

EVALUATING THE IMPACT OF A MOVE TO ORDINARY HOUSING

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INTRODUCTION

The trend towards accommodating people with a mental handicap in ordinary housing as an alternative to hospital or hostel provision has grown significantly in Britain in the 1980s. Government policy as outlined in the 'Care in the Community' document (DHSS 1983) and the All-Wales Strategy (Welsh Office 1983) has provided greater momentum to this trend. In the United States similar policy initiatives have been developed during the 1970's, although, the emphasis, as indicated by state funding, remains with traditional institutional provision (Bruininks, Hauber and Kudla, 1980).

The development of residential alternatives in community settings has frequently been accompanied by evaluative studies. (see Heal, Sigelman and Switzky, 1978). The focus of such evaluations has usually been on examining the community adjustment of individuals, with a particular emphasis on skill acquisition, and successful community living being defined as not returning to institutional care. (Lakin, Bruininks and Sigford, 1981). More recently, the use made of generic services and community facilities have been included in evaluative studies (Humphreys, Lowe and Blunden, 1983). However the size of the populations studied usually preclude detailed examination of the effects of community living on the lives of the individuals concerned.

Consequently, there is little, particularly British, detailed evidence of the impact of ordinary housing projects on individual mentally handicapped people. Scheerenberger (1974) on the basis of research work states that the American experience shows that "community residences can become as dehumanised as large institutions". As Sluyter (1985) in a review of literature relating to deinstitutionalization states "the relocation of people to such places does not help us achieve the goals of normalization and appropriateness". Zigler and Balla (1977) argue that "research must take into account not only the behavioral functioning of residents but the quality of life they experience, the extent to which they maintain contact with the community and whether they are successfully discharged to community placement".

Clearly, statements regarding the success or otherwise of community placements on the quality of life of individuals, require the researchers to make explicit the values on which such judgements are based. Debates surrounding issues of 'quality of life' appear to have achieved little except reluctance on behalf of researchers to undertake research which concentrates on detailed examinations of the lives of service recipients. Therefore, in the study described, there is an assumption that to participate in a range of activities is good, and that regularly interacting with a range of people is also good. In addition, it is assumed that contact between handicapped people and non-handicapped people in ordinary settings is of value to all concerned.

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AIMS

The study had the aim of evaluating the impact of the residential component of the NIMROD community-based service (Welsh Office, 1978) on the lives of four of NIMROD's clients. The impact was to be evaluated in terms of changes in the lifestyles of the individuals. The term lifestyle is used to refer to the day-to-day activities of individuals, the settings in which they occur, and the people they meet.

PARTICIPANTS AND SETTINGS

Anne

Anne was a 27 year old woman who had been living in a mental handicap hospital for a period of 8 years. While in hospital she lived in a 28 bedded unit which was described as providing a living environment for people with a severe mental handicap who displayed asocial or disturbed behaviour. Anne was described by hospital staff as being fully ambulant, continent and capable of dressing herself completely. She was also reported to have full use of speech. It was reported that she had some difficult behaviours and was frequently aggressive to others. Staff, however, said that she was not a severe management problem. When described by hospital staff, Anne was referred to as a "loner" with no identifiable friends.

Sarah

Sarah was a 78 year old woman who had been living in hospital for 31 years. While in hospital Sarah had lived on three of the wards. Prior to moving to the house she was living on a 28 bedded unit which was described as accommodating elderly severely mentally handicapped men and women. Sarah was described by staff as having difficulties in getting around (due to an earlier hip fracture) and walked with a frame, but was fully continent and able to dress herself. Staff reported that although she had no behaviour problems, she could at times be anti-social.

Mary

Mary was a 27 year old woman who lived at home with her parents and grandmother. Both her parents were reported to be chronically ill, her father having had to retire early. While living with her parents Mary attended a local Adult Training Centre and received regular short term care at a mental handicap hospital. Mary was described by her parents as being fully ambulant but having toilet accidents occasionally. It was stated that Mary suffered from athetosis, a condition which affects co-ordination and movement of the limbs. It was also reported that she had severe sensory disabilities; she was deaf and communicated mainly through the use of gestures and signs. In addition, her parents stated that she had some behavioural difficulties which they found difficult to manage.

Linda

Linda was a 39 year old woman who had been living in hospital for 29 years. Linda lived in a 25 bedded unit within the hospital which provided accommodation for severely physically and mentally handicapped women. All of the women in the unit, with the exception of Linda, were non-ambulant and very dependent on staff. Linda, however, was described by staff as being very able, fully ambulant and having no physical handicap. Staff, also, reported that Linda had no difficult behaviour.

The four participants had been offered accommodation in a staffed house of the NIMROD service. One of the participants (Linda) declined the offer to move to the house and remained within hospital.

In May 1984 three of the participants moved into a staffed terraced house in the north west of Cardiff. The ground floor consisted of a dining room, living room, kitchen, utility room, bathroom and toilet and a single bedroom. On the upper floor there were four bedrooms, a bathroom and a separate toilet.

The philosophy of the NIMROD service argues that the provision of accommodation in ordinary houses provides residents with an increased opportunity to live as normal a life as possible. The work of the staff was directed at meeting the needs of residents on an individual basis and to support individuals in participating in ordinary activities in community facilities. The house was staffed twenty-four hours a day and had a staff compliment of eleven: 1 Senior Care Worker, 4 full-time and 3 part-time Care Workers and 2 Night Care Workers. In addition to the three research participants, the house had a further two female residents.

METHOD

Two methods of data collection were employed for the study; direct observation, and diaries. Each of these is described below. Pre-move data were collected for all individuals in May 1983 and post-move data eighteen months later, three months after the individuals had moved to the house. The length of time that elapsed between data collection points was due to delays in finishing repairs and alterations to the house.

1. Observational Data

An interval recording method was used for collecting observational data. This method involved recording the main activity for every five minute interval of the observation period. When more than one activity occurred in an interval, the one of the longest duration was recorded. In addition, the location in which the individual spent most time in every five minute interval was recorded; whether the person was engaged in an activity with someone else; and any contact, physical or verbal, initiated by the individual or made to her was recorded.

Observational data were collected for each individual on two evenings, in both phases of the study, between the hours of 4.00 p.m. and 8.00 p.m. During the pre-move phase all observational data were collected in the same week as diaries were kept for individuals. In the post-move phase, for those clients having moved to the house, observations were made on only one evening during which diaries were kept, and one evening following the completion of the diaries. To respect the individual's right to privacy, observations were made in the communal areas of the settings and in the community or hospital grounds. In order that the presence of researchers would not be intrusive, observation procedures directed researchers to respond to initiations made by others including the client being observed, but not to initiate conversation.

Inter-Observer Agreement

Observations were shared between the authors. Prior to both pre-move and post-move data collection, the researchers simultaneously but independently observed sequences of video film to obtain data on the level of inter-observer agree-

ment. The subjects and settings of the film were not those of the study. The level of agreement was calculated as:

$$\frac{\text{No. of intervals on which observers agreed}}{\text{Total No. of intervals}} \times 100$$

Inter-observer agreement ranged from 76.9% to 100% in the pre-move phase, and from 84.6% to 100% in the post-move phase.

2. Diary Data

The primary carer was asked to complete a diary for the participant for a one week period in both the pre-move and post-move phases of the study. The carer was asked to record the activities of the individual, their duration and her location throughout the waking day. Researchers visited the carer daily when the diary was being kept, to examine it and to ensure that all times of the day were accounted for, and to ascertain whether the carer was encountering any difficulties in completing the diary. When the individual left the home without the carer, only the destination of the individual and the time the individual left and returned home were recorded.

Observation-Diary Agreement

Due to the fact that observations were conducted in the same week as diaries were being kept, data were obtained on the extent to which the observations made by researchers were in agreement with the diary record kept by staff and families. The comparisons were made to obtain an indication of the accuracy of the diary data. The level of agreement was calculated for each five minute observation interval for the categories of 'location' and 'location plus activity'. The level of agreement was calculated as:

$$\frac{\text{No. of intervals in which observations and diaries agreed}}{\text{Total No. of intervals}} \times 100$$

TABLE 1
Percentage Agreement Between Diary and Observational Data

CLIENT	Pre-Move		Post-Move	
	Location	Location & Activity	Location	Location & Activity
Anne	81.2	76.0	64.6	62.5
Sarah	61.5	42.7	45.8	33.3
Mary	81.3	74.2	71.0	60.4
Linda	87.0	73.0	83.5	66.5

Table 1 reveals that the level of agreement between diaries and direct observations was of an acceptable standard for three of the four participants. However, agreement levels for Sarah were generally lower and consequently these data must be used with some caution. In addition, higher levels of agreement were obtained in the pre-move settings. For an agreement on location to be scored, it was necessary for the diaries and observation records to agree on the specific room the

individual was located. It appears that this was easier in the hospital settings because there were fewer rooms available to individuals.

RESULTS

Data will be presented in this section for all four participants describing the changes in where they spent time, and the main activities undertaken as recorded in their diaries. In addition, the changes in contacts made to, or by, participants as recorded by observation, will also be presented.

TABLE 2
Percentage Time Spent in Settings

Location/Subject	Anne		Sarah		Mary		Linda	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Community	4.9	16	3.6	2.9	9.3	14	0	0
Mental Handicap Services	34.1	32.2	1	0	36.0	31.0	22	24
Living Setting	61	51.8	95.4	97.1	54.7	55.0	78.0	76.0

Table 2 shows the proportion of time awake spent by participants in various locations during the pre and post move phases of the study. The category of 'Community' refers to times when the individuals were both outside of their living settings and not in any other mental handicap service. The category 'Mental Handicap Service' refers to attendance at an Adult Training Centre, an occupation Centre within hospital or attending recreational or leisure events within hospital. The category 'Living Setting' refers to time spent within the subject's home, or living unit within hospital.

The data show that for all individuals, the majority of their time was spent within the living setting. The main changes that can be observed are for Anne and Mary, who moved into the staffed house from hospital and parents' home respectively. Anne spent more time (+ 11.1%) in community settings following her move to the house. This increase is accounted for by visits to the cinema and pubs, and going shopping.

Mary also spent more time in the community following her move from her parents' home. This increase was matched by a decrease in time spent in other Mental Handicap Services. Mary spent the most time, of the four subjects, in community settings in the pre-move phase. This time consisted of visits to her sister's house and going out for a ride in her father's car. Following her move to the house, contact with her family was maintained, but in addition visits were made to pubs and places of interest with a member of staff or her volunteer.

For Sarah and Linda, little change is shown in the time spent in the various locations over the period of the study. For Sarah, however, the post-move data may be atypical. During that period she was unwell and many of her reported routine activities, for example, shopping, had not taken place, to the same extent. Linda who remained in hospital, showed little change in the time she spent in various

locations. As can be seen from Table 2, she spent all of her time, either within the unit where she lives, or within the hospital grounds.

TABLE 3
Percentage of Time Spent in Activities

Activity/Subject	Anne		Sarah		Mary		Linda	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Personal Care	15.8	11.0	16.5	13.4	15.6	17.4	20.5	17.1
Eating/Drinking	13.3	12.6	16.9	11.1	20.3	20.3	14.1	17.1
Domestic	0.6	17.7	0	9.5	17.2	14.5	30.8	35.5
Recreational	50.8	35.2	47.4	27.4	28.1	21.7	32	30.3
Social	5.9	9.5	8.2	14.1	6.2	11.6	0	0
Sitting	13.6	13.9	7	16.8	10.9	4.3	2.6	0.7

Table 3 presents data, collected by diaries, on the proportion of time individuals were engaged in various activities for the two phases of the study. The data excludes times when the participants were at their day setting. For Anne and Sarah, who moved to the house from the hospital, the main change that can be observed is an increase in time spent engaged in domestic activities within the house. In the pre-move phase of the study very little, or no time, was recorded for them being engaged in domestic activities. Following her move to the house, however, Anne helped to prepare food for herself and others, and also participated in planning grocery requirements for the week. Sarah also participated in meal preparation and in looking after the laundry.

For both these participants there were large decreases in the time spent engaged in recreational activities following the move to the house. Recreational activities in the pre-move setting consisted, largely, of watching television and sitting in the ward reading books. Watching television still played a major part in the two individual's lives at the staffed house, but there was a shift towards other activities such as art work. For Mary there was also a small decrease in the time she was recorded as being engaged in recreational activities following the move. While living at her parents' home the time she was recorded as being engaged in recreational activities consisted of making woolly pom-poms. After her move, recreational activities included visiting places of interest with a volunteer and looking through photograph albums. For all three women who moved into the house there were recorded increases in the time spent in social activities. Largely, such activities comprised of talking with fellow residents and staff.

For Linda, who remained in hospital, there were few recorded changes. During both periods of the study, more than 60% of her time was spent engaged in domestic and recreational activities. Linda spent a considerable amount of her time in helping nursing staff with laundry, bed making and other general duties. During the second phase of the study, it was reported that her domestic activities had been extended and more time was recorded for Linda as being engaged in such duties. The remaining time was spent engaged, mostly, in recreational activities. This time consisted largely of watching T.V. in the 'day area' of the hospital unit, along with fellow residents.

TABLE 4
The Number of Contacts Made to or by Participants

Participant Contact	Anne		Sarah		Mary		Linda	
	Pre	Post	Pre	Post	Pre	Post	Pre	Post
Staff to X	19	80	20	45	50	125	72	101
Clients to X	15	27	70	58	0	28	5	0
Others to X	0	0	55	25	0	3	3	2
X to Staff	38	64	25	71	38	26	26	28
X to Clients	13	23	18	12	0	3	1	6
X to Others	17	19	2	5	27	18	3	4
TOTAL	92	213	190	216	122	208	110	141

Table 4 presents the number of contacts, physical or verbal, made to or by participants over two four-hour periods, as recorded by observation. For all participants there were increases in the total number of contacts made in the second phase of the study. The increase for Anne was the largest of the four subjects, increasing from 92 contacts in 2 hours to 213 following her move to the house. For Sarah, who had the highest total number of contacts in the pre-move phase, the percentage increase is smaller than for the other three subjects. For Linda, there is an increase in the total number of contacts, although in the second phase of the study she had far less contact 'with others' than the three participants in the house. For Mary, who moved to the house from her parents' home, a direct comparison of pre and post move is not entirely valid as she had only limited contact with staff and other people with a mental handicap in the pre-move period. The number of contacts with 'Others' in the pre-move data represents contacts made with her parents. The high number of contacts made to or by Mary is significant given that she is deaf and has no use of language.

For both Anne and Sarah, the major changes were in the number and proportion of contacts made to or by staff. The proportion of contacts between staff and the two women increased following their move, from 58% to 62% for Anne and 24% to 54% for Sarah. For Mary, contact with staff accounted for 60% of all contacts made in the post-move observational period. With regard to contact with other people with a mental handicap the data shows no overall trend. For Anne there was an increase in the number of contacts she initiated and received with other clients. For Sarah, however, the number of contacts with clients decreased.

The data also shows that contact with non-handicapped people, other than staff, remained low in the post-move period.

DISCUSSION

This evaluation was concerned with examining the impact of moving into a staffed house of the NIMROD Service on the lives of three women. In addition, data were collected on a further individual who declined the offer to move to the house. The results reveal that changes had occurred in the lifestyles of the indiv-

iduals who had moved to the house, but that these were more individualised than general. This is not surprising given the different backgrounds, ages, and degree of handicap of the participants of the study. The changes that were observed were not dramatic but did seem to highlight some of the benefits associated with moving into a smaller, living setting.

For Anne and Sarah, who moved from hospital, changes were more clearly demonstrated. For Anne, there appeared to be more opportunity to take part in activities both within the house and within a wide range of community facilities. For Sarah there was more opportunity to participate in domestic and social activities in the house. Benefits were also identified for Mary who had moved from her parents' home. She had the opportunity to interact with more people of her own age and to maintain both a presence in the community and her contact with her family. It appears from the data that moving into a house in the community allowed the individuals to develop, or in Mary's case maintain, a presence within the community. For Linda, who remained in hospital, there were few recorded changes in lifestyle comparable with those of the other three individuals.

Analysis of the contacts made to or by participants revealed the most striking changes for the three participants who moved into the house. The results demonstrate a higher level of contact between them and staff members. In the main, those changes can be attributed to increases in the number of staff initiated contacts, and informal observation suggested that staff were adopting a committed and encouraging role in offering opportunities and choices to the participants. However, the level of contact between the three participants and non-handicapped people, other than staff, remained low in both periods of the study. Post-move data were collected only three months after the individuals had moved to the house and consequently, the changes that were observed in the lifestyles of the three individuals can be attributed to moving into a smaller living setting and to the commitment of staff, rather than to large scale individual training.

The opportunity to participate more in a wide range of activities, both within and outside of the house was related to, and to some extent, dependent upon staff commitment. However, being able to develop and pursue relationships with people outside of the living setting is an area in which little change was observed and highlights an area where some attention is required in improving the quality of life of individuals. While the move has meant that the individuals may have increased the likelihood of interacting with, rather than merely being present in the community, it seems that its realisation will again depend upon the commitment of staff. Such commitment was demonstrated by staff in successfully finding a volunteer for Mary. The volunteer lived locally and visited Mary and regularly took her on outings.

Overall, however, the researchers feel that the extent of the transformation in the lives of the individuals was not fully demonstrated in the data obtained. Clearly, such observations have implications for future research which aims to evaluate and inform the growing trend towards supporting people with a mental handicap in the community. On the basis of this study, there are areas which deserve further examination, for example, the level of choice that is offered to individuals and the extent to which individuals participate in the community through forming relationships with non-handicapped people.

The methods of data collection used in the study were however, both feasible and valuable. The observation measure developed for the study enabled the researchers to examine a small segment of an individual's life in detail and was reported by those in the house as not being too intrusive or disruptive of the usual

house routine. A major limitation was that it was time consuming and potentially, unrepresentative of people's lifestyles. However, used in conjunction with other methods, direct observation of individuals is vital to this kind of study. The method of obtaining a more general picture of an individual's life by use of diaries was generally accurate and again useful. However, the one case of low agreement between diary and observational data suggests that more guidance and more specific written descriptions of the type of information required should increase the accuracy of the data.

The indicators used in this study suggest that there were improvements in quality of life experienced by individuals after their move into a staffed house in the community. Although positive outcomes emerged from the move, for example, increased interaction between staff and clients and wider use of community facilities, it was noted that there were still areas that required development if people are to be given the opportunity to have more control over their lives and to form valued relationships. Such developments require staff to consolidate and build upon those changes that have taken place, changes which demonstrate that people with a severe mental handicap can successfully live in smaller, more personalised living settings.

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