

MEETING THE CHALLENGES OF THE COMMUNITY: THE RESPONSE OF CLIENTS AND STAFF*

Introduction

In the late 1970's and the early 1980's there was a rapid development of ideas and projects about the provision of care based on the principles of normalization developed by Wolfensberger. In 1985 the first coherent hospital closure plan was put forward in Leeds and this eventually formed the basis of the joint strategy for community care with social services. Since 1985 some 200 people resident at Meanwood Park Hospital have been resettled into the community. 80% of these people now live in N.H.S. group homes which cater for 2 to 5 people or in voluntary homes.

Since 1984 we have continued to collect data on the effect on clients, staff, carers and the local community. Our key findings are:

People who moved from hospital prior to 1984

Community Mental Handicap teams had contact with some 9 people who lived alone. 6 had spent 10 or more years in Meanwood Park. The other 3 had lived with their parents.

The findings were that physically all were a "success" i.e. they were not in debt, their housing was of a standard both internally and externally compatible with their neighbours and they had easy access to shops,

buses, amenities, etc. but socially they were very isolated. Their hobbies and interests were very narrow in range and mostly of a passive and/or solitary nature e.g. listening to the radio, t.v., records or going for walks. Women coped better with leisure time than men having interests such as sewing and knitting.

Contact with other people was very poor. Only 3 had occupations. Diary records of visits to and from relatives and friends indicated a poverty of social contact. Two people had no relatives and a further one had no contact with his relatives. Only one person had weekly or more visits to and from relatives. Although three people claimed to have more than one friend, only two of these had more than cursory contact. All nine spent large amounts of time alone. This seemed to be a vicious circle of poor social skills and few opportunities leading to a difficulty in making friends which further decreased opportunities and social contacts. The implication of this study is that simply providing people with physical settings which are integrated into the community and giving them some opportunities does not in itself improve quality of life. These basic requirements must be backed up with support and practical help in enabling people to take advantage of the opportunities around them.

* Based on an address to the British Society for Developmental Disabilities and the Walsall Community Health Council, 28th October, 1992, on the theme "Learning to Live Together".

Minimally Staffed Housing

We have over 50 people living in ordinary housing in the community in groups of between two - four people. Usually one staff is on duty in the evenings and in the mornings and for some time over the weekend. Some groups have periods of a few hours without staff on duty. Some groups have sleep-in staff. The staffing level depends on the needs of the residents.

Our study involved three matched groups of people: eight from the general population, eight from mental handicap hospital and eight from minimally staffed housing. A diary of activity over a four week period was kept for each person in the groups either by the individuals themselves or by a staff member.

Prior to the study we anticipated that the general population would have the greatest variety and highest proportion of integrated activities. We anticipated that the community groups' breadth and variety of activities would not be as great as that of the general population. We also anticipated that their results would be higher than the equivalent ones for the hospital group. In fact of all the activities listed, we found that the hospital had twice as many activities as the community group. Although the hospital group had many more passive activities (watching television, listening to records etc.) than the community group, it was the finding that the hospital group also had many more active interests (entertaining friends, holding a party, writing etc.) than the community group which is the most significant. A similar pattern was found with outdoor activities; the hospital having many more segregated activities (Gateway, hospital evening classes) than

the community group but also having significantly more integrated activities (church, pub, visiting etc.). The general population had no segregated activities and were also able to take advantage of activities which were expensive e.g. restaurant, concerts, car repairs, photography etc.

The findings of the study again indicate that being in the community does not always automatically mean improvement and integration in quality of life. We need to understand what is valuable and worthwhile in a hospital setting and to compensate or transfer this to the community. In our case the hospital had an active leisure and recreation department staffed to facilitate integration. The situation in minimally staffed group homes was such if you were unable to go out on your own, social activities were limited unless efforts were made to recruit volunteers, mobility helpers. Leisure and recreation services have now been extended to community group homes and staff are more aware of the need to involve other people in the local community.

Highly Staffed Housing

A number of teenagers and young adults, who were labelled as having severe learning disabilities and severely challenging behaviour, were also amongst the first to move into the community in the planned resettlement of 1984 onwards.

As this was a group for which there was little research evidence to guide practice it was decided to research, as thoroughly as possible, the effects of moving into the community on the young people themselves, their relatives, and the staff working with them. A further study looked at the images of people with

learning disabilities held by the wider community and the factors influencing these images.

Parental Views

Parents were naturally very concerned about the effects of the move on their offspring. Prior to the move parents expressed the hopes that their son/daughter would be given more opportunities to learn and develop within the community, that they would integrate and that their relationships with their carers and parents would improve. They also were anxious about their child's safety, negative reactions from the public, and staff facing the same problems they had experienced when their offspring had lived at home.

Parents were also asked their views six months - one year following the moves into the community. They felt most of their hopes had been realised and they viewed the moves as successful. However, some worries remained: that staff might take over their role as parents, that staff might become worn out and isolated as they had done and what would happen if their son or daughter "failed".

Young People

Overall the young people make marked improvements in their self-care and domestic behaviours following the move. Statistically these were shown to be related to time living in the community - with better staff ratios, improved quality of experiences - rather than to maturation alone. These skills maintained and improved at a two year follow-up.

Challenging behaviours decreased overall. However these were slower to change and were very individual. A few people found the move itself stressful and their challenging

behaviours showed an increase in the initial settling-in period. This can be reduced by good preparation and resettlement procedures and keeping other aspects of the person's life stable during this period. A small number of people became distressed and disruptive following some twelve months living in the community. This seemed to be due to long-term, deep-seated problems, usually of an emotional nature, emerging in the greater security and closer relationships provided by the small community houses. In other words there was psychological development as well as skills development but this was sometimes too traumatic for the person (and the staff) to manage.

Finally, with regard to use of community facilities, a significant increase in the use of all types of facilities, including leisure facilities can be seen. Two factors seemed to influence the degree to which contact and integration with the community progressed - the position of the house (central/isolated) and the attitudes of staff (care - giving/risk taking).

Staff

Parents were the first to voice concerns about the stress staff might be put under, working in the community. They were sensitive to this aspect of care in the community based on their own experiences.

Most of the causes of staff stress and anxiety are indeed general to everyone caring in the community, some a little more specific. Generally they come into the categories of being in the public gaze, training, support and working relationships and emergencies.

However, although staff stress is high and getting higher as evidenced by increased sick leave, there is little staff turnover in the

highly staffed houses. In other words, the sources of satisfaction are currently outweighing the stress factors. Nevertheless the issues of isolation, support, and institutionalization need to be investigated further, and the findings heeded, if staff burn-out and demoralization are not to be the result.

Community Attitudes

The findings of this study, of attitudes in 5 neighbourhoods surrounding different residential establishments for people with learning disabilities, quite clearly show that type of accommodation does have an important influence on attitudes. Basically the neighbourhood around the large hospital had the least positive attitudes, the neighbourhood around the longest established group home had the most positive attitudes.

The results support the argument that "people are accepted into a community more readily if they are seen to live in similar circumstances to other people and are not labelled as being different".

Implications of Research Findings

For Management

- 1) Agreed and shared philosophy of care which encompasses:
 - adequate staffing for implementation
 - risk-taking
 - managing vacancies
- 2) The importance of team building and trust.
 - regular meetings with staff
 - handover time
- 3) Supporting a system that responds to individual development.

- for some a home for life may not be appropriate

- 4) Acknowledging residents', staffs' and carers' anxieties and providing time and support for dealing with them
- 5) Transferring good practices, services and facilities into the community
- 6) The community is as a learning situation for all - need for constant monitoring and research.

For Clients

- 1) Practical daily living skills are not enough - a greater emphasis throughout on social/communication skills, emotional expression, understanding feelings etc. is necessary
- 2) Ability does not predict success. People are often selected on the basis of ability but emotional maturity, ability to cope with relationships and with the demands of being in the community are also important
- 3) Resettlement can increase challenging behaviour for a time and such behaviour is slower to improve than practical skills. For some people change produces immediate stress, for others stress occurs later when deeper seated anxieties may become exposed. Also institutional programmes aimed at controlling behaviour are a poor preparation for successful community care.
- 4) Too many changes increase failure as does a lack of day care.

For Staff

- 1) Staff attitudes are crucial in staff selection
- 2) Development of problem solving approach requires time for discussion outside hand-over periods

- 3) *Staff training and preparation demands*
 - greater emphasis on emotional development
 - working with and managing groups
 - use of leisure opportunities
- 4) *Career structure.*
- 5) *Emergency cover must be*
 - easily accessible
 - knowledgeable about group homes
 - known to residents

Ongoing Issues

- 1) *Working in the residents' own home and responding in an adult to adult relationship. The residents' right to choose and to make decisions is important. Achieving a balance between staff enabling and staff controlling. Who decides whether a resident's decision is reasonable or not? It is important for residents to become involved in staff selection. What should happen if a resident does not like a member of staff? Residents have a right to say no and to criticize, this can be very hard for staff to accept.*
- 2) *Setting and monitoring standards - since there are many different standards whose standards do we monitor? We are faced with many regulations - COSHH, Health and Safety, Fire etc. Also how can standards be monitored? There is no automatic right of access into somebody else's house nor is there an automatic right to look in cupboards, to criticize etc. How do we achieve good quality care and respect residents' privacy, dignity and rights?*
- 3) *Autonomy versus seeking help - staff in group homes are in a much more autonomous position. They have no help readily available and they have to cope on a day to*

day basis. This often increases staff confidence and assertiveness. Whilst generally beneficial, this can have the consequence of leading to an unwillingness to acknowledge when help is really needed. Staff proud of their ability to cope can consider seeking help as a failure. The latter needs to be avoided if the service is not to become insular, inward looking and not in the best interests of clients.

Conclusions

Our research to date has shown that many people resettled from a hospital to the community can and do benefit from the change. They learn new skills, have a wide variety of new experiences and can develop socially and emotionally. Staff too develop self confidence and take pride in the achievements in the people they have helped. However, we can never be satisfied that we have got care in the community right. We need to continue to monitor and question if we are to maintain a service that does enhance personal development and opportunities. Our research has also shown us that mistakes have been made and has given us ideas of where changes and improvements can be made. Without such monitoring, it would be all too easy for community care to drift into isolated, segregated institutionalization.

Managers as well as staff feel stressed by trying to maintain good quality care in the face of pressures of hospital closure, budget cuts, expediency, pressure for places and criticism when things go wrong. Many staff working within community settings are dedicated, generous and have a strong commitment to the client group. Although these qualities are essential for a good quality

service, the service cannot rely on these alone. Community services need to be backed up by a sound management structure and by mutual desire to learn from the experiences of residents, parents and staff.

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