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**The views of trainee clinical psychologists and student nurses about the involvement of clients with a learning disability in their training**



## **Abstract**

The present study compares the views of trainee clinical psychologists (n=31) and student nurses (n=15) about user involvement in formal teaching. The study found no significant differences between group views. Eighty-two percent of the all participants thought that user involvement was important, but only 29% had had such involvement in their own teaching. Of these, the mean rating of usefulness was 2.2, indicating that it was not perceived as being particularly useful. The group were significantly more likely to identify the area of 'service provision' as an area of teaching for clients to be involved in and 'gaining client perspective' as a benefit of user involvement in teaching. Client difficulties, such as communication were identified by a significant number of participants as a drawback of involving clients in teaching. The implications of these findings, in terms of promoting meaningful user involvement in formal training programmes are discussed.

## **Introduction**

“A fair and enabling society is one that accepts minority groups and makes efforts to positively value their contribution” (May, 2001). The contribution that service users make to psychology has given cause for debate over recent years. Ward (1998) reports that, before the 1980’s, user views were obtained through carers or professionals rather than the user themselves. Within all disciplines of psychology there is an increase of user and advocacy groups, as individuals demand the right to have a say in the services that ultimately effect them (Campbell, 2001). Newnes (2001) reminds us that we are all current or potential users of services, and that psychology is not conspicuously interested in advocacy and user involvement.

There are a number of explanations for the lack of user involvement within psychology services. Harper et al (2003) lists professional protectionism, tokenism and not knowing how to do it as reasons for this. The scientist- practitioner model of psychology does not fit with the subjective views of the user (May, 2001), and therefore user involvement is often seen as an add-on extra. Wolpert et al (2001) argues, however, that involving service users may increase their and others’ positive sense of the service. Newnes (2001) also suggests that we need to think what we would want from services should we ever find ourselves using them.

There are however, some areas of clinical psychology that appear more advanced in terms of facilitating user involvement. The specialty of learning disability has a

comparatively long tradition of involving service users. In particular, since the implementation of social role valorization (Wolfensberger, 1972) there has been an increase in the empowerment of people with a learning disability. This has been advocated by government legislation. The recent review of services for people with a learning disability (Scottish Executive, 2000), held workshops and seminars specifically for people with a learning disability. Similarly the English equivalent, the National Learning Disability Strategy (NLDS) (2000), has also highlighted the need for user involvement in services.

Learning disability service users have been included in evaluating the quality of health services (Murray et al, 1998; Witts & Gibson, 1997), and day care services (Foote & Rose 1993). There has also been a move to include service users in the recruitment of staff in residential services (Townesley and Macadam, 1996) and psychology posts (Cheseldine et al 2001).

An area of user involvement, in which there has been less work carried out in, is that of formal education and training to staff. 'The Same as You?' (Scottish Executive, 2000) and the NLDS (2000) highlight the importance of user involvement in this area. The Scottish Consortium for Learning Disabilities, developed as a result of 'The Same as You?', run a programme which teaches adults with a learning disability to provide formal presentations and training. Despite this there are few initiatives where this happens (Fisher and Coyle).

The barriers to this are similar to those given for lack of user involvement generally, however, within the learning disability field, the clients' cognitive ability and more limited understanding is also frequently used as an excuse (Cheseldine et al, 2001). Other reasons given for lack of user involvement in teaching include the clients' communication difficulties, the stress that the teaching may have on the client and the question of whether clients' views would be representative of those of differing abilities. Fisher and Coyle (1999) provide a number of counter arguments to these claims and conclude that client involvement is central to improving service provision.

Towell and Hollins (2000) report a programme where clients with a learning disability teach medical students about their experience of going to the doctor. They also review an American model, the University Affiliated Programme, in which universities work in partnership with disabled people and their families. The programme involves clients in all areas of the teaching process, including the development of training materials, the evaluation of teaching and research.

The funding which clients receive for involvement in such initiatives is given as a pragmatic barrier to involvement in formal teaching programmes. Payment for clients involved in teaching can effect their benefits, however, Cheseldine et al (2001), suggest that a consultancy payment can be made to user groups such as 'People First' rather than to individuals. The cost to the university for involving clients in teaching and research can be met by funding organisations. The Joseph Rowntree Foundation specifies that there must be meaningful involvement from clients before they will award research grants (Joseph Rowntree Foundation, 1994). Clients could therefore.

be meaningfully involved in teaching sessions by disseminating research findings. Ward (1998) provides examples of this type of participatory research.

Recent research by McKenzie et al (1999, 1999a) indicate that staff working in learning disability services often lack knowledge about the area, including an understanding of what a learning disability is. This could imply that if staff lack knowledge of what could be considered a fundamental aspect of their job, then they might not have much idea of what a person with a learning disability can offer in a teaching capacity. By definition clients with a learning disability would require support to be able to do this. Organisations such as the Scottish Consortium for Learning Disabilities are able to give advice and support in this area. The involvement of clients with a learning disability at the early stages of training and education may help improve staff knowledge and increase their understanding of basic issues.

It is likely, however, that clients with a learning disability, academic staff and students will continue to have some questions about how participation will work in practice. Client participation which failed to meet the needs of all those involved, would be at risk of being viewed as tokenistic and of limited value. The following study, therefore, aims to examine and compare the views of trainee clinical psychologists and student nurses about their perception of the following:

- The importance of client involvement in professional training programmes.
- The areas where they feel such involvement would be beneficial.
- The benefits and drawbacks of such involvement.

- Their own experience of user involvement in their education and how useful they found this to be.

## **Method**

Thirty- one trainee clinical psychologists and 15 student nurses participated. Both of these professions were chosen for their specific input to learning disability teaching, particularly the nurses where learning disability is a branch programme. All were enrolled in a 3-year training programme. Of the trainee clinical psychologists, 13 were in their first year of training, 10 were in second year and 8 were in third year. Of the student nurses, 7 were in their second year of training, while 8 were in third year. There were no first year student nurses included in the study.

All participants completed a short questionnaire, (appendix 1), which asked the following:

- Do you think it is important to have clients with a learning disability involved in the clinical psychology/ nurse training programme? If so why?
- Which areas of teaching do you think clients should be involved in (if any)?
- What do you think the benefits of client involvement are?
- What do you think the drawbacks of client involvement are?
- Have you had previous experience of client involvement in your formal teaching sessions (i.e. not on placement)?
- Those who had were asked to rate how useful they had found this on a scale of 1 to 5, with 1, indicating useless and 5, very useful.



Participants were also asked which year of study they were currently in and the amount of experience they had in working with clients with a learning disability.

All participants entered the study voluntarily and were informed that their responses were anonymous. There was no information collected that would identify participants.

The questionnaire was adapted to suit the profession the individual was in i.e. nursing or psychology. It was piloted with a group of lecturers in the learning disability specialty to ensure it had face validity. Inter-rater reliability was assessed by two raters, coding 24% of the participants' responses. The results were analysed using Kappa statistic.

## **Results**

### Inter- rater reliability

For all results that could be computed using Kappa, significance levels were less than 0.001. ( $p < 0.001$ ), indicating significant agreement between raters.

### Whole group analyses

There were no significant differences between group responses to the questionnaire. Only one significant difference was found between groups, with nurses having more experience of working with people with a learning disability, (mean = 46.67 months, sd = 20.43), compared with psychology trainees, (mean = 20.25 months, sd = 23.54), ( $T = 3.715$ ,  $df = 44$ ,  $p < 0.001$ ).

### User involvement

Eighty-two percent of respondents thought user involvement in teaching was important, while 13% thought it would be more relevant to get experience of client involvement on placement. A variety of reasons were given by participants as to why they viewed such involvement as important:

- Twenty-seven respondents (58.7%) felt it would give an opportunity to learn what the priorities were for people with a learning disability from their perspective.
- Fifteen respondents (32.6%) felt it would personally benefit them, as they'd had no experience of working with this client group.
- The responses of eleven respondents (23.9%) were coded as 'other' and included advocacy, improved communication, making teaching more interesting as examples of this.

### Identified areas of teaching for clients to be involved in

Table 1. illustrates the areas of teaching that the respondents identified for clients to be involved in.

**Table 1: Areas of teaching for clients to be involved in**

<b>Area</b>	<b>Example</b>	<b>Number</b>	<b>Percentage</b>
Service Provision	'how day centres work' 'client perspective of psychology'	20	43.5
Changes in Care	'impact of legislation'	10	21.7
Increasing Awareness	'how learning disability affects them'	10	21.7
Emotional/Social Aspects	'Sex, sexuality & avoiding loneliness 'Thoughts & feelings'	8	17.4
Communication	'How to improve communication' 'Communication strategies'	5	10.9
Other	'advocacy' 'health' 'videos' 'employment issues'	21	45.5

A Cochran's Q test found significant differences in responses in relation to identified areas of teaching. ( $Q = 15.143$ ,  $df = 4$ ,  $p < 0.01$ ). Respondents were significantly more likely to identify the areas of 'service provision' than 'emotional/ social aspects' (binominal test  $n = 46$ ,  $p < 0.05$ ) and communication (binominal test  $n = 46$ ,  $p < 0.001$ ).

#### Benefits and drawbacks of client involvement

Table 2 illustrates the benefits and drawbacks of client involvement identified by respondents.

**Table 2: The benefits and drawbacks of client involvement identified by respondents.**

<b>Benefit</b>	<b>No.</b>	<b>%</b>	<b>Drawback</b>	<b>No.</b>	<b>%</b>
Gains client perspective	25	54.3	May be tokenistic	13	28.3
Benefit to Trainee	10	21.7	Difficult for client	11	23.9
Practical rather than theoretical input (e.g. meeting clients)	8	17.4	None	7	15.2
Improve relationship and understanding	8	17.4	Practical difficulties (e.g. accessing buildings)	5	10.9
Other e.g. empowering for clients,	17	37	Other e.g. the course would have to change	12	26.1

A Cochran's Q test ( $Q = 19.157$ ,  $df = 3$ ,  $p < 0.0001$ ) found significant differences in responses. Respondents were significantly more likely to identify 'client perspective' than 'practical input' (binominal test  $n = 46$ ,  $p < 0.005$ ) and benefit to trainee (binominal test,  $n = 46$ ,  $p < 0.001$ ) as the benefits of client involvement.

Significant differences were also found in relation to identified drawbacks ( $Q = 21$ ,  $df = 3$ ,  $p < 0.0001$ ). Respondents were significantly more likely to identify 'client

difficulties' than 'tokenism' (binominal test  $n=46$   $p < 0.01$ ) or 'practical difficulties' (binominal test  $n=46$ ,  $p < 0.05$ ) as drawbacks of client involvement.

#### Previous experience of client involvement in formal teaching

Twenty eight percent of participants had previous experience of client involvement in formal teaching. Of those who had, the mean rating on a scale of 1 to 5 (1= useless, 5 = very useful) was 2.21.

#### **Discussion**

The study examined the views of trainee clinical psychologists and student nurses about user involvement in their teaching programme. There were no differences found between the professional groups overall except nurses had more experience of working with clients with a learning disability. This is unsurprising as the nursing programme is dedicated to working with people with a learning disability, whereas the clinical psychology training programme only includes this as one of the core components of generic training. The results, therefore, were analysed in relation to the whole group.

The study found that the majority of people thought that user involvement was important. The main reason given for involvement was to find out the priorities for people with a learning disability. A large group of participants felt that user involvement would benefit them, as it would help familiarise them with clients before going on placement. Typical examples of this include, "it would reduce the anxiety of people who have never worked in learning disability", and "to help dispel myths

people may hold about clients before going on placement”. This supports the work of McKenzie and her colleagues (1999) that professionals lack knowledge and understanding of what it means to have a learning disability, and that this client group may be viewed as a homogenous group.

Those who did not think that client involvement in teaching was necessary gave reasons such as involvement would be based on politics and tokenism and concerns that the clients would be on show. Fisher and Coyle (1999) acknowledge that there would be little value in bringing someone with a profound learning disability into teaching, but remind us that people with mild and moderate impairments are more than able and ready to have their voice heard. It is worthwhile noting that none of the participants who thought that involvement in teaching was not important, had had any experience of this. May (2001) argues that the ‘them and us’ divide should be challenged and that user involvement in psychology training is well placed to tackle this.

The most commonly identified area of teaching was service provision i.e. what clients want from the two professions. Examples given by respondents included, “treatment of psychological problems”, and “asking them what they want from us”. There is a difference between asking service users about how services can be improved to best meet their needs and asking them to tell us what type of treatment we should deliver. Asking clients what we should be doing implies a lack of clarity about what our role is. The move from medical to social care within learning disability services has particularly effected the learning disability nursing profession as many of their

traditional roles have been taken over by social carers (Turnbull, 1999). It has been suggested that the declining number of nurse training places (English National Board, 1999) has left learning disability nurses with a feeling of disempowerment similar to that experienced by their clients. The history of learning disability nursing highlights that the subordination of the profession to other professional groups, namely psychiatry and psychology, has stifled its development and identity (Mitchell, 1998, Turnbull, 1999). It is, therefore, unsurprising that there is confusion about the role of nursing and a need to ask the client group what it is they should be doing.

In relation to psychology, a core purpose of the psychologists' role within the learning disability field is that of assessment. Psychologists are the only profession that are trained to carry out an individually administered, standardised psychometric assessment that is required for the diagnosis of learning disability (BPS, 2001). The results of which are used to define need (BPS, 1994) and identify the levels of support that an individual may require (McKenzie and Murray, 2002). Asking the client their opinion on the type of intervention they would prefer also implies a lack of clarity about their role. The responses could, however, indicate that lack of experience equates with a lack of knowledge of the client group.

The main benefit of user involvement given by respondents was obtaining the client's perspective. It is important to understand the subjective experience of any individual and Harper et al (2003) note that this is the most common use of teaching sessions in clinical psychology courses that actively involve service users. They argue, however, that user involvement should be more than inviting individuals to talk about their

experience of distress. Towells and Hollins (2000) identify academic institutions that involve learning disability clients in a number of research and teaching initiatives. They suggest that academic institutions should act as champions of service development and evaluation.

The main drawbacks of user involvement identified by respondents were tokenism and difficulty for the client. Examples included exploitation of clients and the anxiety that teaching would bring. Some participants related this to their own experience of having to carry out presentations and highlighted the communication difficulties clients may have which would contribute to their anxiety. Some participants reported that the clients' experience would not be representative of the views of all clients. This view may assume that clients can only be used in teaching to talk about their personal experiences.

Tokenism is a common reason given for lack of user involvement (Harper et al 2001; Wolpert et al 2001), however, client involvement may be perceived as tokenistic if it is not beneficial to either the client or the trainee/student. Fisher and Coyle (1999) argue that these issues can be addressed and should not be used as excuses for lack of involvement. The Scottish Consortium for Learning Disabilities work with clients on competence- building to help overcome anxiety and make teaching meaningful to all. Colleagues with learning disabilities have been involved in chairing and presenting at conferences (Grant, 2001), indicating that they can also contribute meaningfully in the teaching of professionals.

Despite policy changes and organisations such as the Scottish Consortium actively encouraging user involvement, only 28% of respondents had previously had any user involvement in teaching. Some of the respondents identified presentations from parents/ carers as examples of user involvement, however, this raises the issue of what is meant by the term user involvement. Fisher and Coyle (1999) report that parents of people with learning disabilities are often considered to be the real users of services. Advocacy services have been critical of this view (SCOVO 1996) and work to ensure that the person with the learning disability is heard. Government policies such as ‘The Same as You?’ (2000) recommend that people with a learning disability are involved in anything that will directly effect them.

The mean rating given by respondents with previous experience of user involvement was 2.2, which indicates that they did not think highly of this. This suggests that user involvement in teaching needs to be clearly thought out and have meaning to both parties.

The study has a number of limitations, in particular the small sample size from both professions. This number, was, however, necessarily restricted by the number of people involved in training at the time of the study. The questionnaire, while having face validity and inter-rater reliability, was not examined in terms of other forms of validity and reliability. Parametric tests were used to analyse the results of the rating scale and because the data was not measured on an interval or ratio scale, some authors would argue that non- parametric tests should be used (Bradley, 1968). Other



authors, however, argue that parametric tests are sufficiently robust to be used with ordinal data (Howell, 1997; Cramer, 1998).

In summary, the participants were generally positive about user involvement in formal teaching. They felt that the main benefits were to gain the clients' perspective and the experience would be of benefit to them before going on placement. Tokenism and difficulties that the client may experience were given as the main drawbacks to user involvement. However, there are many good initiatives that can help overcome these difficulties. The views of people with learning disabilities have often been marginalized (Norway, 2001). Government policies have been developed in response to this and although the majority of people in this study said that that user involvement was useful or important it would appear that practice hasn't caught up with the policies.

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