# The Step-Down Challenge
## Service user perspectives on the realities of moving-on in residential care

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## Abstract

A series of interviews was carried out by a Counselling Psychologist and Assistant Clinical Psychologist based in a community mental health team in South East London to discover what its Service Users believe helps them to step down through levels of supported accommodation. The aim was to increase understanding of Service User perspectives of 'step-down care' and give insight into ways to facilitate movement out of high-support residential care settings. A qualitative thematic analysis was used to analyse the data following a series of semi-structured interviews with Service Users. The results showed that there was ambivalence among Service Users around step-down care and that there was more that residential care homes could be doing to prepare Service Users for stepping down.

**Key words**: Recovery; Service Users

Declaration of interest: None

## Introduction:

Supporting individuals with long-term mental health difficulties to 'step down' from hospital and high-support accommodation into less restrictive community living is a well-recognised vision within mental-health care. Enabling individuals to live with greater independence and access to the community is considered to be both cost-effective and recovery-focused. However, what this experience is actually like for the individual Service User and what can sometimes prevent such 'step-down care' from working effectively is rarely explored. To discover what the step-down experience is like and what services might be doing better, a service evaluation was conducted by a community recovery team in London. This paper presents the outcomes and makes some recommendations for improving the step-down experience for people with long-term mental health challenges.

That good housing is central to general wellbeing and good outcomes for individuals with mental health needs has been raised by recent UK campaigns such as Rethink Mental Illness: Schizophrenia Commissioners Report (2012). This highlights that areas such as housing, social support, access to meaningful activities, social inclusion and general wellbeing are arguably as central to quality of life as symptom reduction. This has links to other research that highlights the key role that housing plays in the lives of mental health clients. Tanzman (1993) for example, found that clients want independent housing (their own home), want to live with a friend not with other people with mental illness, and want staff support available on a 24-hour basis but not live-in staff. Nelson, Hall and Forchuk (2003) found that 79% of mental health clients living in residential settings wanted to live in a place of their own but only 38% of the sample were housed in a place they preferred.

Studies that reviewed psychosocial models used to support individuals in their recovery have found that Service Users responded to environments which were less restrictive and less clinical (Hallam and Trieman, 2001). Most notable was 'a marked preference by patients for community rather than hospital residence' (Thornicroft, et al, 2005), a theme identified across re-provision literature (Newton et al, 2000; Leff, 2000; de Girolamo and Bassi, 2004).

Manuel et al (2010) found that the subjective perception of clients that have been institutionalized within care systems can prevent and delay move on. They found clients identified lack of support, social isolation, stigma and lack of resources to meet daily needs as potential challenges to moving on. The supports that participants identified as important to help facilitate their rehabilitation into the community were: flexibility around access to treatment, being oriented to the local neighbourhood and connection to local support.

One residential care report, the Acumentra Health Executive Summary (2010), found that clients were not being supported in developing relevant skills to support their preparation to move on and while often supported in medication compliance and adherence to their treatment plan did not receive support around move-on skills.

There is also some literature on the concern that clients can get stuck in the system and not move on. The risk has been highlighted that clients are maintained in what appear to be community settings but what are actually 'virtual asylums' (Poole et al, 2002). Poole et al point out: 'Private facilities have developed without a policy framework for the protection of patients' long-term interests making them vulnerable to changes in the institution's niche in the market. They concluded that the network is a "virtual asylum", dispersed, invisible, and inadequately regulated'.

There is also a small but growing literature from Service Users themselves describing their experience. Sources such as Psychosis, Stories of Recovery and Hope (Cordle et al 2011), begin to provide a different sort of resource for understanding experiences of psychosis, including how services users feel whilst transitioning through care pathways.

**The Recovery Model**
In recent years, people labelled with diagnoses such as schizophrenia have been able to challenge the traditional notion that they will not make good progress through their experiences and achieve recovery (Bellack 2006). Recent UK

government directives such as No Health Without Mental Health (2012) highlight the centrality of recovery to mental health planning. Recovery literature highlights the importance of self-direction, individualized and person-centered ways of working, empowerment, holism, non-linearity, strengths-based thinking, peer support, respect, responsibility and hope ( Bellack, 2006).

However, it is still relatively rare to come across literature that gives a voice to the Service Users' subjective appraisal of their care, and (as in this case) of what it is like to move through step-down care. Accordingly this paper will aim to explore the recovery-led step-down 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, most of whom live in residential care settings (where most things are done for them by staff). Part of the remit of the team is to try to help Service Users to 'step-down' from this high level of care into supported-living arrangements (usually private apartments within a block where they can cook and clean for themselves but there is some in-house support available) and thence, ideally, to independent flats in the community. In recent years the team has made progress with some clients who have successfully negotiated this step-down system, but there has been a sense that some clients also become 'stuck' and find it hard to take the step away from high levels of support and move down through the system. For both financially-driven and recovery-driven reasons, move-on has become a key priority. So it was decided to conduct interviews to ask the clients what they find either helps or hinders step-down care.

To this end, two short questionnaires were devised, one to interview clients who have successfully negotiated the step-down system, and the other to interview clients who have remained for considerable time in residential care. Both questionnaires used 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.

Method and Procedure
Service users were selected based on where they were within the stepped care model. The evaluation sought to find clients with the following attributes:
- Clients who had stepped down successfully through the care system and were able to reflect on what was helpful and effective in that process.
- Clients who seemed to have become 'stuck' in the system and not able to move down from high-support accommodation and were able to reflect on what might help to move forward and facilitate step-down.

Some clinical judgement was also used in the selection of clients: would they be able to cope with an interview? Would they find the questions manageable? Discussion around these decisions was undertaken with Care Coordinators and senior staff.

Informed consent was obtained in writing from each service-user who chose to participate. It was explained that survey information would be confidential and identifying 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 a 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.

Most questions had two parts: a statement (such as 'I would like to move on at some point in the future') 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 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 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. 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**
14 Service Users were approached. Of these, 2 declined. Demographic information was gathered from NHS records about the 12 who agreed to participate. This data is shown in Table 1.

Table 1: Demographic information

| Gender | Male | 6 | 50% |
|---|---|---|---|
| | Female | 6 | 50% |
| Age | 40 – 50 | 3 | 25% |
| | 50 – 60 | 5 | 42% |
| | 60-70 | 4 | 33% |
| Ethnicity | White British | 9 | 75% |
| | Black British | 1 | 8% |
| | Black and White Caribbean | 1 | 8% |
| | Turkish Cypriot | 1 | 8% |
| Clinical diagnosis | Schizophrenia | 4 | 33% |
| | Paranoid Schizophrenia | 3 | 25% |
| | Schizoaffective disorder | 2 | 17% |
| | Personality disorder | 2 | 17% |
| | Biopolar affective disorder | 1 | 8% |

| | | | |
|---|---|---|---|
| Housing/ Accommodation types | Independent living | 2 | 17% |
| | Floating support | 2 | 17% |
| | Supported accommodation | 2 | 17% |
| | Residential care home | 6 | 50% |

s 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 and Discussion
Several themes emerged from the interviews conducted. Under these broad headings it was possible to shed light on how step-down care (moving on/or not) was experienced and understood by participants.

**Social support**
Service users from both groups highlighted the importance of social support systems with notable emphasis placed on the value of social interaction. Statements such as "...Having someone to help, helped", "I have a friend coming round every so often", "I still get help sometimes from (the outreach team), I get support over the phone, I know I can call them if I need help" seemed to speak to the need for regular social connection when moving on.

Clients at all levels of care expressed their fears and concerns about the loss of that support and fear of loneliness following move-on. Responses describing fear of "trying to cope on my own, knowing that I'm on my own", and the importance of staff "…it's good to know staff are here for me when I'm not so able"; "when I'm having a bad day, having someone to talk to" suggested a concern around reducing support. The importance of social interaction within these homes and the value of having peopled around seemed to be an important message communicated in the interviews "I'd miss everyone if I moved"; "I'd miss the time I spend with staff".

A sub-theme within the social/support theme was the risk of being socially isolated as a result of stigma. Comments such as "getting used to change, new people, because I don't know how people will react", "With paranoid schizophrenia, it's got such a bad reputation, they always report the bad stuff in the papers" shed light on this.

**Environment and living skills**
The physical environment and living space were unsurprisingly seen as important by many participants and this seemed to speak to the idea that it is not just moving that is important but finding the right place to move to and feeling 'at home' there. Preferences for "more space", "bigger rooms", "more privacy" and "…supermarkets close by" were mentioned.

A sub-theme focusing on the environment as a space that can promote independence and personal growth also emerged. Statements such as "…a place to do my art", "I can organize my time and activities", "I cook on my own in the kitchen in my flat", "I can have my meals at my own time" seem to reflect a positive view of having an independent space to

conduct personally-valued activities.

This fed into the skills necessary for living more independently, which were listed variously as cooking, cleaning, self-medication, money-management and decision-making. Having a role to play within a care home was seen as one good way to develop these skills with participants mentioning "running an IT group", "running residence meetings" and "laying the tables for meal times", as important in their own development. Fears existed around not being skilled enough, worries around managing bills, ensuring there was enough gas or electricity and so on. Clients often seemed to believe they were not being supported in developing the right practical skills to help them move forward. These findings seem to reflect those from the Acumentra Health Care Report ( 2010).

**Independence versus loneliness**
Independence and control seemed to be a theme linking across a number of different responses in both groups. An awareness that with increased independence would come more privacy, more capacity to make decisions, to be more self- determining was highlighted. Responses such as "I have my own flat, it's homely. Home sweet home", "I've independence, and more freedom…do what I want to do", "I've got freedom, I can go out on my own", seemed to highlight the sense of increased independence that stepping down wrought. Positive responses such as "I'm proud of it", "I want to stay here", "worthwhile", seemed to reveal a sense of achievement and pride as a result of moving on.

However, alongside this ran a general concern about isolation and loneliness with comments such as "I would probably die, I don't like loneliness" highlighting the fear that increased independence might be a negative experience. There was also a sense of participants who were still in residential care feeling attached to their current home and enjoying that level of support, one client even described their current residential care home as like "Butlins" (a holiday camp).

The fact that participants often spoke in emotional terms about move-on seemed significant. Alongside positives such as "worthwhile", words such as "sad", "nervousness" and "loneliness" were associated with changing homes. Clients who were finding it hard to step-down often used strong emotional language such as "I'd probably cope but I wouldn't be living", or "I would be gigantically miserable (following move on)" to vividly express their feelings. These findings seem to echo Manuel et al (2010) and their finding that often the subjective perception of clients serves as a barrier to moving on.

Timeliness and homeliness
The idea of knowing when it felt right to move on seemed to emerge as a theme from both groups. Clients mentioned they "felt ready...", "it felt right" or said "I was there (in a residential care home) for two and a half years…it was enough time to get me well". The fact that staff were described as having an "expectation" of clients moving on also suggests that clients often felt that they moved on with a sense of timeliness and readiness.

The sense that a residential home rarely felt like a home in the true sense of the word was also often mentioned. Participants described the lack of a "front door", living in a "room within a home"; "staff have a key and come in to bother you…sometimes I want to be left"; "it feels like a hospital and you want to be at home but you can't". Comments like these seemed to suggest an interest in moving on to a more independent setting and the difficulty of being 'at home' in a staffed setting.

# Recommendations:

Below is a list of recommendations that flowed from this evaluation. This list is not definitive and other possible responses may also emerge over time.

- The emphasis that participants put on practical concerns seemed significant. The development of skills while living in a residential care setting seems vital and it may be that care teams can do more to facilitate the development of such core skills while service users are living in residential settings. In other words residential care should not be a place where people are simply maintained, but rather one where they are 'skilled up' ready

for move on.

• The tension that seems to exist between wanting independence and fearing change may need to be considered. Clients in both groups (those who had moved on and those who had not) at times seemed ambivalent about managing with less support. It might be important to acknowledge this and to help clients to think through their reservations about move-on and to find mechanisms for managing worries. One method might be to invite graduates of the step-down process to return and talk to clients experiencing ambivalence to ensure they are aware of the realities of the step-down experience.

• The interviews seemed to suggest how vital social relationships are. Isolation or loss of relationships was something that both groups of Service Users mentioned as possible downsides to step-down. Therefore finding ways to value, continue and expand social networks ready for move-on would seem a key facet when working with this client group. For instance organising social groups for clients through the period of transition and beyond; or encouraging Service Users to return to activities within the homes they have left might be ways to avoid this sense of step-down having such potentially negative impacts.

• The fear of loneliness and of negative emotional experience following move-on was clear in the interviews. It may be that this could be addressed prior to beginning a step-down process through more information about the process, through visits to a range of homes, through group-work and education.

• The high level of ambivalence expressed in both groups around living in residential care suggests that the homes might do a better job of developing a homely environment. There was also the suggestion that the homes themselves could do more to prepare their clients for stepping down and bringing about a sense of timeliness. All residential care homes having programmes of Recovery practice in which the assumption is that the homes' role is to skill-up their clients ready for move on might be an important change of culture in residential care.

## Conclusion

The plan was to explore the experiences of adult mental health clients around the step-down care process. The findings highlight the importance of social networks to this client group and the need for continuing support even following move on. It suggested that the environment in which a client lives is important to the success of a move and that having the necessary practical skills is key to the move being successful. Most participants appeared to want more independence and to see stepping down as a positive. But there was a sense that this needed to happen at the right time when a client is ready. The evaluation also brought up the potential emotional significance of a move, both in terms of the people and places left behind, and the fear of loneliness that more independence might bring. Residential care homes can be part of this process by preparing clients for the challenges of stepping down and growing a sense of homeliness and timeliness around these core decisions in Service Users' lives.

## References

Bredski J et al (2011) The prediction of discharge from in-patient psychiatric rehabilitation: a case-control study. *BMC Psychiatry*, 11: 149

Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts, and implications. Schizophrenia bulletin, 32(3), 432-442.

Bolton J (2009) *The use of resources in adult social care: a guide for local authorities*. Department of Health

Cordle, H., Fradgley, J., Carson, J., Holloway, F., Richards, P. (2011) Psychosis Stories of Recovery and Hope. Quay Books, London

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 (2011) No health without mental health: A cross government mental health outcomes strategy for people of all ages.

Gilmer TP, Stefancic A & Etter S (2010). Effect of Full-Service Partnership on homelessness, use and costs of mental health services, and quality of life among adults with serious mental
illness, Archives of General Psychiatry 67(6): 645-652.

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

Holloway, F. (2005) The Forgotten Need for Rehabilitation in Contemporary Mental Health Services: A Position Statement from the Executive Committee of the Faculty of Rehabilitation and Social Psychiatry Royal College of Psychiatrists.

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

Killaspy H et al (2008) Mental health needs of clients of rehabilitation services: as survey in one trust. *Journal of Mental Health;* 17: 2, 201-218.

Killaspy, H., Bebbington, P. E., Blizard, R., et al (2006) The REACT study: a randomised evaluation of assertive community treatment in north London. BMJ, 332, 815–820.

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

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

Nelson G, Hall GB, Forchuk C. Current and preferred housing of psychiatric consumers/survivors. Canadian Journal of Community Mental Health. 2003;22:5–19. [PubMed]

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

Patterson ML, Moniruzzaman A & Somers JM (2013) Community participation and belonging among formerly homeless adults with mental illness after 12 months of Housing First in Vancouver, British Columbia: a randomized controlled trial. Community Mental Health Journal.

Poole, R et al. (2002). The NHS, the private sector, and the virtual asylum. British Medical Journal. Aug 17, 2002; 325(7360): 349– 350.

Rog DJ, Marshall T, Dougherty RH, George P, Daniels AS, Ghose SS & Delphin-Rittmon ME (2014). Permanent supportive housing: assessing the evidence. Psychiatric Services 65(3): 287-294.

South London and Maudsley NHS Foundation Trust (2007) Social Inclusion, Rehabilitation and Recovry 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]

Stefancic A & Tsemberis S (2007). Housing First for long-term shelter dwellers with psychiatric disabilities in a suburban county: a four-year study of housing access and retention. Journal of Primary Prevention 28: 265-279.

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

Time To Change. Time to Change is led by Mind and Rethink Mental Illness. http://www.time-to-change.org.uk/