

## MENTAL HANDICAP: A TIME TO RE-ASSESS THE SERVICE OFFERED

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### Introduction

This paper hopes to: examine the current service offered to mentally handicapped persons and their families; highlight deficiencies and some reasons for them, and make some proposals for the future. The contents of this paper are drawn up from our experiences in South Devon, and are in no way intended to be representative of other areas or the country as a whole. We welcome constructive criticism and alternative approaches from fellow professionals to what we see as 'deficiencies'.

Our starting point was to look at the service offered to severely and profoundly mentally handicapped individuals attending a Special Development Day Centre in our area. The Centre offers a service to 23 individuals ranging in age from 19 to 47, who live at home with their parents.

The level of individual attention and development is, we feel, of a high quality, although we must admit to being a little biased, as one of us has the role of Supervisor there, and the other a regular input. When we looked at the service offered to other members of the handicapped persons family however, particularly parents, the picture was somewhat different.

Parental involvement at the Centre comprises attendance at review meetings for their son or daughter, which are usually held every six or twelve months; assistance in carrying out programmes devised for their sons or daughters; and social events. In each of these three, the mentally handicapped person is identified as the one needing support, and in pursuit of this, parents help is enlisted. This implicitly places parents and professionals in an alliance or partnership, which in one sense it is, if the Centre is seen as providing a parenting role during the day. The other implication is however on entering an alliance with professionals, parents relinquish the right to problems of their own. This is, we feel, because of what being a professional has historically meant. Professionals are seen as helpers, curers, know-alls, and generally O.K. people, whereas clients or patients are seen as sick, ill in need of help, and definitely not O.K. people.

We feel the 'professional' label and all it implies is a distortion of reality which has led to deficiencies in the services we offer, for a number of reasons. Firstly, the birth of a mentally handicapped person into a family makes it a family affair, not an individual one. Some people feel that following the birth of a handicapped child the family enters a bereavement process, where grief is for the normal child which was never born. The bereavement process involves feelings of denial, guilt, anger, despair, and other strong, deep seated emotions. Unlike bereavement for a dead person, whose non-presence partially facilitates recovery over time, bereavement in respect of mental handicap is hindered by the ever-present reminder of the handicapped person. Quite obviously, if one accepts this notion, all members of the family have needs and feelings to work through. This is not catered for if professionals and parents become partners, because for the purposes of the exercise one then becomes labelled trouble-free and should act accordingly.

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Working with this initial premise we felt a need to find out more about the needs and feelings of other members of the family, which can then hopefully help to plan a more comprehensive and effective service.

#### **Contents of group meetings.**

Initially, letters were sent to all parents whose son or daughter attended the Centre, requesting their help. The letter stated the points about service deficiencies and we felt a more comprehensive and effective service would result from an understanding of the needs and feelings of other family members. Eleven replies indicated a willingness to assist, some responded as couples, other replies came from mothers only. We selected a group of six mothers, as we thought that a mixture of couples and single parents might lead to confusion, in terms of both the dynamics and homogeneity of the group. The group was led by the Supervisor of the Centre and a Clinical Psychologist. The group met initially for five fortnightly sessions.

We began by asking the mothers to share some of the experiences that they had had as a result of having a handicapped child.

(a) **The early years.** The first fact expressed by all group members was the lack of facilities and help in their children's early years. For some, when their child was born, the words "mentally handicapped" were never used and they were left with a sense that something was wrong but an uncertainty as to what it was. If they were told they had a child who was handicapped it was like being given a "dead" piece of knowledge which they did not know how to use. One of the mothers said that before her own child she had no contact with a mentally handicapped person and therefore did not know what to expect. All felt, in retrospect, from the moment of birth the presence of this new member of the family changed their pattern of life. The importance of the way parents are told that they have a handicapped child and the way in which they are supported in the early years was highlighted by the mothers' vivid memories of their own experiences.

One of the significant factors which emerged was that the mothers saw themselves as the sole carriers of the burden of responsibility for their handicapped children. In some cases they had the feelings that they alone were aware that something was amiss. Not only did they see their role as being one of carer of the handicapped child but also as one of protector of the rest of the family. They saw themselves as having to shield everyone else from the disruption of their normal lives. Some mothers stressed the resistance they felt in acknowledging the fact that their child was not 'normal'. They highlighted this by saying that when their children were small they did not want to meet others in the same position as themselves because they were frightened of what the may have been forced to acknowledge. Some spoke of the very high expectations that they placed on the child during the early years of life. It was as though they held the belief the child would be alright and that through effort on their part the 'imperfect' would be made 'perfect'. In the early years the feelings of guilt, remorse and anger the mothers experienced (and still do experience) were born out of the realisation that they had produced something that was 'imperfect'. This guilt was made easier, they thought, if the child became handicapped after birth. The mother could then feel that the 'fault' lay outside of herself.

It was partly because of this determination to make their child 'normal' that, with hindsight, it was felt that conflict between themselves and the professionals

involved may have arisen. The professional was a constant reminder that the child was mentally handicapped, conflicting with what the mother was striving for (i.e. normality). There had been a need in those early years for support however; someone who was reliable, friendly, consistent and trustworthy. It was felt perhaps someone outside of the field of mental handicap was in a better position to develop such a relationship. As soon as this 'outsider' began spending time with the family however, they would by definition become part of the mental handicap sector. It is difficult to see how this might be resolved. The time it took to resolve the dilemma between the desire to make 'normal' and the tremendous difficulties experienced in trying to accept the situation varied a great deal. All mothers felt, to a greater or lesser degree, this gradual process of acceptance had not been resolved and probably never would be.

The difficulty of assessing the quality of their son or daughter's life and the acceptance of the person's lifestyle were discussed, and was highlighted by an unresolved discussion on whether the mentally handicapped person had the right, or otherwise, to live.

(b) **The later years.** The initial feeling was of an awareness of age - the mothers' own increasing age and the physical difficulties they had in coping, and the increasing age of their sons and daughters and the embarrassment caused as the handicap loomed larger, for all to see. Age in the mothers brought tiredness, less energy and less motivation to do things. This in turn created guilt feelings and a lack of honesty with professionals; feeling they may 'give-up' if they thought the mother was not 'pulling her weight'. Consequently, new conflict between mothers and professionals arises in the later years to replace the previously identified conflict in the early years. Expectations of, and demands upon the handicapped person differed and by their very nature the demands made by the professional person when enlisting mothers help resulted in guilt feelings in the mothers, when they could not meet the demands placed upon them. The lack of a secure, understanding relationship between parents and professionals led to conflict and confusion which affected the mentally handicapped person's future.

The mother's lower expectations of their grown son or daughter forms a striking contrast with the high expectations placed upon the child in the early years. This change arises not only from increasing age but also from lack of hope. The person is now an adult, not 'normal' and the striving to make 'perfect' is over. The mothers still saw themselves as the central figure. Their role was to prevent the family from breaking up, thereby developing in them the belief that their strength and ability to cope was fundamental to the continuing existence of the family. Help from friends, professionals or family was not seen as sharing but something for which the mother should feel grateful because the responsibility was hers and hers alone. Over the years these beliefs and feelings created a very strong relationship between the mother and the handicapped child. Other relationships inside and outside of the family were disrupted and the mother-child bond replaced the husband-wife relationship in terms of both time and commitment. As the handicapped person got older the mothers were faced with what they saw as their decision regarding when their son or daughter should leave home. They in turn felt guilty because it was as though they were sending them away and this was felt to be an act of rejection.

All the mothers in the group thought they had been changed by having a handicapped child. They did not see themselves as being normal mothers and

constantly felt that other mothers would not understand them or what they did. One mother described herself as 'neurotic' and another said she would have been a totally different person if she had not had a handicapped son. A third mother however, put forward a different perspective. She suggested perhaps the handicapped person had merely highlighted what already existed and there was a danger of scape-goating the son or daughter.

In the fifth and final session, the group reviewed what it had achieved. The unanimous feeling was to continue, and as a result a further five sessions were agreed. The group leaders isolated three important themes arising in the first meeting and during the course of the second session, it was agreed to look at each of the following in greater depth:—

- (1) Leaving home,
- (2) Life without the handicapped member of the family,
- (3) Relationships with professionals.

During the first meeting each person, including the two group leaders thought of things which made their own experiences of leaving home easier or more difficult. A consensus was reached by the group and the mothers were then asked to relate these ideas to their sons and daughters. Initially the ideas were taken at face value (e.g. "going to university") and no relationship between them and the handicapped person's life could be seen. When the function was considered however, (e.g. meeting new people; seeing different places; becoming more independent, etc) the group began to appreciate the similarities.

The need to allow the handicapped person, within their own limitations, to experience the same life processes and to acknowledge that the basic needs and rights are the same for all was a difficult concept to grasp, because of the mothers very strong feelings of responsibility. The bond they had with the handicapped person was such that separation was difficult to envisage. The mothers felt that they alone were expected to make the vital decisions and carry the burden of any change. The thought that the handicapped person was not leaving to live an independent life and fear that the person was being asked to do something that he or she did not wish to do were two issues raised. It was particularly difficult to know whether one was doing the right thing for someone who could not communicate in a formal way. Such a dilemma can deny the person the right to face and overcome new challenges however because one resolution was to keep the son or daughter at home permanently.

The third and fourth meetings took on a new dimension with the introduction of a role play situation centred around a couple who had a mentally handicapped son in his twenties. Difficulties arose because the 'mother' was extremely resistant to her son leaving home whereas her husband, who worked away from home most of the time, put forward strong arguments, tempered by loyalty to his wife, for his son to be given the opportunity to grow and develop outside of the family. The role play involved the couple meeting with the staff at a residential establishment and a social worker, with a view to offering short-term care. The group leaders took the parents role; the mothers those of the professionals. This served to sharpen the content of the meetings and showed each member of the group a perspective other than their own. Within the role play the group leaders were able to experience some of the tremendous difficulties and strong feelings of the parents. They were also able to experience the feeling of being 'trapped' by well-meaning professionals.

From the mothers point of view they saw a marital relationship in conflict; a strong bond between mother and son, which took precedence over the bond between wife and husband; a mother who, by her own actions and intense feelings served to distance her husband and to reinforce the feeling that she shouldered the entire responsibility and burden for their handicapped son. Another very important function of the role play was in drawing the members close together as a group, developing a more honest and trusting way of communicating with each other.

The final meeting was a review session and an opportunity to discuss how information and feelings experienced by the group could be shared with others. The mothers are currently writing two journal articles, one for social workers, the other for doctors. The group leaders are writing their own paper. The group meets regularly to review the progress of this current project.

### **The group process.**

In the early meetings anxiety, doubt, wariness and fear were expressed by everyone. The group leaders' anxieties were due to the responsibilities they felt in making a success of a new venture. The mothers' anxieties reflected their uncertainty about what was expected of them, and these were heightened by the nature of what was being discussed. Thoughts and feelings which had been secreted, often for many years, were recounted and relived, a painful task in itself, let alone in front of a group. This experience proved too much for two group members, who withdrew after the first meeting, although one returned at a later stage.

From a collection of anxious individuals the group developed an identity and commitment which continues to the present day. The reasons for this are varied but include the following:—

- (i) the developing familiarity and trust one group member was able to place in another,
- (ii) the growing realisation that experiences previously thought to be unique to themselves were also shared by other group members.
- (iii) the developing trust group members developed in the group leaders, and vice versa.
- (iv) the growing belief the group had something useful to contribute and communicate, which might assist in developing a more comprehensive and effective service.

The group's commitment and strength was evidenced by the decision to convene a second set of meetings. In addition to this, in writing their articles the group has met on a number of occasions over and above the regular meetings, and without the group leaders, further evidence of its growing stature.

### **Conclusion**

The successful establishment and continued existence of the group is probably the best testimony to its value. It serves a number of functions. It is educational for the group leaders in as much as we have gained much knowledge about the intra- and inter- personal dynamics of families with a mentally handicapped member. The group has a therapeutic and supportive function for the mothers, and offers each member a perspective of mental handicap outside of the own set of personal experiences. The group has facilitated more trust and honesty between the group

leaders (i.e. the professionals) and the other members (i.e. the clients). We feel this latter development is the cornerstone and the key to the development of more appropriate and effective service developments because it is this which has facilitated the previously-mentioned group developments. We would welcome and encourage fellow professionals to take time to re-assess the service offered to mentally handicapped persons and their families.