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Moving On as a Key Part of Recovery:

What issues arise for Service Users when moving from mental health units into community care?

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Abstract

Accommodation for long-term and enduring mental health patients experiencing psychosis has traditionally been provided within statutory provision such as hospitals and wards-in-the-community. More recently this picture has begun to change and many patients have moved out into community-based settings. Recently, in one London borough, 15 clients of the local community rehabilitation team moved out of the ward-in-the-community and into privately-run residential care settings. Following the move the psychology staff on the team conducted a service evaluation to explore Service User experience, to try to understand from a client perspective what such a move was like and to consider ways to improve client experience in the future. This paper presents the outcomes and makes some recommendations for improving the move-on experience for this client group.

Introduction:

The move from large psychiatric hospitals to more community-based provision has been a feature of mental health services over recent decades (Newton et al, 2001). This process has been occurring across most countries in the developed world (Fakhoury and Priebe, 2002). In the UK the change has been recorded and assessed largely by the Team of Assessment of Psychiatric Service (TAPS) project, which has charted the closure of large psychiatric hospitals (Leff et al, 2000).

Studies evaluating the effectiveness of placements have highlighted a range of outcomes, often in relation to basic living skills, social networks, relapse and behaviours (Trieman and Leff, 2002). Most notable is 'a marked preference by patients for community rather than hospital residence' (Thornicroft, Bebbington and Leff, 2005), a theme identified across re-provision literature (Newton et al, 2000; Leff, 2000; de Girolamo and Bassi, 2004). Hallam and Trieman (2001) found that service-users responded to environments which were less restrictive and offered a less clinical environment. Other research seems to suggest that the benefits are more social and personal than necessarily clinical, Leff (2000) reports data following 523 clients who moved out of a large long-stay asylum as showing 'no change in the patients' clinical state or their problems of social behaviour. However they gained domestic and community living skills. They also acquired friends and confidants. They were living in much freer conditions and the great majority wanted to remain in their current homes'

While quality of life post re-provision has often been measured using self-report measures, one area that has not been much explored is noted by Thornicroft, Bebbington and Leff (2005) in that there is relatively little literature relating to the service-user perspective on the process of deinstitutionalisation. This paper looks at a project to ask Service Users about their experience of moving out of a ward setting and into community residential settings and the attempts to bring about a necessary move while remaining true to Recovery principles.

The Recovery model

The concept of recovery has become a central tenet of mental health planning in recent history. There is also a drive towards this approach from government legislation such as the 'No Health Without Mental Health' (2012) cross-government mental health strategy for people of all ages. One of the clear objectives of the implementation framework is that 'people with mental health problems will recover' (No Health Without Mental Health 2012). There is therefore a drive for all services to be working in a recovery-focussed way. Recovery highlights the centrality of Self-Direction, Individualized and Person-Centered ways of working, Empowerment, Holism, Nonlinearity, Strengths-Based thinking, Peer Support, Respect, Responsibility and Hope (Bellack, 2006).

In line with this people labelled with diagnoses such as schizophrenia have, in recent years, been able to challenge the traditional notion that they will not make good progress through their experiences and achieve recovery (Bellack 2006). Recovery in this context looks above and beyond any symptoms and is based in understanding and recognising that psychotic experience can have an impact on many areas of life including self esteem, relationships with family and friends, social engagement and the experience of social stigma.

However, most recovery criteria, including Liberman et al's (2002), do not consider the service users' subjective appraisal of their own functioning or whether they are satisfied with their life. This exclusion of service users' views on their own recovery means that the recovery information provided will be an objective perspective of their level of functioning even when varying subjective feelings personal to the service user may exist, such as distress as a result of residual symptoms, frustration with inability to achieve personal ambitions and hopelessness about the future (Bellack, 2006). Accordingly this paper will aim to explore the recovery-led move-on experience from a Service User perspective.

The study

The authors, work as part of a community-based mental health team supporting long-term mental health Service Users with psychosis. After 15 Service Users moved out of the local ward-based setting (due to a reprovision of the ward), and into community-based residential care, they undertook a survey to evaluate the service-user experience of the re-provision process. To this end, a short questionnaire was devised using a semi-structured interview and Likert-scale items and a range of questions were asked around key topics.

Within previous literature there is a trend towards using qualitative methods as a means of exploring service-user experience (McCourt, 2001; Humberstone, 2002). The current study adopted both a quantitative and qualitative approach in order better to engage service-users and obtain informative data.

The purpose of the evaluation was to try to discover what worked well and what did not in the move-on and transition process from the Service User perspective. Questions addressed included:

- Did the Service User feel s/he had enough involvement in decision-making?
- Was there enough planning/advance preparation for the move?
- Was s/he given enough choice of placement?
- What were the advantages and disadvantages of moving to the new placement?
- What was his/her overall view of the transition process?
- What was the impact of the move on quality of life, social inclusion, hope and wellbeing?

Method and Procedure

The 15 Service Users who had moved on as part of the reprovision were approached regarding the project. They were offered information about the proposed evaluation and details of the interview process. Care-coordinators, psychiatrists and managers of the residences where the Service Users now lived were also given verbal and written information about the project. Because all possible participants were diagnosed with severe and enduring mental health problems, with a range of associated cognitive or social difficulties, extra time was allowed so that they could discuss and consider the information. Service Users were asked if they wanted to take part only after the information had been thoroughly discussed and questions or concerns answered. It was emphasised that participation was voluntary, and the interviewees could decline questions or decline to complete the interview if they wished. Participants were asked to sign a consent form if they agreed to take part.

Consent

Informed consent was obtained from each service-user who chose to participate. It was explained that survey information would be confidential and identifiable information would not be used in the final report. It was also made clear that no person was under obligation to participate, and that a participant could withdraw at any time.

Interview

Those that agreed to take part participated in an 18-topic semi-structured interview with a five-point Likert scale carried out by the authors in a setting agreed with the individual participant (usually at the participants' residential setting, in rooms other than their bedroom/or flat). In some instances the interview was conducted over more than one session, depending on the Service User's needs. The Likert scale wrought quantitative data, and qualitative data was obtained from the open-ended questions. Due to participant characteristics, the interview was kept relatively short and the language straightforward.

The interview was split into two parts:
- Pre-move experience: memories of choice and discussion regarding new placements, visits to new placements, option to move on and emotional responses;
- New accommodation: new location, independence, impact on well-being, individual care/support, and a free response area.

Most questions had two parts: a statement (such as ‘I was given enough warning of the move’) to which there could be responses through the five-part scale: Strongly Agree; Agree; Neutral; Disagree; Strongly Disagree; and a comments section led by the question ‘Could you please tell me more about that’. A conversational approach was taken throughout the interviews intended to to encourage participants to speak naturally and express their full opinions. There was also an open section at the end of the interview where participants could express any other feelings or thoughts they might have about the move or the interview itself.

Analysis
Thematic Analysis was employed to evaluate the qualitative data (see below). This is a technique that helps identify the themes and patterns in qualitative data. Thematic analysis principles were used as a guide to extract themes and sub-themes from the qualitative data, which were then explored to gain an in-depth understanding of the re-provision experience and any additional themes that emerged. The quantitative data was analysed using a computer program, SPSS. It is worth noting that the interviews were not recorded but transcribed verbatim by the interviewers. This may have led to some bias or misunderstanding which might have been avoided had recording methods been used.

Participants
The 15 Service Users who moved on were approached. Of these, five declined, leaving a total of 10 participants. Demographic information was gathered from NHS records about the 10 who agreed to participate. This data is shown in Table 1.

Table 1 Demographic Information

Gender	Female	3 (30%)
	Male	7 (70%)
Age	40-50	3 (30%)
	50-60	3 (30%)
	60-70	3 (30%)
	70-80	1 (10%)
Ethnicity (Using SLAM Monitoring Categories)	White British (A)	6 (60%)
	Black British (PD)	2 (20%)
	Caribbean (M)	2 (20%)
Clinical Diagnosis	Schizophrenia (F20)	4(40%)
	Paranoid Schizophrenia (F20.0)	4 (40%)
	Other Schizophrenia (F20.8)	2 (20%)

Table 1: showing demographic information for participants

As noted in the above table, all participants had formal diagnoses on the schizophrenia spectrum however; two service-users were also identified as having learning difficulties. All participants were in receipt of the Care Programme Approach (CPA). One participant was subject to a Community Treatment Order (CTO).

As noted by Newton et al (2001), there can be inherent difficulties with interviewing participants with severe and enduring mental health problems. Particular consideration was given to the difficulties faced by some participants regarding concentration, attention-span, learning difficulties, paranoid/psychotic ideations and communication difficulties. In light of this, every effort was taken to reduce the stress that participants might experience when meeting with an unfamiliar person. Advice was sought on how to approach each participant and advance meetings were arranged with potential participants in order to discuss the survey and supply written information.

As mentioned above, the option was offered of conducting the interviews over several sessions in order to control for fatigue, stress, concentration difficulties, and other cognitive impairments that might affect engagement. It was emphasised that participants' real opinions and views were of interest and would be valued and respected.

Results

Response rate and process

The ten Service Users who gave consent to participate in the survey represented a 67% response rate of all 15 clients who took part in the re-provision process. Of these four (40%) required only one session for the interview, five (50%) required two sessions, and one (10%) required three sessions to complete the interview.

Quantitative results

The Likert-scaled items yielded quantitative data, but the small sample size (n=10) precluded statistical analysis, beyond calculation of percentages. It is important to bear in mind that in this small sample size, one participant is expressed as 10% of the sample. In order to prevent results appearing inflated, both actual numbers and percentages are given. In addition, some questions remained unanswered, due to participants either being unable to remember (in relation to past experiences), or indicating that they did not fully understand the question despite it being paraphrased and repeated.

Table 2: Quantitative Data

Question	Strongly Agree%	Agree	Neutral	Disagree	Strongly Disagree	No response	Mean	Standard deviation
1) I was given enough warning of the move	20%	40%	10%	0%	30%	0%	2.50	1.18
2) I was given enough relevant information about the move in	30%	40%	10%	10%	10%	0%	2.30	1.34

advance								
3) I understand why I had to move	30%	10%	10%	30%	20%	0%	3.00	1.63
4) I felt involved in the decision-making around the move	30%	0%	10%	20%	30%	10%	3.50	1.90
5) I had the opportunity to discuss a choice of possible new placements with my care coordinator/ team	30%	10%	10%	40%	10%	0%	2.90	1.52
6) I was given an opportunity to visit the new placement before I moved	70%	20%	10%	0%	0%	0%	1.40	0.70
7) How did you feel when you were told you would have to move?	0%	0%	0%	0%	0%	0%	0%	0%
8) I was given space to express the feelings I	20%	40%	10%	20%	0%	10%	2.70	1.57

had?								
9) There are things I miss about the ward	20%	10%	10%	40%	20%	0%	3.30	1.49
10) There are things I was glad to leave behind at the ward?	10%	50%	10%	30%	0%	0%	2.60	1.07
11) I am satisfied with the home I live in now	50%	30%	10%	10%	0%	0%	1.80	1.03
12) I am satisfied with the area I live in now	50%	30%	20%	0%	0%	0%	1.70	0.82
13) I like my new home less than the ward	0%	10%	10%	30%	50%	0%	4.20	1.45
14) I am more independent now than I was before the move	40%	40%	20%	0%	0%	0%	1.80	0.79
15) I have less friends/social contacts in my new home than I did before	10%	10%	20%	40%	10%	10%	3.60	1.43
16) I am involved in as many	30%	10%	10%	40%	0%	10%	3.00	1.70

social activities in my new home as I was at the ward								
17) I feel less hopeful about the future since the move	20%	0%	0%	50%	30%	0%	3.90	1.10
18) I feel generally supported in my new home	30%	50%	20%	0%	0%	0%	1.90	0.74
N= 10								

Qualitative results

The interpretation of the qualitative data used Thematic Analysis as a guiding principle. Thematic Analysis seeks to report the experiences and reality of the experience of participants and attempts to draw meaning from them by identifying and analysing patterns in order to describe the data in detail (Braun and Clarke, 2006).

A theme is considered to be a defining feature of the data if it is found at least more than once within the data, or alternatively, a theme can be an aspect of individual experience that appears uniquely within the data (Humberstone, 2002). Themes are defined in that they should display both internal homogeneity and external heterogeneity (Braun and Clarke, 2006). The definition of a theme is that data within themes should be consistent, whereas between themes should be clearly identifiable.

For analysis of the data in the current survey, consideration was given to the above established approaches and principles. The method was as follows: the qualitative material was read separately by both researchers. Both researchers grouped material into apparent themes. The researchers met and the material was discussed as to whether it should remain in certain themes or be represented by different themes. Overarching themes were then agreed. By this means, several different overarching themes were identified which were further sub-divided into specific themes.

Discussion

Themes

The four over-arching themes extracted from the qualitative data were: Control, Hope, Relationship and Environment. These are discussed below.

Control

The theme of control came up across a range of areas of Service User experience. The word ‘told’ appeared regularly in Service User descriptions of the experience, such as: *‘They never told me about options. I was brought here’*, giving a sense that often a move such as this is something that is experienced as being done to rather than with. This was reflected too in uncertainties around why the move was necessary and a sense of less information (especially in written form) being available than some Service Users would have liked, ‘*There was no info on why I was moving. They just moved me out’*.

Generally, most participants did not feel they were part of the decision making process, with one participant stating that ‘*someone else made the decision’*. Alongside that was a sense that being given choices was important and meaningful: *‘I came and saw it (the new residence) and thought at once: this is the right place for me’*.

Overall most people viewed two or three places before the move, some only saw one. This highlights the limited number of placements available to service users in this client group, which may explain the lack of choice highlighted by some of the participants. This is in line with McCourt (2001) findings that exercising choice over new placements and being made aware of alternatives was not often afforded to service-users. However it is important to note that some participants indicated that they were able to make empowered decisions regarding placements, saying that they visited enough places to make a choice and gave a clear justification for accepting a placement. This expression of empowerment is in line the characteristics suggested as central to a recovery-oriented service (Ballack, 2006).

Most participants reported that the move felt sudden. Comments included “*…actual move happened too quickly, which I was not happy with*.’ This highlights that moves which are not service-user led can present challenges when trying to deliver an effective recovery-oriented service (Ballack, 2006). During further discussion about warning and information, it became clear that some Service Users viewed the move as a reflection on themselves and their difficulties and internalised this. One Service User said ‘*I was told it’s time move on because of my illness. I was getting worse so they moved me to this place*’.

Most participants commented on the increased control they have over their lives in the new setting. One participant stated that s/he now has ‘*a nice, big large room and I could put all the furniture in that I require’*. Other comments related to the difference in the settings: ‘(*the old unit) is a secure unit and this is a house. (I) spent 27 years in secure units... (I am) glad to leave secure unit’*. This comment is in line with studies that have highlighted the international process of deinstitutionalisation as beneficial (Fakhoury and Priebe, 2002) and that Service Users prefer to live in the community rather than hospitals (Thornicroft, Bebbington and Leff, 2005).

The new housing provision was generally smaller in size than the ward-in-the-community and this seemed to find positive response from Service Users. This fits with de Girolamo and Bassi (2004) description of smaller size settings which are said to be a critical variable for a successful placement. Possibly the ‘homely’ environment instead of a secure unit may also account for the satisfaction with smaller size placements. However, there was direct challenge to this view by one participant who stated (when contrasting the new home to the old), ‘*It seems so lonely in here; we don’t talk to each other*’. The potential for loneliness in community placements was identified by McCourt (2001), who pointed out that whilst community placements were consistently favoured over hospital style settings, some Service Users were positive about having larger numbers of people to interact with.

Hope

Hope is one of the central tenets of Recovery thinking and it arose regularly as a topic during the interviews. There was a general sense that participants were happy to move on and that moving in itself represented a sense of forward progress and grounds for being hopeful. Comments regarding the move included: ‘*I felt well* *over the moon'*. '*Pleased that I had to move'*. '*A new way of living'*; '*a bit hopeful'*. '*I want to get married, have kids and be a reggae DJ'*. This last quote illustrated what seemed central for several of the interviewees: that the move was perceived as part of a stepped-process towards other life goals. One participant commented on feeling *'less hopeful'* following the move but did not state the reason.

Most of the hopes and ambitions described were linked with the move-on. One Service User stated that '*moving was a great big achievement for me'*. It can therefore be said that service users may view moving on as a sound measure of their personal development and mental health recovery. It may therefore be important for those supporting Service Users to acknowledge these aspirations during the transition period and when a move is unavoidable (as here) to help the Service User to make these links and find the postives in the experience.

Relationship
With a client group such as this, the centrality of relationships can easily be forgotten and there was a sense of participants reminding the interviewers of how important relationships are. This included both positive experience and negative and related both to the old residence and the new. Some mentioned the importance of talking through a big life change such as a move with people they trust, e.g.: '*(I) expressed it to my next-door neighbour, the psychiatric nurse and also discussed with my sisters'*. Others spoke of loss of key relationships following a move: *'I miss all my friends up there. I miss D's cooking – he used to cook Jamaican food*'; '*I used to be friends with C at (the ward) and I miss him'.* But a number also spoke of the new relationships that had formed since the move and how important these were, e.g.: *'…now I'm learning to cook. I go to two clubs. I play dominoes and chess'*

Environment
Previous literature emphasises the importance of the physical environment, and its potential impact on well-being. Generally, less clinical or restrictive settings are preferred (Hallam and Trieman, 2001; Leff et al, 2000). Comments in this survey about environment included: '*I have a nice, big large room'; '*(I am) *satisfied with all the staff because I can communicate with them and discuss anything that is disturbing me*'; '*There is a much more relaxed atmosphere'; 'I think this is a really nice area'*

Conclusions and Recommendations

Move-on is sometimes inevitable in the lives of people with psychosis and long-term difficulties. It can represent a challenge but also (if managed well) can become an achievement and an important step towards life goals. It seemed important to Service Users in this survey that information about a move should be presented early in the process and as wide a range of choices regarding new placements should be offered as possible. There was also some sense that the information when presented was not always understood clearly. One method discussed for improving this was regular small group meetings at which written information is shared. And perhaps if there were more clarity around the move, Service Users would feel more able to have ownership over the experience of the move and a sense of the experience being planned 'with' rather than happening 'to'.

Having a sense of control over the move (even if the move is unavoidable) seemed important to Service Users who gave at times a sense of being excluded from some decision-making processes. Including Service Users in decision-making such as this presents challenges (it may be that they do have to move, and it may be that there are only a limited number of new placements that can manage their support needs), however it may be that a longer consultation period and smaller group information sharing would alter the perception of being 'told' what will happen to them.

The high importance of relationships and the fact that these can sometimes be valued less than they might be for other client groups seems relevant That people, both staff and fellow-residents, were missed and that new friendships were an important aspect of the new living arrangement was apparent from the data.

The environment in which people live seems central: size of room, pleasant staff, opportunities for self-sufficiency (as appropriate), accessibility of the local community, understanding of independence around money… all were highlighted as important and meaningful to the lives of Service Users. When planning a move, all these factors need to be taken into account and considered. Ensuring that a Service User's unique interests (access to local clubs for example) are considered is clearly necessary in planning a move that will be successful.

The subsequent experiences of the placements seemed mainly positive, with satisfaction expressed regarding placement facilities, the general ambience of the placements and locations. Often there was a sense of greater freedom and self-determination following the move and a feeling that, at best, the move represented something positive, an achievement, for the Service User.

Generally, there seems good reason to involve Service Users as early as possible in their own move-on and overall there seemed a sense that move from ward-based settings to community care can be a positive and meaningful experience for Service Users.

References

Braun, V and Clarke, C (2006) Using thematic analysis in psychology. Qualitative Research in Psychology. 3, 77-101

de Girolamo, G and Bassi, M (2004) Residential facilities as the new scenario of long-term psychiatric care. Current Opinion in Psychiatry. 17, 275-281

Department of Health (1999) National Service Framework for Mental Health: Modern Standards and Service Models. London: The Stationery Office

Fakhoury, W and Priebe, S (2002) The process of deinstitutionalisation: an international overview. Current Opinion in Psychiatry. 15, 187-192

Hallam, A and Trieman N (2001) The cost effectiveness of specialised facilities for service users with persistent challenging behaviours. Health and Social care in the community. 9 (6), 429-435

Hobbs, C., Tennant, C., Rosen, A., Newton, L., Lapsley, H, M., Tribe, K and Brown, J, E (2000) Deinstitutionalisation for long-term mental illness: a 2-year clinical evaluation. Australian and New Zealand Journal of Psychiatry. 34, 476-483

Humberstone, V (2002) The experiences of people with schizophrenia living in supported accommodation: a qualitative study using grounded theory methodology. Australian and New Zealand Journal of Psychiatry. 36, 367-372

Knight, M, T, D., Wykes, T and Hayward, P (2003) 'People don't understand': an investigation of stigma in schizophrenia using Interpretive Phenomenological Analysis (IPA). Journal of Mental Health. 12 (3), 209-222

Leff, J (2000) Can we manage without the mental hospital? Australian and New Zealand Journal of Psychiatry. 35, 421-427

Leff, J., Trieman, N., Knapp, M. and Hallam, A (2000) The TAPS Project: A report on 13 years of research, 1985-1998. Psychiatric Bulletin. 24, 165-168

Lelliot, P., Beevor, A., Hogman, G., Hyslop, J., Lathlean, J and Ward, M (2001) Carers' and Users' Expectations of

Services – User Version (CUES-U): a new instrument to measure the experiences of users of mental health services. British Journal of Psychiatry. 179, 67-72

MacNamara, J., Smith, P., Martin, G and Coonan, L (Unpublished) Quality of Life Survey 2003-4 Service users satisfaction with services and quality of life. Personal Communication.

McCourt, C, A (2001) Life after hospital closure: users view of living in residential ‘resettlement’ projects. A case study in consumer-led research. Health Expectations. 3 (3) 192-202

Newton, L., Rosen, A., Tennant, C., Hobbs, C., Lapsley, H, M and Tribe, K (2000) Deinstitutionalisation for long-term mental illness: an ethnographic study. Australian and New Zealand Journal of Psychiatry. 34, 484-490

South London and Maudsley NHS Foundation Trust (2007) Social Inclusion, Rehabilitation and Recovery Strategy 2007-2010 [online]. London: South London and Maudsley NHS Foundation Trust. http://www.slam.nhs.uk/news/boardmin/docs/20feb07/SIRR%20strategy%20final%20v2.doc [Accessed 9 July 2009]

Thornicroft, G., Bebbington, P and Leff, J (2005) Outcomes for long-term patients one year after discharge from a psychiatric hospital. Psychiatric Services. 56 (11), 1416-1422

Trieman, N and Leff, J (2002) Long term outcome of long-stay psychiatric in-patients considered unsuitable to live in the community (TAPS Project 44). British Journal of Psychiatry. 181, 428-432

Harrow M, Grossman L, Jobe TH, Herbener ES. Do patients with schizophrenia ever show periods of recovery? a 15-year multi-follow-up study. Schizophr Bull. 2005;31:723–734.

Torgalsbøen AK, Rund BR. Lessons learned from three studies of recovery from schizophrenia. Int Rev Psychiatry. 2002; 14:312–317.

Liberman RP, Kopelowicz A, Ventura J, Gutkind D. Operational criteria and factors related to recovery from schizophrenia. Int Rev Psychiatry. 2002;14:256–272.