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CARDIFF UNIVERSITIES SOCIAL SERVICES

"HOMES NOT HOSPITALS"

- a review of the C.U.S.S. Group Home.

Based on a paper given by J.I. Howard at a conference of the National Society for Mentally Handicapped Children on 11th March 1978.

C.U.S.S. is a university-based voluntary organisation that specialises in working with mentally handicapped people and their families. Its origins date back to the late sixties when C.U.S.S. was a loosely organised group of undergraduate students engaged in a variety of traditional voluntary work. The late sixties saw a growth of political awareness within students unions, an awareness which questioned the value of traditional community service. The concept of voluntary work as the passive, apolitical and uncomplaining supplement to the statutory services gave way to a new philosophy in which students were seen as catalysts, exposing and focussing attention on wider structural problems. A new emphasis was laid on action that would lead to significant change. This new approach commanded attention in the affairs of student unions and in so doing secured a greater share of the available resources.

The result of this in Cardiff was that two student groups secured funds from the University College and U.W.I.S.T. Unions. One was the Student Community Action group which took up a diverse range of community projects, and the other was C.U.S.S.

At this time C.U.S.S. was running a project with a group of mentally handicapped children from Ely Hospital in Cardiff. The children were taken out each Saturday morning to the cinema accompanied for the first year or so by one nursing assistant. It was exactly this kind of project that new students with new ideas felt was useless. They were faced with children from a barren institutional environment, children who had no personal possessions, who lived in conditions that would not be tolerated for other children in care, and all they were offering them was a trip to the cinema. The students were appalled by what they saw in hospital, the bleakness of the environment devoid of any features that would either ameliorate the children's handicaps or create a warm and caring atmosphere for the children to grow up in.

Early in 1971 C.U.S.S. wound up the remnants of other projects and devoted itself solely to working with the mentally handicapped.

It became clear that the hospital had not worked out what volunteers were for; it was not that they had an out-of-date approach towards the role of volunteers or a policy that C.U.S.S. disagreed with; the hospital simply had no policy at all. So it was up to the students to work out what they should do and how they should work. The turnover of volunteers in C.U.S.S. was high at this stage. This reflected the feeling amongst students that they were not getting anywhere, that there was no ultimate purpose behind their work. It became clear that the work had to be immediately rewarding totthe student to attract and maintain his interest in the first stages of involvement, and at the same time students had to see some value in their work in the medium and long term. This meant that the volunteers' work with the children had to become rehabilitative rather than simply diversional.

Here the hospital's function provided a new problem. While professing rehabilitative aims, like any other hospital, there were few opportunities for learning everyday skills. This was largely because of the physical nature of the hospital environment. If residents were ever to have the chance of living in the community, how were they to learn to serve, let alone cook meals, when the plated meal service provided for everyone? How could they learn to cross roads in a setting where everyone walked in the middle of the road; how could they learn to take care of clothes when the central laundry catered for everyone, irrespective of their own abilities? There are more subtle effects than this; one of the attributes testifying to 'severe handicap' in the eyes of the staff, and poor prospects for rehabilitation was in-

appropriate behaviour, for example screaming, rocking, head-banging. But this kind of behaviour occurred in wards where the environment was lacking any materials for constructive play, where there were few adults to interact with and therefore little opportunity to learn appropriate behaviour. In short the ward was an abnormal environment which was conducive to the display of abnormal behaviour.

The students' experience of what life in hospital was like led to the idea of a group home where students would live with a small group of mentally handicapped teenagers. In the autumn of 1971 an outline brief for such a project won £200 from a local MIND competition to develop the idea further.

To describe every step over the next two years would be to recount the problems of getting money, familiar to all voluntary organisations. It would also entail a discussion in more depth than is possible here of the tooth and nail opposition of some people in the traditional hospital disciplines. Suffice it to say that eventually it was necessary to approach directly the Welsh Hospital Board, who very kindly indicated which way the wind was blowing to the hospital management. One very important exception to this was the Senior Clinical Psychologist at Ely Hospital, who became a major source both of technical expertise and also of vigorous encouragement. His involvement introduced the students to behaviour modification and the use of teaching programmes, leading gradually to a weaning away from the unsystematic approaches of early work to a learning theory approach in all the projects.

In January 1974 a four-month rehabilitation programme was started at Ely Hospital to prepare a group of five residents from a potential group of eight. The hospital were reluctant to use their own staff for the programme but this problem was overcome by appointing staff to carry out the training by means of a grant from the Kings Fund Centre. The results of the rehabilitation programme were adequate but disappointing.

In a report (1) at that time attention was drawn to the limitations of the hospital environment.

"Despite the good performance of the group of five, certain factors have prevented further progress. These may be summed up as (i) the institutional environment in which training has to be conducted, (ii) the institutional routine the clients had been subject to in the past and when the Trainers were not on duty, (iii) the presence of intermittent rewarding of undesirable behaviour by hospital staff and other patients, and (iv) the different attitudes, training and values of nursing staff which in a minority of cases has led to some disagreement."

Overall there was a tendency for hospital staff to preserve standards of efficiency and uniformity, and these values, intrinsic to the smooth running of a large organisation, conflicted with the goals of personal responsibility and independence which were basic to the rehabilitation programme. In the light of this experience it seems clear that rehabilitation programmes cannot be effectively carried out in a typical hospital environment. Training in domestic and social skills is far more successful if it takes place away from the hospital, in a normal domestic setting, preferably the one to which residents will eventually move.

By this time the search for suitable accommodation for the group home was

but nothing suitable was offered. The basic criterion in the search for accommodation was that the home should be of normal domestic scale and design, with no special features that would distinguish it from the surrounding neighbourhood. Not more than two should share a bedroom; cooking and bathroom facilities should be typical of a family household, and there should be a communal living room. No special living areas for 'staff' were to be provided since this would encourage social distance between handicapped and non-handicapped residents, characteristic of institutional patterns of management. The situation was finally resolved in March 1974 when the University College offered to house the project in one of its own properties close to the Students Union.

The home opened in July 1974. Four students live with five mentally handicapped people all of whom were classified by the hospital as 'severaly subnormal'. These five were amongst the group of youngsters with whom the students had been working since the early days of cinema outings. Apart from severe mental handicap two of the residents have serious speech difficulties, one is diabetic, and one is epileptic with a minor physical handicap.

The home is financially self-supporting in that the residents receive either student grants or supplementary benefit, and all pay the same economic rent to the University. Residents attend adult training centre or their college classes during the day, while at evenings or weekends they share housework tasks or participate in leisure activities which make as much use of the neighbourhood facilities as possible. Student holidays are covered by other students or social work students on placement in the Group Home. Support also comes from non-resident volunteers who undertake some training programmes and from the full-time social worker, employed to develop community links and monitor progress in the home. The social worker's salary is met by grant-aid from the South Glamorgan County Council and South Glamorgan Health Authority.

When the home opened there was an immediate increase in ability all round; more was learnt in the first three months than in the previous three years. This showed the enormous scope for developing the potential of these five handicapped people, given the right environment and training.

The role of the student resident is part trainer, part friend (2) In the early months emphasis lay in the training aspect of the role, because of the need for developing basic skills like crossing roads, preparing simple meals and doing household jobs. At this time activities in the home were closely organised, much more so than they are now. A simple checklist was used, with which each resident's activities were reviewed at the end of day. A rota system was set up to allocate tasks in the house such as cooking, washing-up etc. and to arrange times for individuals to do their laundry and ironing. With increasing mastery over such skills the training aspect of the student's role has since become less marked. Greater attention can now be paid to the development of individual personalities, the encouragement of outside interests and hobbies, and the widening of friendships outside the home. Developing personal choice, initiative and responsibility are the broad aims that the students work towards in their relationships with the residents.

Even in a small home there is a risk that institutional practices may develop, perhaps without people really noticing. Therefore it was important early on to set fairly specific guidelines about standards of care in the home. The students and social worker set about drawing up these guidelines in the form of an operational policy, now called the

initially by drawing attention to particular institutional practices which we wished to avoid. These include:

1) Rigidity of routine.
2) Block treatment. This means the general regimentation of residents in groups for certain activities such as bathing or toiletting.
3) Depersonalization. This refers to the lack of personal possessions and privacy or the lack of opportunites to make decisions and choices.
4) Social distance. This refers to the extent to which staff and residents mix together, whether for example they eat together or separately.

The Guide to Good Practice guards against these types of practices developing in the home. Paragraph 48, for example is aimed at avoiding rigid routines: 'Mealtimes shall be flexible enough to allow for (i) individual choice and (ii) participation in other activities.' Paragraph 42 is to do with social distance: 'No areas in the house shall be restricted exclusively to non-handicapped or handicapped residents'. Part of the social worker's role is to monitor practices in the home according to the standards drawn up in the Guide to Good Practice.

Training in the Group Home is now dealt with using the American method of 'Goal Planning' (45) This was introduced with guidance from the Unit for Research into Mental Handicap in Wales. Goal planning is a set of principles and techniques for training. It involves the breaking down of each skill to be taught into a series of small graded steps, each of which can be achieved in a short period of time by the trainee. Only when one step has been fjlly mastered does the trainee pass on to the next step. Goals must always be stated unambiguously in behavioural terms so that there is no problem in deciding when a goal has been achieved. Goal planning has proved to be a very useful strategy for several reasons:

1) The setting of specific goals for the trainee means that progress is measurable in terms of goal achievement, and also indicates to the trainer the particular areas on which he and the trainee should be working. Kushlick (1966) has pointed out that when goals are described only in very general terms, such as for example, 'to develop the potential of the handicapped person', they become impossible to achieve. It is much more useful to work towards the achievement of specified skills or behaviours, no matter how small the steps have to be.

2) A well-written goal plan includes full information as to who is to do what in the steps achieving the goal. One important factor which may help to account for the failure of many training progreammes in hospitals and other settings is the diffusion of responsibility which occurs amongst the staff - where it is not made clear exactly what contribution each person makes to the training process.

3) Goal Planning stresses the importance of involving the trainee in the setting of goals. This should be possible even for someone who is profoundly handicapped by always attempting to make choices available, and by incorporating what the person is good at doing and likes doing in the methods used to achieve the goal. Being involved in planning his or her own goals is a basic right of each handicapped person. This simple right is often overlooked by professionals in planning programmes.

4) The use of written goal plans means that information about the training programme is readily available to people who are not directly involved in training. In the group home this means that volunteers can see what areas of training are being covered and re-inforce these areas of learning if they have the opportunity. Having clear written plans also makes it easy for information to be passed on to the CUSS Board of Trustees, who act as an ethical review body. Information can also be passed on readily to the Adult Training Centre where this is to benefit of the residents. Whilst liaison of this kind is important certain training programmes are treated with confidentiality.

5) Goals are broken down to small, manageable steps, and a target date is set for the achievement of each step. This helps to ensure constant progress which is reinforcing for both trainer and trainee.

In October 1976 two instructors were employed by C.U.S.S. under the Job Creation Programme. Each handicapped resident now spends two days a week working with an instructor on a one-to-one basis. At the start of the project the trainers and two of the non-handicapped residents attended a two day goal planning workshop organised by the C.U.S.S. social worker, who had previously attended such a workshop herself. The workshop outlined the basic strategies involved in goal planning as well as giving practice in writing goal plans and opportunities for discussion.

As part of establishing goal planning in the group home a small core of 'resource people' were identified who agreed to help with particular problems as they arose. These included the Director of the Research Unit into Mental Handicap in Wales, the clinical psychologist at Ely Hospital, and later, a speech therapist.

Fortnightly meetings take place between the social worker, the non-handicapped residents and instructors to review achievements and set new goals. These meetings also offer opportunities for students to discuss how they can best reinforce the skills being taught by the instructors, for example, if one of the residents is learning to tell the time the students can reinforce this by asking him to give them the time at suitable moments. This co-operation between the residents and the instructors is very important in helping to ensure that the skills are generalised from the rather specific training setting to other applied situations. The handicapped residents who are available at the time of the meeting are invited to attend and participate as much as possible.

Meetings between the social worker, trustees and instructors are arranged at approximately three monthly intervals so that the Trustees can monitor the sort of goals and methods used in the group home, and help to ensure that these are in the best interests of the residents.

The instructors now working in the home are looking at ways of developing work skills amongst the residents. Each of the five are interested in having a job of some kind and each have their own particular strengths to offer. There is general optimism about their capacity for acquiring new practical skills, but areas such as time-keeping and application to the task in hand will require extra attention. At the time of writing two of the residents have been offered the opportunity to test out their work abilities in a local bottling factory. A trial period has been arranged at the end of which temporary paid employment may be offered. During this period the instructors employed by C.U.S.S. will work alongside them teaching them the skills they need to do the job.

One of the most worthwhile results of the Group Home has been the difference it has made for the families of the handicapped residents. They have all taken great pleasure in seeing the progress that the residents have made since leaving hospital, and the independence they have achieved. Visiting is now a more enjoyable and positive experience for these relatives. The home can accommodate visits at practically any time, there is privacy for a quiet chat, another place can be laid for tea if someone wants to stay, and the welcome from all the residents is unambiguous. Now that the residents have a more active and interesting life there is much more to talk about, and improved language skills make communication that much easier. There are also more activities at hand for relatives to share in. These aspects, together with a general improvement in social behaviour, have enhanced the relationships between the residents and their families, making contact a mutually rewarding experience. The only drawback to developing more frequent contact is the geographical distance of some of the families from the home. This in part results from the large catchment area served by the hospital from which the residents came. We look forward to the time when residential services for mentally handicapped people are organised on a truly localised basis with small homes serving local neighbourhoods. Such a service will help important family bonds to be maintained when the handicapped member enters residential care.

The Group Home residents have established many contacts in the local neighbourhood, through their frequent use of local facilities such as shops, launderette, post office and pub. Through these daily encounters they have become accepted on individuals in their own right, not distinguished as a group through their handicap, but identified as individuals through their own unique personalities. It is this experience of meeting handicapped people in the context of ordinary day-to-day activities that breaks down the stereotypes of handicap. The experience of the Group Home is that severely mentally handicapped people can be accepted and valued by others in the community, and that people are willing and pleased to give that extra bit of help when it's needed. We feel optimistic about the integration of mentally handicapped people into the community; we know the enormous benefits that result for handicapped people in terms of their own fulfilment, but we also believe that the community stands to gain.

The C.U.S.S. Group Home has shown how mentally handicapped people can be cared for successfully in the community. We feel that it has been important in challenging the traditional concept of residential care in large centralised facilities. It has shown how mentally handicapped people can benefit from living a normal life in the community, and that the abilities of handicapped people are often seriously underestimated.

The advantages of community care must be made available to all mentally handicapped people, no matter how severe their handicap. There is a tendency amongst professionals and administrators to distinguish between those who can benefit from community living and those who cannot. In our view this is a spurious distinction which will result in restricting the quality of life for many mentally handicapped people and their families. Clearly we need a system of residential care that offers a full range of support (6) - from unstaffed homes and flats for the most able to highly staffed homes for the small minority of handicapped people who need intensive support. The organisation of a service that

is locally based and that really needs individual needs, will require new effort and commitment on the part of the statutory authorities, and initially it will require more money, but we believe that a home in the community, close to family and friends, is the right of all mentally handicapped people.

The experience of the C.U.S.S. Group Home has given us an optimism that we want to share with parents and professionals alike; we hope that it will add to the weight of evidence in favour of community living for all mentally handicapped people.

R E F E R E N C E S

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