Ambiguity and User Involvement: Issues Arising in Assessments for Young People and their Carers

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SUMMARY

Issues for service users and professional staff arising from contemporary community care policies emphasizing user involvement are reviewed. Against the background of a key expression of these policies, the Disabled Persons' Act of 1986, methods of providing assessments involving young people with learning disabilities were analysed. Problems identified for further study included difficulties arising for young people due to lack of experience and immaturity, the low expectations of their parents or carers, problems arising from the culture of services and how assessments may be developed which provide seriously disabled users themselves with ways of expressing their wants and needs.

INTRODUCTION

Young adults with learning disabilities have had very little say in what happens to them once they leave full time education (Jahoda et al., 1989). Their opportunities to develop 'ordinary' attitudes, interests and skills may be very limited or non-existent. Opportunities for further education and training are also restricted and job opportunities in a harsh economic climate are very scarce, particularly for people with learning disabilities. There are economic and social pressures on them which mean that they have little choice in where they live. Their lifestyles are circumscribed and life can become repetitive and boring. Lack of valued community activity through paid employment...
or voluntary work undermines self respect and for many people with disabilities, opportunities to form emotional or sexual relationships with others may be limited by many factors including the assumptions made by those who care for them and find it hard to let go. The Disabled Persons (Services, Consultation and Representation) Act of 1986 needs to be seen in this context with other community care policies which all emphasized user led services (Department of Health and Social Security, 1981; Griffiths Report, 1988; Department of Health, 1989).

The Disabled Persons (Services, Consultation and Representation) Act, 1986, was intended to improve 'the effectiveness of, and the co-ordination of resources in, the provision of services for people with mental or physical handicap and for people with mental illness, to make further provision for the assessment of the needs of such people, to establish further consultative processes and representational rights for such people, and for connected purposes'. Both this Act and the Chronically Sick and Disabled Persons Act 1970 are characterized by ambiguity, for example in their failure to give clear definitions of terms like 'disability'. Sections of the Act dealing with the representation of people with disabilities were subsequently abandoned. The Act was intended not only to improve the co-ordination of services and the assessment of need, but also to ensure that people with disabilities and their carers were more involved in decision making processes which affect them and had access to information so that they could make genuine choices and exercise their rights. The purpose of assessments was said to be to ensure a smooth transition for young people with disabilities between full time education and adult life.

**METHODS**

This paper is based on an analysis of the processes involved in working with young people with learning disabilities and their families to assess their wants and needs. The assessments of twelve young people living in one social services district in the Midlands which were undertaken by three social workers were studied. The evidence which forms the basis of the paper is drawn from (a) the social workers' records of their interviews with the young people and their families; (b) the assessments completed as a result; (c) supplementary information, for example, school reviews used in compiling the assessments; and (d) information from the social workers involved about their ideas on user involvement in the process of assessment. The paper is based on real written and verbal accounts of all the assessments completed.
in one district before November 1992. The material has been disguised to protect the privacy of the young people. The 'case studies' quoted do not refer to any one identifiable individual as personal details have been altered but the situations and the aspirations described fully represent what were thought to be relevant features of all the young people in the sample. They were all near the age level for leaving school or further education college and were aged between sixteen and twenty when the assessments were carried out. They all had severe learning and communication disabilities. Some of them also had physical difficulties, one young woman had virtually no vision and two people had marked characteristics of autism.

BACKGROUND: ASSESSMENT AND COMMUNITY CARE

The notion of assessment is central in current community care policy statements. There are several reasons for this and they are related, in possibly very obvious ways, to the involvement of people who are disabled in expressing their wants and needs. Assessment, for example, can help the process of communication by enabling service user, carer and social worker to know each other better. The code of practice for community care makes this point:

The code believes that assessment should take the form of a dialogue or conversation. . . . Critically the assessment conversation or dialogue should recognise the consumer as an active participant. The assessor should be especially sensitive to the sort of help the potential consumer would most like to receive and how he or she might react to particular forms of support

- an emphasis on the person's positive abilities and interests and where he or she might contribute as opposed to a concern only with problems
- discussion of what the person enjoys or did enjoy in the past and how this might be built upon (Centre for Policy on Ageing, 1990).

In the field of learning disabilities assessment in the past has often been a one way process which someone applies to someone else. Many assessment procedures have been about assessing people to discover their deficits rather than their strengths and they have been used to fit users to the resources available rather than what they themselves wanted. Individuals were sometimes assigned to grades or labelled and thus treated as one dimensional. This has led to questions about whether recent progress in assessment of people as individuals will be incorporated in current practice (Hogg and Raynes, 1987).
THE POLICY OF USER INVOLVEMENT AND THE ASSESSMENT FORMAT

In implementing the Act the social services department said that they wanted their operating policies to reflect the idea of a more consumer-orientated service. The policy guidance was however given in very general terms. For example, it was recommended that 'the task of assessing the needs of a young person with disabilities leaving school or other full time education should be approached on the basis of a necessary partnership between the young person, his or her carers and relevant professionals . . . as well as any other interested parties (including advocates) as agreed with the consumers'.

The Department devised a special document for recording the assessments required by the Act. The form of assessment was comprehensive. It began with a profile of the strengths and needs of the young person under the headings of (a) advocacy, (b) self-help, (c) health, (d) leisure and recreation, (e) educational and intellectual, (f) relationships, (g) vocational and (h) communication.

This was followed by separate sections on cultural requirements, financial situation (welfare rights) and services which would be required. A section called 'Assessment of Carer' was later expanded but little provision was made on the form for comments about the family and social situation of the individual, nor for a profile of the individuals' personal qualities and aspirations. The social workers and service users involved in the assessments were not consulted about the design of the form, and its rationale and origins are unknown. The Welfare Rights officers were consulted about their part of the assessment but the questions used appeared to take little or no account of their advice. The strengths-needs profile was made up of quite brief sections. Under the heading 'advocacy' it was suggested that the individual's ability to make decisions and choices, to take responsibilities and exercise rights should be recorded. 'Self-help', to take a second example, covers hygiene, dressing, eating, use of toilet and cooking. Much more detailed information on topics like these is found quite frequently in school reviews and training centre assessments and these documents are used in completing Disabled Persons' Act assessments with the permission of the young people and their parents.

THE PRACTICE OF USER INVOLVEMENT: ISSUES IN ASSESSMENT

The following profiles illustrate issues thought to require deeper investigation. They are analysed with reference to (a) the policy of
the Act mentioned above; (b) the reactions of individual young people and their relations to the process; and (c) issues arising in facilitating their involvement.

They show the stress involved in leaving school by youngsters with disabilities, and the need to facilitate the transition. They indicate problems involved for young people as well as their families in the process and the overriding feature of these needs led assessments—the ambiguities involved in the idea of user choice. These points are discussed more fully in the commentary.

MAUREEN

Maureen is a reserved and sensitive person who has found it difficult to form friendships with other people. She did not have an assessment at school. She left at the age of eighteen to go to a further education college in a town ten miles from her home. The transition was abrupt and she found it difficult to come to terms with the change from the more protected school environment, to the less structured college unit. The college experienced problems with her behaviour from the beginning. They found that she abused students and staff, and she refused to go to some classes. She behaved impulsively with dangerous equipment and finally ran away from college, despite a deformed foot. College was a daunting experience for her after the relative security of a small school. After leaving college Maureen remained at home with no day time occupation. This put a good deal of pressure on her mother. She took her to the shops but if she was in a shop for any length of time, Maureen became bored and impatient and demanded her mother's attention. This also happened if her mother had visitors at home or paused to talk to friends in the street.

Maureen had good verbal ability and it was possible for her to be involved in looking at her needs and hopes for the future during the assessment process. There was agreement between Maureen and her family that she was not ready yet for employment, but she said that in the longer term she would like to work in a shop. A nearby day centre was seen as an immediate possibility, and Maureen went to see it with her mother. She reacted positively, said she would like to go there and 'it seems a friendly place. I like the look of the things they do there'. The other possibility that was explored with the family was that Maureen should have some breaks away from home in a residential unit from which everyone might benefit. They agreed to think about this idea and talk about it to a key worker later.
Maureen's experience and the stress she faced in leaving school illustrates clearly the pressures on young people leaving school and the necessity of assessing their needs as young adults. It underlines the importance of the Disabled Persons Act in attempts to improve the co-ordination of services and the place of careful assessment in seeking to achieve a smooth transition to adult life. In part this is a negative example as Maureen moved from school to college without an opportunity to have an assessment. At college she showed that she felt the move imposed on her was unsuitable. Given the opportunity to express her preferences with help, she was able to choose a setting in which she felt more secure.

Greg was a young man aged seventeen who was already at a day centre when he was seen about his assessment. He had moved from another area but the assessment had been arranged before he left school. He used to stay at the hostel attached to the school and visited home in the holidays and some weekends. At the time of the assessment Greg lived with his brother, step-father and mother in a caravan which was compact. His grandmother lived at the same caravan park and two other brothers and two sisters, all older than Greg, lived in a nearby town. Greg had a pleasant smile and usually got on quite well with his immediate family. Junior staff at the day centre lacked experience and training in meeting Greg's special needs and found it difficult to communicate with him. He tended to withdraw if people tried to talk to him for more than a few minutes at a time. At other times he seemed to be looking for adult attention. He constantly repeated sentences like 'I'm laughing at a Benny' and placed his face close to another person and laughed in a high pitched way. His key worker at the centre was very concerned about Greg and felt very perplexed by his behaviour and the difficulty of communicating with him. He was in a group of ten people and she felt he needed more attention than she could give him. She said that he wandered around aimlessly and seemed to have no understanding of common dangers. He giggled and repeated 'Centre' when asked if he liked it there and was unable to concentrate for very long. He was unable to talk directly about the assessment but smiled and scribbled and repeated 'I've got a Benny' many times. When his mother was seen at home she said she was becoming more and more concerned about is behaviour. It had been becoming gradually more difficult
and Greg had to have someone with him if he went out. Both she and Greg’s step-father welcomed the suggestion of respite care for Greg and he was introduced to a residential home when the assessment document was written.

Greg did not contribute verbally to the production of his assessment although he was seen several times at the centre. The assessment was based on information from various sources—mother and step-father, staff at the centre and documents about his school work and the hostel at school as well as previous social services notes. His mother thought that Greg had settled down and seemed to like going to the centre and she did not want to consider alternatives.

**Comment**

Greg’s assessment raised several issues for his family and the social worker and day centre staff. It shows that attempting to involve clients with learning difficulties and communication problems is very difficult to achieve. It also shows the importance of taking account of the attitudes of his family and staff at the day centre, and how they saw his wants. Like many parents of children with learning difficulties, Greg’s parents had had minimal support from social services in the past and their expectations were very low. Their passivity and the problems of communicating with Greg were obvious sources of difficulty and uncertainty in the assessment.

No evidence is available about Greg’s mother’s views on the day centre and her decision not to consider alternative or complementary provision. One may speculate about her views in the light of the study by Hubert (1990) of twenty young people in an age group similar to those described here. She began with the aim of discovering factors influencing decisions to seek admission to long-term care, but it became largely a study of the factors influencing parents’ decisions not to seek such care. In spite of the isolation resulting from caring for their young adult children ‘in the community’ the parents resisted pressure to put their children in long-term care because of their disquiet about the quality of the children’s lives in places where their needs and wishes would not be fully understood.

**Jane**

Jane, a friendly and popular young woman of eighteen was at school when her assessment began. The social worker went to the school each week and worked with Jane’s class and joined outside activities with them. This enabled them to become acquainted with each other.
in the familiar school setting. They were able to get to know one another as individuals in a more relaxed way and the friendliness of the group as a whole supported the process. The social worker also met Jane's mother at a school open day and subsequently visited her at home for several visits to discuss the assessment.

Jane herself was outgoing and usually cheerful and she enjoyed the company of other people. Her memory for people's names was remarkably good and it seemed important in the assessment to note her need for company and for this to be borne in mind in future plans. Jane had very little sight but could distinguish light and dark and was able to recognize people who stood close to her. She needed to be guided when in unfamiliar places. She also had a left-sided hemiplegia and needed help with personal care (washing, bathing, toileting and dressing) and in using her left hand: she needed her food to be cut up for her. She was not aware of the consequences of swallowing food or drink that was too hot and thus needed careful help at mealtimes. Jane indicated her likes and dislikes by her facial expression and she used simple words or short phrases (for example 'want drink'). She had very limited perceptual and number skills and her ability to express herself was also limited as has been indicated. But it was possible to involve her in the assessment process given an understanding that her comprehension, for example of abstractions required in planning for the future, was limited.

The assessment involving her had to be taken slowly and in concrete steps. For example, it was thought that she would like to go to day centres where she would enjoy the company of other people and where she could continue to develop a range of personal skills. This was discussed with her mother, her teacher and Jane herself at school several times and she was able to visit a small health authority unit for people with visual impairments and learning difficulties. After two visits it seemed that it would be worthwhile for her to go there regularly when she left school. She expressed pleasure at going and looked forward to attending and said 'yes' when asked if she did enjoy it. Her regular attendance was arranged and this recommendation was entered in the assessment. Open and sheltered employment were not viable options and, again with feedback from Jane, arrangements were made for additional day care provision and for a key worker to provide practical help for Jane and her mother when this was required (for example arranging for a shower to be installed and advising on welfare benefits). The key worker maintained the contact and Jane continued to enjoy her attendance at both centres: the other people, including staff as well as many clients, enjoyed her company too.
Jane’s assessment also illustrates the difficulty of involving people with learning disabilities, visual handicap and associated communication problems in their assessments. It also illustrates the ways in which the service culture often operates against allowing genuine choice for clients. It can be seen in Jane’s case that the notion of a policy of user involvement is highly ambiguous.

It can often happen that the purposes of assessments and the ways in which information is obtained and used to complete them may be subordinated to the policy needs and procedures of social workers’ departments. At the initial stage when discussions are being made about eligibility even to have an assessment the social worker’s department has considerable power. Further on, during the actual assessment process firm goals may be determined by social workers rather than individual users. Their development as individuals can then be frustrated because attempts to adjust services to relate to individual wants or needs are not made. When services are inflexible and dominant, assessments are at risk of being geared to the system and what it makes available rather than the aspirations of individuals. This comment can apply to almost all of the assessments described but Jane’s case illustrates it particularly well. The social worker could quite well have applied for her to attend the usual local day centre and it seems as if Jane would have been happy there. The additional day care provided at the centre for people with visual handicaps and learning difficulties seemed to provide her with additional stimulation and satisfaction. Arranging her placement there was in fact extremely difficult because it was a health service facility (not social services) and it took some time and persuasive argument to arrange. It was very difficult indeed for Jane to travel there and for some time she had to be taken by a relative in his car. The social services bus called at premises next door to the health day centre but for some time refused to convey Jane. This was a common problem. Often carers seemed resigned to basic service difficulties like these. In spite of the department’s rhetoric about providing user-led services, senior management were singularly reluctant to respond to representations about these deficiencies which were made by parents and social workers.

**DEBBIE**

Debbie, a young woman of 16 was seen at school for one day per week over a period of six months when the social worker joined her class. She was able to sit still only for short periods. She expressed
her wants by her facial expression and by making sounds. Extended observation led to ways of finding how Debbie could indicate choices. She liked running in the school field but needed someone with her as she could run off. It was not possible to find ways to discuss what was involved in the assessment as Debbie was often engaged in obsessional behaviour for example rocking and staring at her fingers unless she was distracted. Debbie's assessment was in many ways similar to Greg's but the possibility of seeing her at school for a longer period made it somewhat easier. She began to spend time at a day centre but was suddenly required to leave school and to attend full time at the day centre. The transition was thus very abrupt and it took her some time to adjust to leaving school.

**COMMENT**

Debbie's assessment provides another illustration of the ambiguities and difficulties inherent in ideas of user involvement, and needs led assessments claimed to be central features of community care policy.

One of the service deficiencies noted in several assessments of people with severe disabilities was the difficulty of finding facilities for short-term respite care. This was noted in Debbie's assessment for example: concern about this was expressed by Debbie's mother and her key worker. When the assessment was completed the social worker sent a memorandum about this service deficiency to the senior professional officer responsible for services for people with learning difficulties with a copy to the team leader. No reply was received. A letter referring to the same concern was sent to the unit general manager of the health authority. She replied and said the service would be reviewed. The social worker sent another letter seeking clarification of provision for people with special needs including challenging behaviour but she did not reply. Senior managers seemed to ignore such representations quite easily. Parents of young people with learning difficulties as well as the social workers in contact with them were obviously frustrated and hurt by this treatment but did not protest further. Perhaps they should have persevered, for example, by using a complaints system which was introduced some time afterwards and which people were encouraged to apply to if necessary.

The position of staff involved in face to face contact with people with disabilities is highlighted by this example of a pervasive and continuing feature of hierarchical structures. Although it is now well-documented and regretted, like the stigmatization of under-valued clients, the staff are not enabled to participate in a real sense in the direction of services. But it should be pointed out, as Ryan and
Thomas (1987) wrote, that the lack of real participation or power can lead to staff feeling that they and their ideas do not count. If they are disregarded this carries over to their work and to the people they should be helping. Clearly this is important in understanding the process of assessment and recommendations about service provision described in this paper.

JOHN

John, a young man of nineteen was at further education college when his assessment started. He was very tall and seemed very reserved. He responded in a very soft tone when spoken to and needed prompting to reply and to express his views. He lived with his mother who was from the Caribbean and her white partner. John’s father was white and the couple had divorced when John was ten. His mother seemed quietly spoken and rather passive but was in sympathy with the aims of the assessment and supported John’s right to express his ideas and wants and to make choices. But this was a problematic area for John and this was recognized in the assessment which said ‘he is not very confident with strangers and needs support with new people and in new situations’. He was seen at college and at home twelve times and the assessment was discussed with him as well as his mother, her partner and the college tutor. He needed time to talk and think about his plans for the future and was very hesitant in formulating his ideas, but it would have been incorrect to assume that he had no opinions. He said that he enjoyed sports and some of the work he did at college. He said he would like to learn more as he did not feel ready to look for a job on leaving college. The assessment worker suggested that he could think about applying to train at a social services department horticultural project and this would enable him to continue at college for one day each week. At first he was very reluctant to consider this idea but after visiting the farm with his mother he felt more confident in applying. Eighteen months after initial assessment John had settled well at the project and was making very good progress in learning a range of gardening skills. He said that he enjoyed being with people of his own age but regretted that the employment situation meant that he could not move on to a paid job.

COMMENT

John’s assessment also illustrates many of the difficulties found in working with someone who has limited social skills. In discussions
with him it was only too easy for the social worker to ask him leading questions rather than giving him time to think. In John's case the difficulties were not resolved but there were several opportunities to meet (over a six month period) during visits to him at home and at college. Talks with college staff and with John's mother provided helpful information which was then discussed with John but there was often uncertainty about what his needs and wants really were and it was difficult for the social worker to encourage him to express his opinions: his mother was more effective in helping him.

DISCUSSION

This paper has been written from the point of view of researchers and social workers seeking to understand the part people with disabilities might wish to play and could be helped to play in assessing their wants and needs. In studying this analysis it is helpful to bear in mind the ways Williams (1978) envisaged that people with learning disabilities might see the situation:

When one of us meets one of you, especially if it is for the first time, we are quite likely to lack many of the skills for successful communication. We may not be able to think of anything appropriate to say, nor to put it into the right words, or to control our facial expression. But you also will show a great lack of skill. You will be embarrassed, you won't be able to think of anything appropriate to say, you will tend to talk in an inappropriate tone of voice, you will tend to have a wide grin on your face and ask questions without really being interested in the answer. The handicap is thus a mutual one. Both of us have difficulty in communicating with and forming relationships with the other.

The brief profiles provide a basis for discussing some issues and topics for more in-depth study of user involvement in assessments of needs and wants and resource provision to meet them. All of the people described were young adults with a range of requirements in their personal development. They all had severe learning disabilities and problems in communication: it was not easy for them to make choices and decisions and express their wants and opinions. The factors which have been identified as of major significance in limiting participation in the assessment process are briefly summarized as follows.

1 Difficulties in communication resulting from speech disorders or autistic tendencies of the young people and the social workers' lack of ability in finding alternative methods for interaction. For the young people who were seen, gaining their attention and maintaining it was
a serious problem and sometimes it could not be overcome. As the students and the social worker got to know each other they became more skilled at understanding, through areas such as eye contact and facial expression, that the other person was paying attention. Non-verbal communication was also important in indicating degrees of understanding of what was said or signed (through pointing at objects or using Makaton signs or pictures for example). For some people it was appropriate to make physical contact but this could not be tolerated by everyone.

As part of planning for future services visits of observation and/or introduction were indispensable. Jane’s assessment illustrates this. Sometimes the individual did not express a positive choice about future involvement in a particular service or activity but it was hoped in these cases that at least the preliminary visits eased the transition. In one case where an introductory visit was not made because a young person left school abruptly and without any real preparation for adult services at all it was evidently a longer process for him or her to settle in a day centre.

A significant obstacle for the people with severe disabilities described in this paper was their inability to do something about it if they were misunderstood. The social worker could discover when this occurred when the same question elicited different and inconsistent responses on different occasions. The young people also needed to learn to say or to show when they did not understand what was said to them. Their dependence on others and passivity was certainly a major reason for lack of involvement in some cases. The difficulty for very disabled people in learning to deal with communication failure is great but they need to learn to identify the source of communication breakdown, to ask for feedback, to find out if the other person is really listening and be able to say ‘I do not want that’.

Medical reports and up-to-date reviews by teachers and day centre staff, supplemented by joint discussions with them and the young people, were of special value. Extended periods of observation of individual young people when the social worker joined them in activities at school and at their centres were mutually helpful and enabled the social worker to better appreciate their personal qualities. This was certainly of help in writing pen portraits as parts of each assessment and thus attempting to give a more rounded picture of a human being rather than an impersonal list of strengths and needs (as required by the form). Drawing pictures and exploring simple equipment and objects were other ways of communicating which may not have contributed directly to the provision of information relevant to the assess-
ment but did involve individual students and the assessor with each other even if this was on a superficial level. Makaton signs were sometimes used in interviews but this was rare. The need to start interviews or meetings where the client was and to proceed at the client's pace are both ideas which seem simple but were not easy to apply. Similarly the need to use simple and clear language, to speak slowly and clearly and to use simple grammar can be easily overlooked and can lead to silences and long pauses. Another mistake is to ask several questions one after another rather than dealing with one at a time. Leading questions make it easier for young people to be involved but many responses which seemed likely to be misleading and invalid have to be checked. It is not always clear what their real opinions, ideas and wants were.

The people discussed in this paper all had severe learning disabilities and sometimes they had sensory handicaps as well. Two people had tendencies to autistic behaviour which had a profound effect on their ability to relate to others. They presented unusual behaviour and were inaccessible: much of their speech was a non-communicative echoing of words and phrases that they had heard. For all of them the comprehension and use of language was a difficulty and they were not able to cope with complex sentences. Obviously the major feature of the social workers' part in the assessments was to facilitate or try to ease communication. Flynn (1986) identified some of the main issues in encouraging adults with learning disabilities to be the main informants about their own lives. Day (1985) discussed interviewing skills and staff training.

2 Inhibitions or difficulties related to the process of assessment itself. Some carers, Greg's parents and Debbie's mother for example, saw the process as a bureaucratic procedure which had doubtful or ambiguous benefits for their son or daughter and one to be dealt with as speedily as possible. Previous uncongenial experience of assessments played a part and all of the people interviewed expected the social worker to fill in the form. This sometimes represented an obstacle to participation but it was not insuperable. The main way of dealing with it was prolonged involvement and genuine attempts to agree on the eventual document.

The assessment itself, with the many negative connotations associated with this process, was for some people an important barrier to participation. For this reason considerable time had to be given to the 'getting to know you' stage and this necessity runs counter to any notion of the routine production of assessments within arbitrarily
defined time limits. Attempts to assess the cost effectiveness of assessments have therefore to use long-term indicators such as the progress a person makes during an extended period following the initial assessment.

3 Difficulties arising from immaturity and lack of experience of the young person. It was not reasonable to ask people like Jane and John, for example, to consider their requirements in an abstract way, for example to understand the nature of a job or a day centre which they had never seen. These difficulties could be partially dealt with by showing young people what their options were and gauging their reactions. Even then their desire to please others could be misleading.

4 Lack of experience and information on the part of carers and in many cases their low expectations of services. In all cases their access to information prior to the assessment had been poor. Inability to accept or absorb information may of course be associated with anxieties about change. Low expectations based on past experience led to some carers, Jane’s family for example, not being fully involved.

5 Problems arising from the service culture. These were illustrated by Jane’s and Debbie’s assessments. Assessors need to be alert to the danger of basing an assessment on their knowledge of available resources rather than thinking of unorthodox options and of what would be ideal. A recent study by Higgins (1992) found that social workers had serious misgivings about the ability of health and local authorities to empower consumers. They saw the organizational culture as one of the principal barriers and most of them relied on their own or their colleagues’ observations to assess consumer need and aspirations.

A potential problem with assessments and especially assessment forms which are lists of headings is that they can become matters of routine which are applied mechanically and impersonally. They can lead social workers to be unimaginative and thus to limit the possibilities which might help in meeting a person’s wants. Assessment forms and checklists may lead clients and workers to overlook or ignore relevant topics or ideas. Forms by their nature constrain and limit thinking and distract attention from concern with the wants the individual may be trying to express. A person cannot want things outside his or her experience. It is very important therefore to remember that additional information may be required as an integral part of the process of assessment.

Strengths and needs assessments are inevitably much influenced by
the values and attitudes of the assessor. Accounts of a person’s strengths are based on selective observations of behaviour and acceptance of the observations and reports of others. Appraisals of peoples’ needs are to a greater or lesser extent the subjective views of assessors. Strengths and needs assessments have often been one way processes in which someone (a social worker or other service provider) reports on another person (the person with disabilities). Potentially these assessments can lead to non-sensical results: some examples have been given by Dowson (1990):

He needs something to do during the day. Therefore he needs an ATC (ATC is an obvious service option but may not be what he wants).

He can wash and iron clothes but not sew buttons. Therefore he should learn to sew buttons (for a career in tailoring, perhaps, but many people get through life without sewing buttons).

CONCLUSION

In general, ideas about disability are characterized by ambiguity: this is reflected in social policy as it affects people with disabilities and also in the conflicts and anomalies found in practice such as the assessment procedures discussed here. Oliver (1983) pointed out that disability does not have meanings which are similar in all cultures and within any one culture there is lack of agreement about what disability is. Wolfensberger (1972) aimed to deal with the ways people with learning disabilities are defined as abnormal and are stigmatized and marginalized. To reverse this devaluation he argued that it was imperative that they should live in an integrated way with non-disabled people. But discussion of the ambiguity of the ideology of normalization has been notably sparse and little attention has been given to the paradox that people with disabilities are devalued through the emphasis on relating to the norms and values of non-disabled people (see Day, 1987; Smith and Brown, 1992).

For every person and social worker in the sample the assessment process was ambiguous. Leaving full-time education is regarded as a normal critical stage in anyone’s lifespan. But limiting the categories of students eligible for an assessment is a segregating process. Some families see the involvement of a social worker, perhaps for the first time, in the student’s life as potentially stigmatizing and resist this labelling and may refuse the assessment. If they go ahead with the assessment their anxieties about it can lead to difficulties and particularly for users, can affect their full participation. The ambiguous
notion that young people could and should be able to make choices about their future is particularly striking. The apparent offering of choice to someone without the experience or information to make the choice placed the young people and their social workers in a confusing position.

From the points of view of both central government policy and local government implementation the difficulties and ambiguities involved in user involvement in needs led assessments are plain. Continuing debates about assessments in 1993 led social services directors to seek legal advice on what to tell social workers about recording (or not recording) unmet needs. There seemed to be some apprehension that service users might take legal action if the needs revealed by their assessments were not met. The evidence quoted in this paper seems to cast considerable doubt about the ability or motivation of demoralized, marginalized and poor people to engage in such litigation but the move further illustrates how service provides may frustrate the aims of legislators. Wistow (1993) commented on the fear of legal challenge and wrote:

Even more challenging, a needs-led service is bound to make the relationship between needs and resources more explicit. ... As the Griffiths Report argued 'what cannot be acceptable is to allow ambitious policies to be embarked upon without adequate funds'. Just as the Department of Health has owned the implementation process so far it must own and develop the link between needs assessment, commercialism and resource planning. Ensuring that the whole community care system becomes needs-led is probably the most demanding long term challenge of all.

The gap between the rhetoric of user and staff participation and the reality, illustrated in this paper in the assessments of Debbie and Jane, has been documented in other studies.

In a study in East Sussex for example Beresford and Croft (1986) found that service users', workers' and local residents' views and experience seemed to have no impact on social services. Most felt they had little or no say in service development. It is now some time since Fisher (1983) argued the case for client studies being used to further the interests of clients at national policy level. He pointed out that such studies often failed to attract the attention of policy makers and to correct inbuilt tendencies in professionals and their organizations to disregard clients as potential partners.

More recently it has been argued that workers who seek to empower users and carers are most likely to succeed in an organization which empowers them. But it is evident that many workers and first line managers experience social services departments as disempowering (Stevenson and Parsloe, 1993). A new organizational culture is needed
involving changed attitudes and approaches at every level which focus on the service user and not on the service (Department of Health, 1991). The 1986 Disabled Persons Act in fact provided the framework in which people with disabilities should have their views considered and gave them rights to representation in the assessment process. So far these rights have been denied. The alternative strategy found in the National Health Service and Community Care Act 1990 separates the assessment of needs and financing services from the provision of services thus enabling greater fiscal control to be exercised. As Sapey and Hewitt (1991) have shown these new organizational structures offer no security to people with disabilities and their carers and the contradictions in policy can be clearly seen.

User involvement, particularly for clients with learning difficulties and communication problems is both very difficult to achieve and, in a climate of resource constraints, very difficult to implement. The culture of service provides often operates against allowing genuine choice for clients as future planning tends to be influenced by the availability of resources rather than clients' wishes. The implementation of care in the community policy remains highly ambiguous. The reactions of people to disability are individual and for this reason the original emphasis in policy statements on developing user-led services based on partnership between users and service providers was welcome. The implementation of the policy by local authorities has become bureaucratic and management led and the spirit of the Griffiths' report (1988) and the White Paper on Community Care (Department of Health, 1989) has been displaced. Front line staff tend not to be consulted very fully, if at all, by managers in local authorities and they feel alienated by bureaucratic processes while partnerships with users are also vague and uncertain. A great deal of guidance issued by central government has emphasized the supposed innovatory nature of future arrangements (from April 1993). It has employed jargonistic language which has seemed more appropriate to manufacturing industry than the provision of services for people who are vulnerable and who require sensitive help. These developments give further support to the view that people who are disabled, sick or elderly are devalued and marginalized not only by their impairments but also by education, health and social services which are supposed to support them.

In conclusion there appears to be an urgent need to consider the political issues which normalization and the proposed growth in user involvement raise. The social workers and the young people had little or no influence on the outcome of the completed assessments and their inability to negotiate for the provision of even very basic services
requires further consideration. The evident disparities between departments and individuals in settling priorities and allocating resources seem not only to reflect practical considerations but also different attitudes and values. The topics discussed here raise complex issues for research in the future. People with severe learning disabilities often have very limited skills in communication. For them and their social workers the idea of user involvement is quite ambiguous but this by no means excludes the possibility, however limited, of gaining some insight into their experience of the effects of social policies. Until comparatively recent times sociologists and other social scientists have been reluctant to discuss subjective experience (their own or that of their subjects). This situation is gradually changing and there are more attempts to study experiences and social processes that appear irrational, uncertain and ambiguous. Sociologists such as Plummer (1983) and policy researchers like Walker (1985) have suggested a variety of techniques of use in studying confusions and contradictions in social processes. Individual profiles have been used in this exploratory paper to examine the uncertainties involved in the complex social process of assessment and to identify some issues for further study.

REFERENCES

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