

**PARENTAL ATTITUDES TO THE COMMUNITY CARE  
OF THEIR MENTALLY HANDICAPPED CHILDREN,  
BEFORE AND AFTER THEY MOVE INTO THE COMMUNITY**

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**INTRODUCTION**

Parental views on community care for their children are usually sought at case conferences before any plans for moving are made. However, these are rarely examined in full. Yet parents should be a valuable fund of information. They have already coped with living and working with a mentally handicapped person in the community. Their experiences of course, would also be different; not least because of the parents' emotional involvement and the fact that they had to cope without much formal support.

By the very fact that their child is now resident in an institution, parents "failed" in their attempt to give their child an ordinary life in the community. It is not surprising, therefore, that parents feel anxious about a second endeavour. What if that too should fail? The level of current generic medical and day-care facilities may not be sufficient to support the needs of the mentally handicapped population and present government policy does not suggest they will be increased.

Family is an important emotional and strategic link to the community for mentally handicapped people. If this link is to be maintained it is vital that we understand more about what community care means for parents of mentally handicapped children.

**Study**

The parents, in one instance an aunt *in loco parentis*, of 8 young people who were receiving long-term care in a hostel for mentally handicapped children or in children's villas in a large mental handicap hospital, were asked their views of community care for mentally handicapped people in general and their children in particular. This was especially pertinent for those parents as they had just consented to their children being placed in small staffed houses in the community.

Two years later the same parents were questioned again. By then their adolescent off-spring had lived in staffed houses in the community for approximately one year.

**Parental Attitudes Before the Move**

**(i) Views on Current Care**

The parents varied widely in the extent to which they were involved with their children's care and life in the two institutions. The type of institution did not matter. Most parents only saw their child when they brought them home for a week-end visit. This was usually the only time they saw any of the staff. Only a few parents telephoned at other times to find out what was happening with their child. Very few visited regularly. It was even more rare for staff to telephone parents to give them any information on their child's progress or details about where they had been or what they had been doing recently. This meant that few parents were involved with the care of their child in some way on a daily to weekly basis, most

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on a month by month basis and a few had contact only every 3 - 6 months. Most parents were happy about the quality of care their child was receiving. Most were also happy about the level of their own involvement. Many reported that although they would like to visit more this was not practicable because their child expected to go home when the parent appeared and became very upset when that did not happen. Parents also felt their child, being an adolescent, should be becoming more independent and they should not smother the child or interfere with the work the staff were doing to promote independence. Many parents also reported that they found visiting the hostel or hospital villa very difficult; they felt guilty about their child living away from home and they felt anxious in the unhomey, institutional atmosphere.

#### **(ii) Views on Community Care in General**

All parents interviewed believed that community care, particularly small staffed houses, was something which would be a positive step in the care of handicapped people. Every parent felt that with adequate funding and staffing levels community care would be practical for all mentally handicapped people, even those who had episodes of being severely disruptive or aggressive.

On the other hand most parents still believed that institutional care would always be necessary. Reasons given were that it would be needed to give short-term relief to parents and community staff, for older mentally handicapped people who had not lived in the outside community for many years and who would be frightened to do so, and for the multiply mentally handicapped people who would be too great a burden for community care staff. However, as one set of parents said, institutional care does not have to mean large hospitals and dormitories, it can also mean small blocks of flats.

#### **(iii) Views on Community Care for their Own Child**

Every parent felt that community care would be definitely beneficial for their child. They were then asked specific questions about the form this benefit might take:

- (a) Would their child make more use of the facilities in the community?
- (b) Would they become more involved in their child's life?
- (c) Would their relationship with their child improve?
- (d) Would the staff's relationship with their child improve?
- (e) Would their own relationship with the staff improve?
- (f) Would staff view their job differently in terms of demands and satisfaction?

Nearly every parent felt that their children would use more facilities in the community, although two were unsure how this would actually happen in practice. The houses were nearer local amenities and staff would find local shops and supermarkets quite convenient to use. Moreover, with fewer children and a better ratio of staff to children it should be easier for the young people to be taken out.

With regard to an increased involvement in their children's lives, parents had very mixed feelings. Some felt they would probably become more involved but almost as many felt they would not. This was partly because they felt the move to community living was an element in moving their child towards greater independence. Under these circumstances parents felt they should be less involved despite their personal wish to be more involved. This ambivalence is reflected in the answers

parents gave to the question of improving their relationship with their child. Improvement lay in being able to treat their teenage child more appropriately for their age. That is, both child and parent should have a certain degree of independence from the other. Like parents of non-handicapped teenagers these parents were unsure how to handle this stage in the relationship with their child. Unlike parents of non-handicapped teenagers they felt guilty lest they were really trying to renounce responsibility for a handicapped child.

On the other hand, all parents were completely sure that the relationship between the care staff and their child would improve. None was suggesting that this relationship was bad, merely that an already good relationship would strengthen. The smaller numbers of staff and children overall would mean that both would get to know each other better.

Parents also felt that their relationship with staff would improve. With the same staff every time they visited they would get a chance to know them better. In the hostel or hospital situation parents were never certain whom they would meet when they collected or returned their child. Finally all parents agreed that staff would find their new job in the community more demanding and at the same time more satisfying. Parents judged it more demanding because of the extra domestic duties, the greater responsibility involved, and the smaller numbers of staff available to give immediate help. Moreover, there would be no staff room where staff could retreat for a cup of coffee and a cigarette for a few moments peace and quiet. The satisfaction of the job would come from being able to work more consistently with fewer people and seeing the progress that they made.

#### **(iv) What Community Care Means for Them**

For parents the anticipated move to the community meant their child would be living in a house which was more like a home. A place where they would become more aware of what goes on in a normal household just by being able to wander into the kitchen when food was being prepared or dishes washed. There would be a normal routine for them. For example, there would be no need to get changed into nightclothes at 7.30 p.m. to be ready for night staff coming on duty as was the practice in the hospital. There would be the chance to have a bath in private without the rest of the children waiting in an outer part of the bathroom for their turn. Individuals would be catered for more easily. Overall there would be more chances for their children to experience a greater variety of everyday life both within and outside the house. There would be the opportunity to form closer relationships with the staff and other people living in the house because they would be fewer, in a smaller environment and more stable (i.e. no disruptions of new children appearing for short-term care every few weeks).

Parents also felt that, for themselves, there would be more chances to visit. Firstly, it would not be like an institution which should make it easier to visit. Secondly, there might be more opportunities just to visit, have a coffee and a chat with their child and the others there, rather than always having to take their child out when they wanted to see him. As one parent said: "They will be living as a family and we can visit as a family". Thirdly, for most parents, their child's home would be nearer their own.

Finally, for parents, community care meant their children would no longer be hidden from public view. The public would at last be educated about mentally handicapped people and, hopefully, learn to accept them.

#### **(v) Parental Anxieties About Community Care**

Most parents had a few worries about the move, only two had a great many worries. Parental anxieties fell into two main types: risks to their child from within and outside the house and the compatibility of those living in the house.

Many of the first type of worry were practical problems like: gates, were they big enough; fires, would they get switched on accidentally; stairs and windows, could their children fall down or out? Most of the young people did not have road sense, what would happen if they went out of the house by themselves? If one of the young people in the house had a temper tantrum would their child be safe? These were anxieties that parents had at the back of their minds and trusted that staff had thought of them too and prepared for them. Outside the house, parents expressed concern about the public reaction to their children. They were worried that neighbours would react negatively, that the community would reject them or that someone might take advantage of them. This might explain why so many parents were anxious about how staff dressed their children. They did not want negative attention to be drawn to their children because they were outlandishly dressed, untidily or shabbily dressed.

In terms of the compatibility of people within the house parents felt that in a small environment it would be imperative that everyone got on well with everyone else. Otherwise, they felt, a negative atmosphere would result. They hoped that people would adjust to each other with time.

Parents did feel anxious that if their child did not settle into the new life-style they might have to return to the institution. Furthermore if a child left, for whatever reason, how would they be replaced to ensure compatibility? Similarly, if a member of staff left how would a compatible replacement be found?

Throughout the interview parents expressed the strongly-held view that the future of the staffed houses greatly depended on the staff themselves. They controlled the extent to which parents were able to be involved, they controlled whether the young people got taught new skills or not, whether they were taken out or not. The atmosphere in the house depended on whether the staff were willing and able to work together as a team and whether they had love for the young people in their charge. At one extreme staff had the power to turn the house into a small institution, at the other extreme they could provide the children with a family home.

#### **Parental Attitudes After the Move**

##### **(i) Views on current care**

After the young people had moved to the various staffed houses in the community and had been living there for about a year, parental contact had become much more frequent and regular. Only one parent, who had been unable to visit her daughter in the hostel because of her feelings of guilt about leaving her there was still unable to visit her child in the staffed house. In fact she reported that contrary to her hopes and expectations, she felt even more guilty about her child not living at home when she visited her in the staffed house. This upsurge of guilt was in fact something that every parent experienced at some time during that first year. Seeing their child in a house not too dissimilar to their own made parents feel they should have been able to cope.

Parents often did not recognise what they were feeling, instead they tended to diffuse their guilt by finding small faults in the house, the staff or in how they ran

the house. Not all parents, by any means, had overcome this feeling of guilt at the time of the second interview.

Most parents still saw staff only when they came to pick up their child to take them home. However, they now tended to stay a while and chat on these occasions. A number of parents had expressed the desire before the move of visiting their children rather than always taking them back home. However, only three sets of parents had had success with this. The other parents who had tried it reported that their child became extremely upset if parents came and did not take the child away with them.

All parents reported that they were trying to show "interest without interference" and most felt that they were achieving this in the more relaxed atmosphere of the staffed house.

#### **(ii) Views on Community Care in General**

All parents still held the view that community care was a positive step and with adequate funding and staffing levels would be a benefit to all groups of mentally handicapped people. The only people they had doubts about were those who were extremely emotionally disturbed and those who were both physically and mentally handicapped.

For these groups of people parents felt a slightly different form of community care might be needed. Parents also reiterated their feelings that somewhere, preferably a small staffed house in the community, should be available for short-term or respite care and that elderly people who were frightened to leave institutional care should be allowed to stay. There was no need to build new large institutions.

#### **(iii) Views on Community Care Received by Their Own Child**

All but one parent believed that community care had been beneficial for their own child. The one parent who felt that the child had not benefitted from community care believed that the other children living in the same house had benefitted, but her child required more stimulation, more to do and a greater chance to get out of the house. What this parent was expressing was a belief that her child's potential could be brought out by living in the community but a staffed house, where a certain amount of restriction was imposed by the limits of other people living in it, might not be the best place for him.

Other parents reported that their child was much more communicative and aware, more interested in his appearance, more independent and generally a lot happier. Parents felt that their children were benefitting from getting more individual time and attention. One parent in particular noted that their child was able to share now whereas in the institution tended to keep all her belongings with her at all times.

Parents on the whole had not become more involved in the everyday life of their child – this "interest without interference" balance again. On the other hand most felt their relationship with their child was much more relaxed. Those who had reported problems in their relationship previously now reported an improvement.

As anticipated by parents, the relationships between their child and staff and themselves and staff had improved. There was a greater feeling of rapport. Parents

did not feel so inhibited about passing a comment or making a suggestion. They also noticed that staff had become more understanding of their problems as parents and they were never too busy to chat when parents called in or telephoned. Parents felt that if they had any problem or query they could telephone staff at any time. As to the demands and satisfactions of the job, parents once again reported that staff did and would continue to find their job both demanding and satisfying. One parent who visited the staffed house regularly noted that staff "often looked shattered" and was worried that they might feel isolated.

**(iv) What Community Care Had Meant for Them**

Parents believed that most of the changes they had envisaged had actually occurred: their child was living in a house which functioned like a normal home, they were more involved in the domestic chores and routines, and they were participating in the everyday life of the community. For parents themselves, the change to a staffed house had meant a pleasanter environment for them to visit. Although, as mentioned earlier, the fact that it was an ordinary house caused them other problems with which they had come to terms. Only some of the parents who wanted to be able to treat their child more as an independent teenager living away from home and visit them without always taking them back to the parental home, had been successful. The other parents had been frustrated in this by their children's insistence on being taken home or else making quite a scene if they were not. However, the experience of other parents might enable them to persist.

**(v) Current Parental Anxieties About Community Care**

Half the parents no longer had any anxieties about their child living in the community. *The worries that parents did have were very different from the worries they expressed before the move.* Two parents were concerned about their own role vis à vis the house. In essence they were concerned about their rights as parents when confronted with their child's second home and second set of "parents". Care staff were probably unaware of this potential area of conflict since parents were rather hesitant about discussing it, although it must be straining the "good" relationship which they reported with staff.

The two remaining anxieties voiced by parents was firstly, the problem of their own child still having aggressive outbursts and putting other people in the house at risk (the reverse of an earlier anxiety) and secondly, the worry that staff were working without much support and looking "shattered" on occasions. Both of these anxieties relate to staff and children adjusting to life in the community and staff being able to cope with any problems that arose. Parents still feared that their child's second chance to live in the community would fail. They highlighted the two factors which had led to the initial collapse – their child's difficult behaviour and their own exhaustion from having to cope too long on their own. By expressing these particular anxieties parents were unconsciously giving a warning to community services.

## **CONCLUSIONS**

Every parent interviewed said that they would recommend staffed houses to any other parents and would be willing to go and chat to them about their anxieties. They may have been anxious initially but they now felt committed to the concept of community care. They felt their children were living in a happier and more stable environment and benefitting from the everyday experiences of family life. Their

children were being treated as individuals and developing emotionally as well as gaining skills. The relationships between all concerned were more relaxed. The fact that families had more contact rather than less is notable.

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