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ASSESSING CLIENT PARTICIPATION IN MENTAL HANDICAP SERVICES: A PILOT STUDY

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INTRODUCTION

One recent trend in the development of services to people with learning difficulties is a growing awareness of the importance of client views in shaping an effective service. This emphasis represents a convergence of disparate trends such as self advocacy movements, the thrust toward planning care on an individual basis and a political climate of growing conservatism giving rise to the search for models of service delivery which could be said to be led by "market forces". Because of the diversity of its origins it is not altogether clear what client participation ought to consist of in this context. It therefore seems potentially useful to explore ways of assessing client involvement which could be used to evaluate a wide range of measures designed to promote it. This paper presents a pilot study of one possible approach to the problem.

There are two assumptions underlying this approach. Firstly that clients behave in relation to the service according to a mental model of that service which explains their role in it. Secondly, that this model will be revealed implicitly in their explanations for events in their lives which are brought about by the workings of their service. It follows that where clients adopt the traditional passive role in relation to their service they will explain events in a way which implies that they are acted upon by processes over which they have no influence and that their only choice is to comply or resist. Where clients have been successfully involved in the service two conditions should apply.

Firstly they should explain events in a way which implies that their own actions have contributed to shaping them. Secondly, these explanations should reflect actual opportunities to exert influence on the behaviour of the service. Hence the approach proposed is designed to elaborate clients' explanations for events, to identify the ways in which staff elicit and act upon clients' views and to examine the extent to which these staff and clients' views correspond in a way which reflects an effective process of entering client views into the shaping of service activities.

The investigation of the views of this client group is a fairly new field and there are no hard and fast rules as to how best to approach the task. It would appear, however, that valid data can be obtained from interviews which have a loose structure which allows for re-phrasing, re-ordering, repetition and probing to enhance responsiveness (e.g. Flynn, 1986; Lovett and Harris, 1987; McEvoy, 1989). It has also been suggested that understanding of client views is best gained by spending considerable time with clients, accompanying them as they go about

their daily activities (Edgerton et al, 1984). It therefore seemed that the best approach might be to conduct interviews with clients during the course of a few days of continuous participant observation of the settings in which service related activities occur. Interviews with staff could also be worked into this period. This participant observation may have the added advantage of allowing staff's accounts of how they involve the client to be understood in the context of the overall service they provide.

It should be borne in mind that staff strategies for involving clients may involve implementing formal measures intended specifically for this purpose. In this case it is assumed that where these procedures operate successfully, client's accounts of these procedures will be consistent with this aim and with staff's accounts of the way the procedures operate. For example, what is the client's awareness of the procedure? How do they account for it? Do staff see the procedure as facilitating client involvement and if so how?

The STEPS Package

In the cases presented in this study, procedures contained in the STEPS package (Chamberlain, 1985a, 1985b) were seen as a vehicle for incorporating client views into the service. The STEPS package was designed by a multi-disciplinary team set up by a joint care planning team.[1] It aims to translate the philosophy of normalisation into practice by establishing staff training and work procedures consistent with this philosophy. It thus provides both training materials for introducing staff to the STEPS system and documents to be used by trained staff in applying the system. The procedures thus established identify needs and plan actions across the entire range of care needs. Among these procedures is a "life plan" which was seen by the relevant managers as the mechanism for actively involving clients in their own care plans. According to Chamberlain the basic aim of this procedure is to ensure that the activities of the service are shaped by the needs of the client group. He goes beyond this, however, to maintain that it is the client's own version of these needs which is of primary importance, asserting for example that;

> "Life planning is a process which begins by identifying the needs of the individual (from their point of view) and then it 'instructs' us to design our services around these needs" (1985a, p. 3)

and that life planning is **not**

> "A meeting where 'we know best' and decide to impose a set of goals on the client 'for their own good' . . . we have to try and identify needs by trying to understand what it might be like to be in their shoes". (1985a, p. 12)

It might therefore be expected that if life planning operates successfully, clients will explain aspects of the service they receive as related to the views they express through life planning or explain life planning in a way which implies that it provides an opportunity to influence the nature of the service they receive.

The usefulness of an assessment of client participation might be said to depend on two things. Firstly does it differentiate between different degrees of client participation? Secondly does it identify factors which influence client

participation? The present study therefore examines two different service settings to see if there are any indications that this approach satisfies either of these criteria.

Settings

"Setting A" is an adult training centre[2] in the North of England which was in the process of implementing STEPS procedures and was operating life plans for five selected clients as a pilot study.

"Setting B" is a housing association[3] managed by a committee made up of members of local MIND (National Association for Mental Health), Health and Education Authorities and Social Services Department. It provides full care for 19 clients and accommodation only for a further 12.

Clients

The two client groups studied were, overall, of equivalent levels of functioning as far as could be judged from their care plans and discussions with staff, although the range may be greater in the case of setting B. In the case of setting A the group represents four of the only five clients to have fully operational life plans. These five had been selected as those most likely to benefit on the basis of learning potential and ability to express themselves. One was in full time employment in a sheltered scheme. All attended adequately to their appearance and hygiene and had demonstrated substantial ability in domestic skills and use of public facilities. The group in setting B represents all the clients thought to have sufficient verbal ability to express themselves in an interview. Two were in part-time regular employment. All contributed to the necessary domestic activities; cooking, cleaning, shopping etc. in their group homes with prompting and verbal assistance from staff.

PROCEDURE

Both settings were visited for three consecutive days. During this time the researcher mixed with clients and staff in an effort to develop relationships and understand their views. Tape recorded interviews with clients and staff were worked into these periods whenever it seemed least inconvenient to those involved. Notes were made on informal discussions which took place during these periods.

Clients were questioned according to the following basic plan:

1. Get the client to name and describe one activity he/she is involved in connected to the service.
2. Ask how the client came to be participating in this activity.
3. Repeat 1 - 2 with as many activities as possible.
4. If life planning is mentioned as an activity the same procedure applies as to other activities.
5. If life planning is mentioned as part of the explanation for another activity, ask the client to elaborate.
6. If life planning is not mentioned spontaneously enquire about it and ask the client to explain it.

Questions were phrased in whatever way seemed most likely to be meaningful to the client. Repetitions, re-phrasings and probes were used freely to encourage the fullest possible responses.

Staff were asked about how they saw their roles, their thoughts on the concept of client participation and what they felt life planning could contribute to it. Most of this discussion was informal but a few tape-recorded interviews took place.

RESULTS

Interviews were obtained from six of the more verbally able clients in Setting B *and from four of the five relevant clients in Setting* A. *Responses varied con*siderably between clients and indicate a difference between the two centres in terms of overall degree of client participation. The following examples may serve to illustrate the range of responses:

1. Attributions for the activities the client is involved in: Some responses attributed events in part to the client's own actions. e.g.:

   I. Can you say how you came to be working (in that situation) in the first place?
   C. Looked in the (name of local newspaper).
   I. Yes?
   C. Went for the interviews

   (there is a digression here but when the subject comes up again)

   I. Did you say you found out about (that kind of work) from looking in the (name of local newspaper)?
   C. Aye — No, day services helped me do it.
   I. Day services got it from the newspaper?
   C. No! helped me.

   Or in another case:

   I. And how did you get involved in this Gateway Club[4] in the first place?
   C. Well, they'd ask us would I like to join and I says "yes!".

   Other responses implied that only the influence of others was involved in determining the client's activities e.g.:

   I. And how did you come to be working on that?
   C. Mr. .... put us on it.
   I. And why did he put you on it?
   C. Um, cause . . . there was somebody, that lad that's on it now he just wanders away and he put me on.

   And another client

   I. And how come you do that sometimes?
   C. Well we just go where (first name) tells us to go into.
   (later in the same interview)
   I. Can you say how that came to be one of the things you do here?
   C. Well we just do some of the things we're asked to do.

   Some of those who attributed activities to their own expressed wishes included life planning in their explanations e.g:.

I. When you thought you'd like to have a job that gets paid, who did you talk to about it?
C. Well, I explained it in my life plan meeting.

In the other cases life planning was not mentioned spontaneously and explanations of it varied considerably, some implied that it was a chance to influence the service e.g.:

I. What's that all about? (pause) what's that for, life plans?
C. To see what you do with yourself, to see what you're wanting to do in your whole self.
I. Right . . .
C. If you want to go out or (pause) just changing your whole self, like going out and um . . .
I. Mhm . . .
C. And, um, wanting to go out more, going out on buses more and going on trips more with (name) and I picked (same name) from day services.

Some other interpretations included:

Life planning as a domestic skills lesson:

C. I think we've got a meeting coming up on (correct date of next life planning meeting).
I. Right . . . what happens at that sort of meeting?
C. Well, we sometimes discuss what kind of food you can cook and things like what we wash, so much we put in the machine, so much we do by hand.
I. Mhm, . . . is that what you talk about when you go to a meeting with (listed staff present at client life plan meeting) is that the place where you talk about how to do the washing?
C. Yes.
I. Or do you talk about something else at that meeting?
C. Well, that's things that we can cop up with like food and things and er, different sorts of food.
I. Right, do you ever have a meeting where they ask you what you want to do in the future?
C. No, I've never had that one I don't think . . .

Life planning as an act of coercion:

I. What happened at the meeting?
C. Just . . . they wanted to know if I'd stay a bit longer here but I (laugh) I took a long time to give an answer, till I said the magic word.
I. What's the magic word?
C. Which was "yes".
I. In what way is yes the magic word?
C. Mmm? Sorry?
I. I'm not sure what you meant when you said that they wanted you to say the magic word and the magic word was "yes".
C. (Laughs nervously) Oh! That lot!
I. Sorry?
C. (Pause, sigh) It was only going to be two days when I started here and that was Monday and Tuesday.

IMPLICATIONS

Although the study involved only a small number of clients the results indicate the potential value of data of this kind in two ways. Firstly they differentiate somewhat between the two settings suggesting that it is possible to show which situation measures like STEPS life planning have been most successful. Secondly some implications for future development can be inferred.

Differences between the Settings

Table I shows the clients classified according to their responses (numbers refer to individuals, letters indicate which setting the client belongs to). This shows the greater tendency of clients in Setting B to perceive themselves as able to exert influence and to understand life planning as a significant event and an opportunity to exert influence.

TABLE I

Classification of ten individuals from two settings according to the responses to a semi-structured interview schedule.

CRITERION	CATEGORIES	CLIENTS*
1. Attribution of events:	a) Partly to own influence	A3, B1, B2, B3, B4, B5, B6
	b) Solely to others' influence	A1, A2, A4
2. How Life Planning came up:	a) As example of an activity	None
	b) As part of explanation for another activity	B1, B3
	c) Recalled when prompted	A2, A3, A4, B2, B4, B5, B6
	d) No apparent awareness	A1
3. Explanation for Life Planning:	a) As opportunity to influence	B1, B2, B3, B5
	b) Other explanation	A2, A3, A4
	c) Not able to explain it	B4, B6
	d) Not able to recall it	A1

*A1 - A4 = Clients from Setting A
B1 - B6 = Clients from Setting B

Implications for Practice

These are not put forward as proposals for action since the sample is far from representative. Rather, the aim here is to show the potential of data of this kind.

Chamberlain seems to be suggesting that his procedures will bring about plans of care which are related to the clients' experience of their situation. We might therefore ask why there is sometimes a considerable gap between service providers view of life planning, as a means of involving the client and client's view of it as a mysterious or inconsequential event or as just another training event or even an act of coercion. In all the cases examined the life planning procedure could have been said to have been done "properly" i.e. the forms were complete, the meetings were held with the required frequency and the required people

attended. We might therefore search for reasons within the life planning procedures themselves or within the way they were implemented in the particular settings.

Taking a closer look at Chamberlain's life planning documents we get some idea as to why his procedures do not necessarily actively involve the client. The life plan consists of 11 forms. The accompanying documents assert that the first 5 of these are designed to help the key worker to achieve the goal of seeing how the clients "see the service they are getting — what it might be like to be in their shoes". However, only one of these — sheet 4, contains any items which involve making any kind of inference whatever about the client's experience. Sheet 1 is concerned with background information (name, next of kin, medical problems etc.) sheet 2 calls for a list of activities in the client's "average day"; sheet 3 is mainly concerned with the client's history and relationships and sheet 5 reviews actions taken on the previous life plan. Sheet 4 does call for some inference about the client's experience in that it is partly concerned with their preferences and wishes for the future. One might hope that this document at least would help to enter the clients' views into the process of care planning. Some information from discussions with staff and from policy documents gives indications as to some of the reasons why this is not always the case.

One possible reason is that the structure of sheet 4 is not flexible enough to accommodate the full range of client views. In particular it does not seem to allow for the degree of passivity with which some clients view their lives. The following is from an interview with a key worker:

I. What are the other prominent issues for something like life planning?

K.W. To get the individuals to make decisions towards their own lives. I think a lot of them are finding it very difficult and I'm trying to begin with very simple decisions like 'do you want tea or coffee?' Because never having had to make any decisions before, a decision about where you want to live is going to be a very difficult thing to do if you can't decide on your own what you want for tea or something, you know, something very simple.

I. And presumably the life plan documents require the person to make a decision about where they would like to live?

K.W. Or what they would actually like to do.

I. Right.

K.W. If they've never had the choice before it's going to be a very difficult thing to do. I mean even someone of a normal I.Q. from some other country. I was first thinking of some of the women from Arab countries. They've never had to make a decision themselves.

This staff member found that clients were sometimes unable to formulate wishes and preferences of the kind required by sheet 4, and attributes this to their life experiences. Others, however, found the same difficulties but put them down to a basic lack of ability e.g.:

> "You have to remember that we're dealing with people whose ability is very low".
> "Mentally handicapped people don't make plans — that's the trouble".

Another possible reason is that the life planning training does not provide all the input necessary to enable the staff to see services 'from the client's point of

view' and understand what it might be like to 'be in their shoes'. There was a feeling among many staff that client participation would require "a new way of relating" (to clients) or "a major change in attitude" (on the part of staff). The life planning training was seen as failing to facilitate this because it was concerned with tangibles like "how to arrange meetings, how to fill in the forms and so on". Similar concerns are expressed by authors such as Middleton (1988) and Brechin and Swain (1988) who argue that the whole area of staff-client relationship in mental handicap needs a lot more attention than it has been given.

We might also look for explanations in the way in which life planning was implemented. Setting B was a relatively new scheme which adopted STEPS as a model from the outset. In the case of Setting A, it appeared that the pressure to adopt STEPS had come from fairly high up in the service and that consultation with the "grass roots" had come only when considerable time and money had already been invested in the package. This seemed to have led to a situation in which the staff felt under considerable pressure to put life planning procedures into action. For example, a policy document concerning the implementation begins with a "target" of getting: "40% of clients life planned" by a specified date. A country-wide meeting of managers to discuss progress on life planning began with some strong words from a senior manager for the "malcontents" who were objecting to the difficulties it posed.

This may explain how the preferences and wishes for the future sections of the life plan documents came to be completed for clients who, both from their interviews and by the assessment of their key workers seemed out of touch with their preferences and not ready to formulate plans for the future: the "target" is more likely to be met if staff use a little licence in their account of the client's position.

One problem which key workers had with life planning was that it lacked any guidelines on dealing with differences of opinion between client and key worker as to the client's need. How do staff deal with situations of this kind? The following may give some indication:

I. So, what sort of implications does this have for this concept of user participation?
K.W. It means staff can manipulate it really can't we, we can still, at the end of the day, get it to do what you want it to do if you don't feel what the client is saying is — what he's saying he wants to do with his life is right you can not listen or turn it back.
I. Not listen or manipulate in some way?
K.W. I mean hopefully that would only be done if it was because you felt that the client couldn't make the right choices for himself and that you as a professional felt that in order for his best interests you had to.
I. Non-hopefully, under what circumstances might that happen?
K.W. Where it was more convenient for staff for some reason not to go along with something the client wanted, or for policy makers not to go along with it because it had financial implications.
I. So you can see that happening as well?
K.W. It could, yes.
I. Easily?
K.W. Not easily I would think and I would hope it wouldn't at all. I mean it shouldn't.

Suppose we are optimistic about this key worker's projections: assume that the "hopeful" scenario eventuates and the "non hopeful" one doesn't. We still have a situation in which the client expresses a wish and the staff member is deliberately evasive or leads the client while claiming to be led by him. Rather than actively involve the client, this kind of response seems likely to further mystify the plan of care he is subject to. But what are the alternatives for the staff member? Pull rank on the client openly and be seen as failing to involve him? Point out that the policy on client choice lacks guidelines for these situations and be classed among the "malcontents"? The staff members approach seems entirely understandable. What about the effect on the client? It is desirable that clients move from their passive role to a position where they can influence the service so that it suits them better. However, it seems possible that the client's position can be changed from an unequivocally passive one to one where the real rules are hidden. This may do more harm than good since the client no longer knows what to expect. Overall, STEPS life planning emerges as a rather incomplete recipe for client involvement and one which has the potential to create an illusion of progress while obscuring some of the difficulties inherent in client involvement.

CONCLUSION

The conclusion drawn from this study must be tentative because of the small amount of data involved. However, it does appear that data of this kind can at least differentiate between settings. This suggests the possibility of identifying those situations where client involvement is greatest and of monitoring the impact of measures designed to promote client involvement. This approach also appears capable of identifying obstacles to client involvement arising from the peculiarities of individual settings. Hence, it appears that research along these lines may yield solutions to the problem of client involvement.

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1. Joint care planning teams have statutory responsibility for services to groups with special needs including those with mental handicaps. They are composed of representatives of Health Authorities, Education Authorities and Social Services Departments.

2. Adult Training Centres are administered by Social Services Departments. They provide sheltered employment and vocational and self care training for adults identified as having a mental hadicap.
3. Housing Associations may be formed by voluntary management committees under an Act of Parliament which enables them to obtain financial support to provide housing for people with special needs.
4. Gateway Clubs are a national network of voluntary groups which aim to provide social and recreational activities for people with disabilities and to facilitate their participation in the community.