

COMMUNITY-BASED SERVICE - WHAT CONSUMERS THINK

Kathy Lowe

Introduction

Recent policy changes have accelerated the shift towards care in the community for people with learning difficulties (HMSO, 1989). The emphasis in service development to date has been largely on the resettlement of hospital residents into ordinary housing and in establishing the service networks necessary to support them. It has also been recognised by policy makers that adequate support for people still living at home and for the families who care for them is a vital element in the community care plan (Welsh Office, 1983). The development of comprehensive community-based services, however, is still relatively new, and the monitoring of their quality and efficacy remains an important component in the planning and delivery of resources.

Traditionally, service users have been viewed as passive recipients, although in recent years there has been a growing awareness of the importance of consumer participation in effective service planning and delivery. In discussing community-based psychiatric services,

Denner and Halprin (1974) consider the design of services to meet the needs of the people served and the accountability of professionals to service users to be central tenets of the consumer movement. Justice and McBee (1978) view the investigation of client satisfaction with services as profitable and necessary in allowing service recipients the opportunity to express their opinions and highlight areas of dissatisfaction. Moreover, Morrison (1978) states that, as the present trust towards consumer psychology continues, more and more professionals will come to see people with mental handicap and their families, not only as consumers, but as the rightful evaluators of services.

NIMROD (Welsh Office, 1978), established in Cardiff in 1981, was a major innovation in the development of services to people with learning difficulties in this country, being one of the earliest community based initiatives to support people in different living situations, including those in their family home. From its inception, the service was the subject of a five year research study (Lowe and de Paiva, 1991), part of which

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examined levels of satisfaction with the service as expressed both by clients and families.

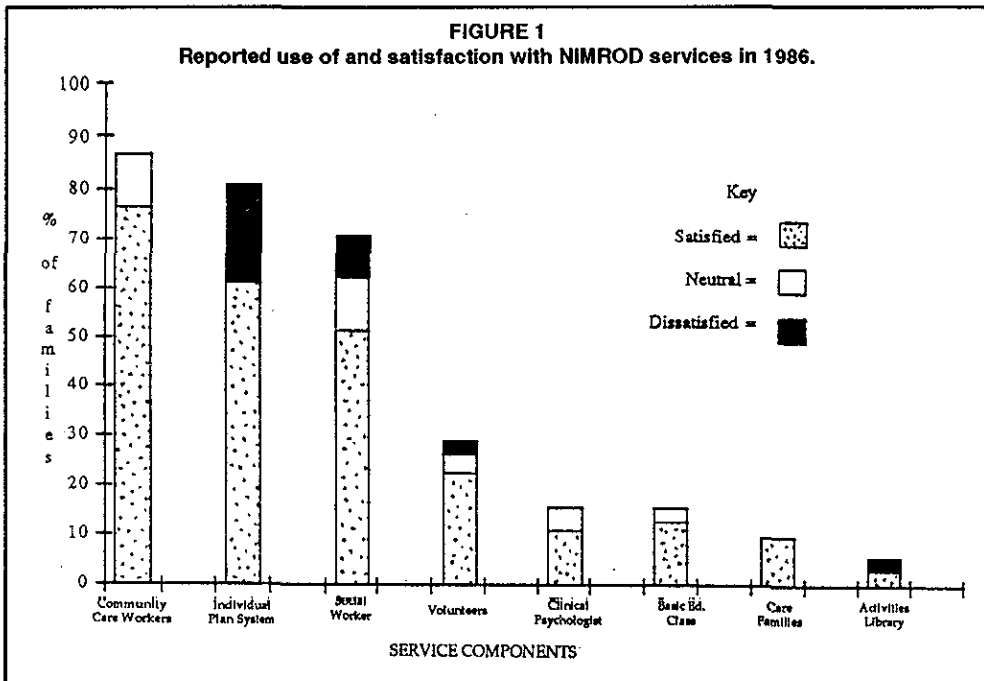
NIMROD was offered to all people with learning difficulties in a defined catchment area of around 60,000 total population. The area was subdivided into four districts (called 'communities') of equal population size and the service was introduced to one district at a time between 1981 and 1983. The service aimed to provide individual plans and key-workers for each client living in or coming from the service area, staffed accommodation in ordinary housing for those requiring residential care, comprehensive social work and clinical psychology support, peripatetic care workers serving people primarily in their own homes and minimally staffed houses, a volunteer scheme, respite care with local families, an advisory service and additional components such as a basic education class. The NIMROD centre, as well as providing a staff base, also housed an activities library, an information room and a basic education class, and served as a meeting place for clients and families. NIMROD also operated an open record system, whereby clients and their families had access to their own personal files. Family representation was encouraged through the formation of an independent consumer group.

Families' Views

Thirty-one families whose relatives lived with them participated in this study, which was designed to ascertain their views on the services they received, their service needs, and who they saw as

their primary source of support (de Paiva and Lowe, 1987). This number of families represented just over half of the total number of such families served. Around three quarters of these families comprised two carers, usually parents, and in just over half, siblings were still part of the household. In around 60% of the households, the eldest carers were aged between 45 and 64 years, and in around a fifth, the eldest carers were 65 years or older. All 31 families were interviewed three times, at two-yearly intervals. This article presents their views in 1986, towards the end of the evaluation period. By this time all had been in receipt of the service for between two and a half and five years and were, therefore, in a position to express informed opinions.

Figure 1 shows that the services available within NIMROD used by the highest proportions of the families were Community Care Workers (CCWs), Individual Plans (IPs) and Social Workers (all 75% or above). In general, high levels of satisfaction with these components were reported. CCWs were assigned to work with individual clients on goals set at IP meetings. Contact was usually on a one to one basis for about an hour each week. Families highlighted the importance of the good personal relationships that CCWs has developed with their relatives. They liked the general approach adopted by the CCW service, and appreciated the practical help they had received. As one family said: "*He's very good. His approach is a physical, active and practical one. Our son goes very willingly. We're glad of having him in contact with other people, and sleeping away in preparation for when we*



are not here anymore". No families were dissatisfied with their CCW.

IP meetings were held approximately every six months, and were usually attended by clients with their families, together with NIMROD personnel and other agencies involved with the client. IPs were liked by the majority of families, mainly because they provided an opportunity for everyone who was involved with their relative to meet together. For example, "We enjoy going. I like the idea of all the services getting together, rather than seeing people separately. It's a very good idea..." Dissatisfaction with IPs centred on the issue of talk without action. Some felt that the IP system failed to put ideas into practice. For example:

"They really get me down. We've had about six meetings and all they do is talk about what they're going to do, and we never get things done. They said loads of things at the first meeting, and even those things haven't materialized". The repetitive nature of IPs was also criticized: "There's nothing left to say. All has been discussed before. It seems rather an empty occasion as nothing is left to discuss"; and linked with this was the feeling that the interval between meetings was too short: "I think six months is too soon. We go over the same things. She hasn't had enough time to progress..."

Reasons given by families for satisfaction with their NIMROD Social Workers included the fact that they were approachable, that they provided

practical assistance such as in obtaining benefits, and that they were available whenever families needed them. As expressed by one parent: *"Fantastic. She's been great, got the bath hoist for us and the slope recemented. She's very willing and has done a lot. She got the (incontinence) pads changed and arranged the dentist. She's very down to earth. You can talk to her about anything and know it won't go wrong. She doesn't make you feel a fool as people have done in the past"*. Most of the reasons given for families feeling dissatisfied with their NIMROD social worker related to their keyworker role, particularly in terms of the lack of liaison with families and last minute preparation for IP meetings. For example: *"It was a long time before she contacted us when our son was ill. There used to be a better liaison between us, the social worker and the centre, but that's all gone now"; "I see very little of her. She talks a lot but there's not a lot of results. She loses papers - vital ones, and always does things at the last minute. She has great ideas at IP meetings, but nothing ever gets done"*.

Only a minority of families had had contact with the other services offered. The psychologist carried keyworker responsibility for only a small number of clients, and so contact was mainly in her professional clinical capacity. The service has experienced difficulty in developing fully the volunteer service, the family-based respite care scheme and the activities library, mainly due to insufficient staff resources. The basic education class served clients from one half of the catchment area only, for similar reasons. Most of the families who had used these components were satisfied with them.

Dissatisfaction was expressed only about the volunteer scheme and the activities library: in terms of the lack of continuity of the former, and the poor variety of equipment in the latter.

It had been anticipated that the NIMROD centre would provide a focus for clients and families, and can be used by them individually and in groups for meetings, social functions and casual visiting. Although the majority of families had visited the centre, most had done so on only a few occasions, usually to attend IP meetings and appointments with staff. Reasons for the centre being viewed favourably were that it was accessible, friendly and provided a point of contact. For example, one family said: *"It's a good idea and seems to be working very well. It helps you to feel you're not out on a limb - to have a contact centre. It's just like visiting someone at a house, rather than being very official. It's a lot better to have a more informal place"*. However, some families felt that, as the service had expanded and needed to accommodate increasingly large numbers of staff, the centre had become more of an office base: *"The meeting room isn't big enough. I used to think the centre was 'our' centre, but more and more over the years it's been taken over as a social services building. The staff are taking it over more and more. It's not free for us to use as patients"*.

All client records were stored at the centre, but very few families had taken the opportunity to view their relatives' file. The majority did not know that this facility was available to them and, indeed, several families indicated that they were not aware of the existence of any

file kept on their relative. Although some expressed a wish to see their file, others felt this to be unnecessary as information was regularly sent to them following each IP meeting. The majority of families regularly received the newsletters produced by the consumer group. Although around half had attended meetings of the group, few considered themselves to be active members. Many of the reasons given for not attending meetings were concerned with lack of time.

Families were asked to indicate from a list of twenty-six professional and informal contacts (including generic and specialist service staff: GPs, dentists, therapists, community nurses, volunteers, employment services, NIMROD personnel, relatives and friends) which people, if any, had been most useful to them during the previous twelve months. Those chosen most frequently were CCWs, mentioned by 19 of the families (61%), relatives (52%), ATC and school staff (45%), NIMROD social workers (39%), with GPs, neighbours and friends each cited by around a quarter. This would indicate that NIMROD staff had become a valuable support to families, but that familial and other service contacts had remained important. Families were also asked to indicate which people they would turn to for help or advice if required. A slightly different pattern from the sources of support was evident, with GPs and NIMROD social workers being mentioned most often (both 48%) followed by relatives (39%), with ATC and school staff and CCWs each mentioned by around a quarter of the families. Clearly, families distinguished

between the roles of different people, and those viewed as valuable in terms of support received were not necessarily those to whom families would turn if they had a problem. This was most striking with regard to the CCWs who were viewed by many more as providers of support rather than as advisors.

Towards the end of each interview, families were asked some open ended questions on what they considered to have been the main achievements of NIMROD, and whether any improvements in the service were needed. Nearly all identified achievements, the most frequently mentioned being the support that the service had provided for families, the help given to clients in gaining confidence and independence, and the development of service components, particularly the CCWs, the literacy class and the IP system. For example: *"It's opened up a new world for mentally handicapped people and their parents. Parents don't feel alone anymore. Parents of mentally handicapped people feel different from other people. They feel comfortable going places like NIMROD and unburdening themselves. If they go there they can get help as they require it"; "The CCW - that's a good thing. My daughter looks forward to it. She's more outgoing now. The CCWs are the most important thing. Also the IP meetings at the training centre. They're all taking more interest in what my daughter's doing. We get to meet people involved with her"*. Reference was also made to the role played by NIMROD in demonstrating the success of community living in the public eye: *"They have proved that people with mental handicap are ordinary people and are entitled*

to live in their own community with support and not end up in hospital. They've proved that people can live at home with their families with support"; ". . . hopefully, they're making mental handicap less frightening to the community in general by taking people out of hospitals and integrating them into local areas".

Almost half of the families interviewed could think of ways in which the service could be improved. An increased staffing complement was suggested, to allow for improved cover during periods of staff absence and to provide more time for direct work with each individual client. Families also identified a need for more resources, firstly to improve existing components such as the activities library and the volunteer scheme and, secondly, to establish new ones. The additional components suggested included respite care in an ordinary house, alternative day care provision, an emergency service to provide practical help in times of family crisis and financial advice, particularly with regard to making provision for relatives when their parents die.

Clients' Views

Eighteen people living in NIMROD accommodation and 28 family home clients expressed their views on the contact they had with the service (Lowe and de Paiva, 1987). Most were generally positive about their experiences with NIMROD, with many emphasizing the social aspect of their contact: "She's quite nice really, she's different. I like meeting different people"/"He's very kind, he's really good. I like being in his company . . . I've been on buses with him, and I like working with

him because he's a devil at times. He likes cracking jokes"/"He's good. I used to know him in Grangetown. He was brought up a few streets from me". For others, contact with the service represented a welcome change in their usual routine: "It's somewhere for me to go"/"It's better than staying in the training centre all the time"/"It's alright, it's not bad to go there on Mondays. I've nothing to do in the house. I get sick of it. It's good to get out".

The majority were able to identify specific ways in which NIMROD had helped them and cited skills they had learned as a result of their contact with the service. Most concentrated on the help they had received with practical tasks and the acquisition of personal skills, such as help with household tasks, shopping, personal appearance, literacy skills and leisure activities. "I've learned to use the tin opener now . . . I don't have to ask other people now"/"I can cook better. I can read quite a lot. I couldn't recognise simple words before"/"I do my goals all the time. I can talk properly every day. Me and the care worker have a talk every day, private study. I'm lazy about how I practise saying things."/ "I've learned to write my name and address. I can do sums now. I can tell the time a little bit now. It's good. It's helped me a lot".

Others specified help of a more personal nature, such as support with personal difficulties, recuperation from an operation and support in dealing with a family bereavement: "It was hard for me to mix with different people. I used to be shy. I'm better now, I mix with people easier. If I didn't go to NIMROD on a Monday night, I probably wouldn't be mixing with people . . . Now I can keep a conversation

going and mix with people and go to different places. I wouldn't go anywhere before."/
"They helped me over my father's death. They helped me get my home back, with money, to gain confidence and to find friends."

Respondents identified various aspects relating to the IP meetings which they felt to be good. One theme which emerged concerned their participation in the meetings, where they evidently enjoyed the personal interactions which took place, and being the focus of the meetings. Another positive aspect concerned their personal development and improvement in skills. Few made criticisms of the meetings, but those who did were generally quite specific about what they disliked: *"I don't like going . . . they take so long. They should only be half an hour, that's enough. I haven't got much to say."/**"They should be once a year, not every six months. I'd like a quick review every six months and one meeting only."/**"It's the same questions I've heard before. They should change the questions every time you have an IP meeting. Sometimes it goes too quick. The one in January lasted only 20 minutes."/**"Sometimes I go to my room and cry, because of what my sister tells them about me."*

A few clients made suggestions for improving the service. Some related this to their personal involvement, while others suggested more general changes: *"I'd like them to change my keyworker. I've had her for a long time now. I like her, but sometimes she doesn't turn up."/**"They could teach me to bathe myself, to read or write . . . "/**"They could get more houses."/**"They should set up a babysitting service. They'd draw more people if they could give mothers a break."*

Discussion

The results of this study showed clearly that NIMROD played a valuable role for families and clients alike. The regularity of contact families had with the service and the knowledge of where to get help if they needed it were of particular value. Both aspects represented quite a major change in some families' experience of service contact. This, together with the fact that the service was approaching families rather than vice versa may have helped to lessen feelings of isolation. It is important to recognise that NIMROD did not replace families' existing contacts, but added to them so broadening their support networks. High levels of satisfaction were generally expressed with the various services offered. Indeed, the improvements suggested indicated that families wanted more of what they were already getting, together with additional types of service, rather than alternatives to what NIMROD was providing.

However, results from 1986, when compared with the previous interviews conducted with these families in 1982 and 1984, suggested that some dissatisfaction was beginning to creep in over time. NIMROD was an innovative service, which, by definition, was breaking new ground and raising expectations from the outset. As families were becoming more familiar with this new type of service, they were perhaps beginning to view the different components with a more critical and experienced eye. There was a suggestion that, overall, as time progressed, families were becoming

more vocal in explaining what they liked and disliked about service provision. The IP system may have played an important part in this development, in that it required families to consider formally their own needs and those of their handicapped relatives. Alternatively, the growing dissatisfaction may reflect the fact that central NIMROD personnel became overstretched as the phased implementation of the service was accomplished. Running a comprehensive system of IPs is breaking new ground. Proper estimates of the personnel resources required not only to implement the system but to take action on matters arising have not yet been made. NIMROD families seem to be saying that resource levels were insufficient to keep up with a fully functioning IP system.

It is interesting to compare high family involvement in the IP system with the contrastingly low involvement in the consumer group, which was intended to be the main forum for providing feedback to the service. This group had no formal status within the service and it is questionable how feasible it would have been for families' views to be accommodated, given that the design of the service was pre-determined and allowed no flexibility for major changes in the services offered during its planned implementation and evaluation. Such rigidity highlights the dilemma for services which actively encourage consumer representation when little opportunity exists to translate recommendations into practice. Moreover, it has to be recognised that this sort of group may not be the best way for services to elicit compre-

hensive or representative views from consumers. Not all are able or willing to commit themselves to active membership and it is likely that the activities of any such body will centre around a small core of people, making it difficult for representativeness to be achieved.

Similar issues apply to eliciting the views of people with learning difficulties, with the further complicating factor of widely varying communication abilities among this group. However, the study showed that even people with limited speech often had a lot of opinions they wished to express. It has to be remembered that most of those interviewed had been actively involved in the IP process for some time and had, therefore become accustomed to being asked their views on different aspects of their lives. Nonetheless, it was apparent that many were, on the whole, less willing to criticize than praise, which may indicate that, for these people, the voicing of opinions was still a relatively new concept.

Soliciting views takes time. However, this study has shown that, if asked individually, families and clients do have many valuable opinions to contribute. In developing effective support services, it would therefore seem a worthwhile exercise for service planners to invest the necessary time and effort into actively eliciting, on an ongoing basis, the individual opinions of all their consumers.

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