardation.

Most parents stressed that both parents should be present when told of their child's condition, in or to give each other emotional support.

The feelings experienced by parents at this time were most intense. The social workers interviewed said that from their experience it is sometimes necessary to tell parents several times about their child. They also stated that it is important at this time to work through, with parents, their feelings about their child and the situation as a whole. A relationship with parents should also be encouraged by the professional in order for effective counselling with the parents to occur.

The types of assistance offered to parents varied. Fifty per cent of parents were offered nothing, and thirty-eight per cent of parents received information. The social workers interviewed commented that information was one of the most helpful sources of assistance that could be given to parents.

Almost one-half (forty-four per cent) of parents had some difficulties with management of their child. Twenty-five per cent of parents indicated that there were no specific difficulties with their children, perhaps because in these cases they were associated with a Day Training Centre. Fifty per cent of parents said they did not seek assistance with their child, primarily because they were unaware of resources which could help them at the time.

The remaining issues to emerge from the interviews related to what parents saw as being desirable practices for professionals when working with parents of intellectually handicapped children. A major concern for parents here, was the fact that no good reason could be given for their child's retardation. Other comments which may be relevant here include such questions as: What went wrong and why? and What have I done? These comments could be seen to be indicative of parents' unresolved, underlying guilt. Perhaps these feelings of guilt could be resolved if a satisfactory cause could be given for the child's retardation.

Many parents also expressed concern about the need for honesty by professionals when telling parents that their child is intellectually handicapped. One-half of the parents interviewed said that their doctors were often reluctant to discuss the child's condition. This could be because in fact in only thirty-six per cent of diagnoses can a concrete explanation be given for the retardation, Pueschel & Murphy (1976).

All parents said that more adequate information should be made available, especially information about training centres for intellectually handicapped children, home help, advice on management of such children and facilities for parent relief.

Forty-four per cent of parents expressed the need for professionals to be accessible to parents, just so that parents know where to go for help. Many parents suggested that home visiting by social workers especially in the early stages after diagnosis, would be beneficial for parents.

Self-help groups were seen by parents to be beneficial. They said that in such groups, parents who are all in a similar situation would be able to give each other support and advice. The social workers interviewed also said that this was worthwhile for parents, to help them avoid slipping into an isolated situation.

The last and most strongly emphasised comment made by parents concerned the question of the future of an intellectually handicapped child once his parents were no longer able to look after him. Many parents expressed doubts about what would become of their child when they died. This is a very real problem for parents, and professionals working with parents of intellectually handicapped children may well have an important role in helping parents plan for their child's future.

The findings from the statistical analysis of items from the parents interviews show four significant results. There appears to be an association between:

a. the type of assistance offered to parents and how it is perceived;
b. crisis times for parents and how the diagnosis is perceived;
c. crisis times for parents and the type of assistance offered to parents;
d. how the diagnosis was presented and the level of understanding of it by parents.

RECOMMENDATIONS

The time when parents are told that their child is intellectually handicapped can be an emotionally distressing one for parents. This has been shown in the present study. From investigating parents' experiences at this time and exploring what would be desirable practices for professionals working with parents of the intellectually handicapped, the following recommendations have been made, which also correspond with the literature. (Pueschel & Murphy, 1976; Patterson, 1956).

1. Always tell both parents together of their child's condition.

2. Be honest as far as possible when telling parents of their child's condition.

3. Provide adequate information about resources, and assistance available for parents of the intellectually handicapped.

4. Be "accessible" to parents.

5. Encourage the establishment of self-help groups for parents.

6. Help parents plan for the future with their child.

This list of recommendations is quite general and is by no means complete, however it could be seen to offer a list of guidelines to which professionals could refer when working with parents of the intellectually handicapped.

Because of time limitations this study only looked at the role of social workers in counselling parents of the intellectually handicapped. Social workers are not the only professionals involved with families of intellectually handicapped individuals and further investigations into the role of other professionals would be highly desirable.

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