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EXPERIENCES OF SERVICE USER INVOLVEMENT AND THEIR  
INFLUENCE ON IDENTITY

Section A: Service User Involvement and Implications for  
Empowerment, Recovery and Identity: A Systematic Literature  
Review

8000 (998) words

Section B: Involving People with Learning Disabilities on Interview  
Panels for Professionals and its Influence on Narrative Identity

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I'd also like to thank my wife, Sherri, for her patience and encouragement, and my son, Dylan, for reminding me that there is life outside of psychology. As with all of my endeavours, I dedicate this to both of you.

## Summary of MRP Portfolio

This portfolio comprises three sections:

**Section A** consists of a systematic review of the literature that explores the personal outcomes for service users who participate in service user involvement in mental health services. The search strategy is described and key findings from 12 papers are synthesised and critically evaluated. Service users described some potential benefits, but also struggled with stigma, tokenism and rigid power structures. These findings are discussed and areas for further research are identified.

**Section B** presents the findings of a study that explored the narrative identities of people with learning disabilities who had been involved in staff recruitment as service user representatives. Seven participants were interviewed, and these were transcribed and analysed using a thematic narrative analysis approach. The results suggested that while for some, being involved in interviewing was transformative, for others it was less significant. These findings are discussed in terms of theoretical, research and clinical implications.

**Section C** consists of appendices and relevant supporting material.

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**MRP Section A**

**Service User Involvement and Implications for Empowerment,  
Recovery and Identity: A Systematic Literature Review**

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## Abstract

**Background:** Service user involvement (SUI) in mental health services has gained momentum since the turn of the century. However, research has tended to focus on the process of involving service users, rather than the outcomes of SUI for those involved. This literature review explored the personal outcomes for service users on three dimensions, identified from conceptual papers: identity, recovery and empowerment.

**Method:** A systematic literature search was carried out, considering SUI at the levels of training and research (meta level), policymaking (macro level) and service planning (meso level). Twelve papers met the inclusion criteria, eight of which described SUI in training and research.

**Results and conclusions:** The papers identified suggested that SUI was empowering, and positively influenced recovery and identity. However, some service users reported that SUI negatively affected them, particularly when they felt that power was unequal or that their involvement was tokenistic. The relative paucity of research into SUI at the macro and meso levels was highlighted as an area for further research. Additionally, this review questioned the degree to which these findings could generalise to other service user groups, such as people with learning disabilities or dementia, indicating a need for further research in this area.

**Keywords:** service user involvement; mental health; social identity; empowerment; recovery

## **Service User Involvement and Implications for Empowerment, Recovery and Identity: A Systematic Literature Review**

Service user involvement (SUI) in mental health services has been increasingly prevalent in recent years (Tambuyzer, Pieters, & Van Audenhove, 2011). Despite this, much of the research literature has focussed on ways to effectively involve service users, with far less research into the effects of SUI on service users (Crawford et al., 2002). This paper describes a systematic literature review aimed at exploring the ways in which SUI influences the recovery, identity and feelings of empowerment for those involved. The paper will first provide an overview of the history and current context of SUI, before describing the literature review methodology and results. Finally, the paper will discuss the key findings and the influence of SUI on empowerment, recovery and identity. Future research directions will also be discussed.

### **Defining SUI**

There is still considerable disagreement about how one should define SUI, and a multitude of terms (e.g. patient involvement; consumer participation; service user activism) have been used to describe it (Renedo & Marston, 2011; Rise et al., 2013; Rise, Solbjør, & Steinsbekk, 2014; Williamson, 2004; Hopton & Nolan, 2003; Tambuyzer et al., 2011). This paper will use 'SUI' as an umbrella term for all of these, where a "service user" is defined as a person who uses, or has used, health services, and "involvement" is defined as "involvement in decision making and active participation in a range of activities (e.g. planning, evaluation, care, research, training, recruitment) starting from the expertise by experience of the person, in collaboration with and as equal partners of professionals" (Tambuyzer et al., 2011, p.142).

As can be seen from Tambuyzer et al.'s (2011) definition, service users can be involved in a wide range of activities, and the authors identify four organisational levels of SUI (Table 1). These levels are used as a framework for this review.

Table 1

Organisational levels of SUI (Tambuyzer et al., 2011)

Organisational level	Example of SUI
Micro/individual level	Involvement in decisions regarding one's own care plan
Meso/service level	SUI on an advisory panel for an inpatient unit
Macro/policy level	Involvement in development of national policy or NICE guidelines
Meta level	Involvement in mental health research or training

SUI occurs in a range of settings, including physical health services (Doherty & Doherty, 2005; Forbat, Hubbard, & Kearney, 2009), services for people with long-term neurological conditions (Fudge, Wolfe, & McKeivitt, 2008), services for people with physical or learning disabilities (Beresford & Campbell, 1994; Hurtado, Timmins, & Seward, 2012; Hoole & Morgan, 2010) and drug treatment services (Schulte, Moring, Meier, & Barrowclough, 2007). Whilst SUI in these settings may share some commonalities, there are also notable differences in terms of service users' needs and the barriers to effective involvement. It is, however, beyond the scope of this review to explore SUI for all service user groups, and this review will focus on mental health services specifically.

## **History and Context of SUI**

The involvement of service users in health and social care services can trace its roots back to the advent of service user/patient organisations in the late 1960s and early 1970s (Beresford & Branfield, 2012). In the UK's National Health Service (NHS), the advent of Community Health Councils in 1974 marked the first time SUI was implemented in national policy. The movement gained momentum throughout the 1980s and 1990s, with policy encouraging the use of patient feedback to guide improvement, increasing emphasis on consumer choice and increasingly including patient voices in health service decision-making (Barnes & Cotterell, 2012). The most recent national policy, the Health and Social Care Act 2012, continued this trend by developing Healthwatch England, a national body that represents service user interests in the NHS, as well as smaller Healthwatch groups in every local authority.

In contrast to users of physical health services, people with mental health problems were historically considered to have no rights or capacity to express choices over their own care, instead being perceived as 'subhuman' or 'moral degenerates' (Felton & Stickley, 2004; Rush, 2004). As a consequence, mental health services were slower in introducing SUI. This started to change in the latter half of the 20<sup>th</sup> century, and service user advocacy groups started calling for greater involvement in services in the mid-1980s (Rose, 2001). National policy around SUI in mental health services first emerged in 1999, when the National Service Framework for Mental Health stated an expectation that services should "involve service users and their carers in planning and delivery of care" (Department of Health, 1999, p.4).

## **Aims and Intended Outcomes of SUI**

There are a range of rationales and outcomes for SUI. Some of these aims have roots in activism and seek to change the political landscape of mental health services, while others

have a smaller scope, aiming to exert influence at the organisational or individual level. These are described below.

### Political and Ideological Outcomes

In a systematic literature review, Tambuyzer et al. (2011) highlighted that many papers argue for SUI as a fundamental right for all citizens in a democratic society and part of a broader trend towards participative forms of governance (Kemp, 2010; Forbat et al., 2009; Tritter & McCallum, 2006). Through this lens, some authors argue that SUI offers the opportunity for social action, and that the central outcomes of SUI are to promote organisational change, challenge contemporary ideologies and redefine power structures (Rose, 2014; Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2003; Cowan, Banks, Crawshaw, & Clifton, 2011). However, some authors have pointed out that service providers are often motivated to maintain existing hierarchies (Martin, 2008; Renedo & Marston, 2011), and that SUI has the potential to be misused as a “technology of legitimation”, in which professionals and managers can reinforce their own interests by strategically and selectively emphasising or dismissing the user voice as it suits them (Harrison, Barnes, & Mort, 1997; Harrison & Mort, 1998).

### Improving Quality of Services

A second central aim of SUI is to make services more accessible and more responsive to the needs of the service users. Tambuyzer et al. (2011) identify outcomes for service users including greater satisfaction with services, more accessible services and better quality of care. There is some evidence to support the notion that SUI at all levels influences these outcomes. For example, some studies have found that SUI in training and education challenges stigma and facilitates learning (Schneebeili, O’Brien, Lampshire, & Hamer, 2010; Terry, 2012). Other authors have suggested that SUI in research allows for a greater depth of

data and more clinical relevance (Townend & Braithwaite, 2002; Trivedi & Wykes, 2002). However, this evidence is equivocal, and other authors have found that increasing SUI within an organisation did not lead to greater satisfaction with care (Storm, Knudsen, Davidson, Hausken, & Johannessen, 2011).

### Therapeutic or Personal Outcomes

Finally, several authors suggest that SUI potentially offers personal outcomes for the involved service users themselves, with many authors reporting improved self-esteem, better quality of life or improved social functioning (Simpson & House, 2002). However, it is less clear to what degree these reported personal benefits emerge from the **consequences** of SUI (e.g. better quality services, more individualised care packages), or whether the **process** of being involved itself also has some therapeutic or personal outcomes. This review seeks to explore the latter in more detail.

Based on the wider literature, there are theoretical reasons to believe that the process of SUI may lead to three specific personal outcomes for those involved: **empowerment**, **recovery** and **identity**. Empowerment can be defined as “the level of choice, influence and control that users of mental health services can exercise over events in their lives” (WHO Regional Office for Europe, 2010, p.2), while recovery is defined as “living a satisfying, hopeful and contributing life even with the limitations caused by illness...[and] the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993; p.527). Tambuyzer et al. (2011) note that SUI shares a number of similarities with the both of these concepts, and so participating in SUI activity might have the potential to influence them. For example, both SUI and empowerment appeal to the strengths and competencies of individuals and aim to facilitate choice and influence.



Similarly, SUI and recovery are both concerned with developing meaning and purpose, and making a contribution to wider communities.

The notion of 'identity' is complex, as it represents a multitude of related concepts (Leary & Tangney, 2012; Ashmore & Jussim, 1997). However, it can be broadly defined as "the set of meanings that define who one is when one is an occupant of a particular role in society, a member of a particular group, or claims particular characteristics that identify him or her as a unique person." (Burke & Stets, 2009, p.3). Of particular relevance to SUI is social identity theory (SIT; Tajfel & Turner, 1979), which suggests that identity is grounded in the groups to which we feel we belong. This "social identity" is fluid, as our perceptions of ourselves change as our identification with different social groups becomes more or less salient (Haslam, Jetten, Postmes, & Haslam, 2009). Tse, Cheung, Kan, Ng and Yau (2012) suggest that SUI offers the opportunity for changes in group identification, and thus can potentially influence the social identity of those involved.

However, Tse et al. (2012) also highlight that the influence of SUI on identity is not straightforward, and can be positive or negative. They identify three "challenges" to developing a positive identity through SUI. First, developing a positive social identity through SUI depends on the perceptions of professionals or colleagues towards mental health: if being a service user representative is seen in terms of strengths and hope, rather than "illness" and vulnerability, then service users' identities are likely to be more positive. Secondly, since SUI may lead to a shift in roles, identity is dependent on how this shift is viewed by others. For example, if colleagues or other service users view this new role with mistrust or scepticism, an individual's social identity may be negatively affected. Finally, any significant change in social identity creates a feeling of discontinuity until a person can

reorient themselves to their new social group. This period of discontinuity is stressful and can affect wellbeing, even if the change in identity is ultimately positive (Iyer, Jetten, & Tsivrikos, 2008).

Based on the papers by Tambuyzer et al. (2011) and Tse et al. (2012), then, it can be hypothesised that SUI may be closely linked with empowerment, recovery, and identity. However, neither Tambuyzer et al. (2011) nor Tse et al. (2012) explored these relationships empirically, and so the evidence for these relationships is unclear. It is the aim of this review to explore this further.

### **Scope and Aims of Review**

This review seeks to systematically identify and synthesise literature to explore the following question:

**In what ways does SUI in mental health services at the meta, macro and meso levels influence recovery, empowerment and identity?**

Using the four-level model of SUI described by Tambuyzer et al. (2011; Table 1), as a framework, this review will focus on SUI at the meta level (training and research), macro level (policymaking) and meso level (service planning). Involvement at the micro level (e.g. involvement in treatment decisions), will be excluded from this review as it is arguably different from SUI at higher levels and has already been discussed extensively in previous systematic literature reviews (e.g. Hamann, Leucht, & Kissling, 2003; Patel, Bakken, & Ruland, 2008; Petersen, Hounsgaard, & Nielsen, 2008).

## Methodology

The inclusion criteria for the systematic literature search were that papers were:

1. peer-reviewed
2. written in English
3. published in or after 2002, when a similar (but less detailed) literature review (Simpson & House, 2002) was published.
4. original, full length, and reported on empirical research
5. concerning SUI in mental health at the meta, macro or meso level
6. studies that made reference to the influence on service users' experience of recovery, empowerment and/or identity

A flow chart summarising the search strategy can be found in Figure 1. Searches were conducted using PsycINFO, CINAHL, Social Policy and Practice, CDSR and PubMed databases. The Boolean keyword search **((patient\* OR user\* OR consumer\*) AND (inclu\* OR involv\* OR participat\*))** was used. This was combined with the “Mental Health” heading from the US National Library of Medicine’s standardised Medical Subheadings (MeSH) indexing system. In order to ensure that relevant papers were not missed, the search also included any papers whose title contained terms used to describe SUI (e.g. “user involvement”, “consumer participation”, etc.), irrespective of whether results also contained the “mental health” MeSH term. This was done using the Boolean title search **((patient\* OR user\* OR consumer\*) ADJ (inclu\* OR involv\* OR participat\*))<sup>1</sup>**

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<sup>1</sup> The function “AND” was used for the title search of the CINAHL database because the database does not support the “ADJ” Boolean function.

An initial search of all databases yielded 10,087 papers. After applying the first three inclusion criteria (English language; peer-reviewed; and published in or after 2002), the total number of papers was reduced to 6,797. The titles and abstracts of each of these papers were read to assess their potential suitability according to the latter three inclusion criteria (full-length; concerning SUI at the higher levels; and making reference to empowerment, recovery and/or identity). Following this process, 57 papers were identified as potentially suitable for inclusion. The reference sections of these papers were screened to identify further relevant papers (a process known as “snowballing”; Sayers, 2007). One additional paper was included.

After reading the 58 remaining papers in full, a total of 12 papers were found to wholly meet the inclusion criteria. Table 2 provides an outline of these and their relevant findings.

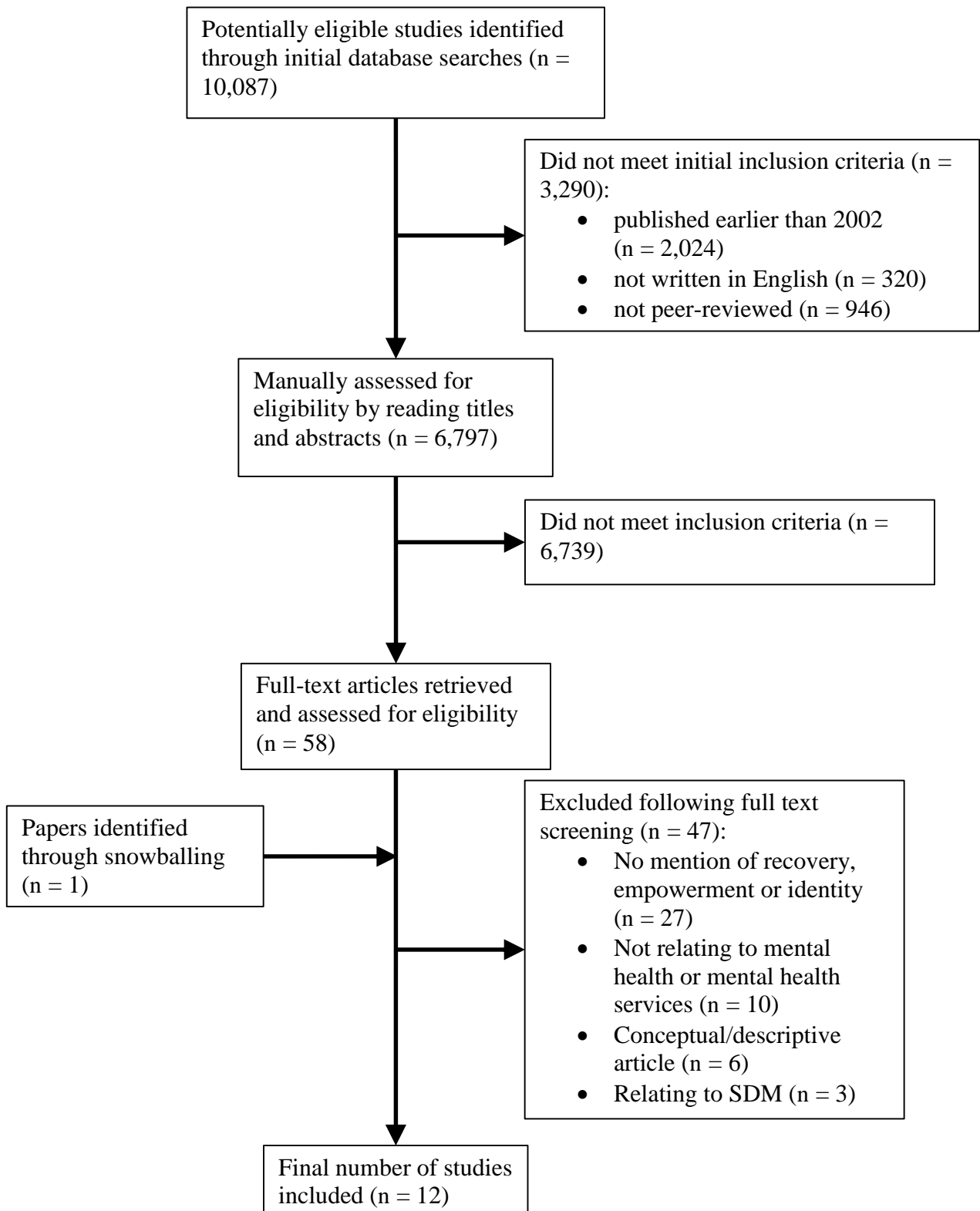


Figure 1. Literature search strategy flow chart

Table 2

## Summary of Studies Identified for Review

Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Omeni, Barnes, MacDonald, Crawford, and Rose (2014)	Service users' and professionals' perceptions of the outcomes of SUI policies.	Sample of service users (n = 302) and professionals (n = 143).	Cross-sectional survey across three NHS trusts. Quantitative data analysed using logistic regression; qualitative data analysed using thematic content analysis.	<ul style="list-style-type: none"> <li>- 45.7% of service users had had some kind of SUI experience, most commonly evaluating services (46.4%).</li> <li>- SUI generally evaluated as having positive impact, with participants feeling like that had a say and were included.</li> <li>- Small number of participants (n = 5) reported a negative impact on mental health.</li> </ul>
Hutchinson and Lovell (2013)	Experiences of service users as researchers who had been involved in a 3-year participatory action research study.	Six service user researchers. Five female.	Semi-structured face-to-face interviews. Analysed using qualitative methods, although precise approach not made clear.	<ul style="list-style-type: none"> <li>- Felt listened to, noticed and included</li> <li>- Felt less self-critical.</li> <li>- Involvement experienced as an “affirmation of worth...and a key step in their recovery” (p.646).</li> <li>- Participants valued feeling connected to others through the project and more able to acknowledge their achievements.</li> <li>- Distancing from label: from a self-stigmatising identity of “illness” to a newer, more positive “credible definition of self” as a researcher.</li> </ul>

Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Moltu, Stefansen, Svisdahl, and Veseth (2012)	Explored experiences of service users who had attended a five-day training programme in research methods and were subsequently involved in a participatory action research project.	Twelve service users. Nine female. Age range = 30-70 years.	Two focus groups of six participants. Focus groups met once at the end of the research school, and once three months later. Data analysed using a hermeneutic-phenomenological approach to identify themes.	<ul style="list-style-type: none"> <li>- Attendance at “research school” programme fostered group identity with a clear purpose and role.</li> <li>- Increased knowledge and spending time with academic researchers also helped to clarify unique role of “coresearchers” and to differentiate role from that of academic researchers.</li> <li>- Tension of maintaining identity as service user representative vs. becoming a non-representative but more influential “super user”.</li> </ul>
Taggart, Franks, Osborne and Collins (2013)	Experiences of young people involved in a participatory action research study into the impact of stigma.	Eight service users aged between 17 and 22.	Semi-structured interviews. Transcripts analysed using grounded theory.	<ul style="list-style-type: none"> <li>- Participants felt a sense of achievement and pride, feeling like they were making a difference.</li> <li>- Participants noticed increased confidence and independence, and had more confidence to speak out against poor quality services.</li> <li>- Participants also felt more able to manage responsibility and solve problems.</li> <li>- Emotive nature of the project was distressing for some.</li> </ul>
Patterson, Trite, and Weaver (2014)	Experience of service users involved in research in any capacity other than as a participant.	N = 166. Mean age = 46.8 years; 62.8% female; 77.9% White British; 63.9% educated to graduate level.	National cross-sectional study using online questionnaire. Quantitative data presented descriptively,	<ul style="list-style-type: none"> <li>- SUI experienced as empowering but a majority (68.5%) reported that people with mental health problems were marginalised in research.</li> <li>- Most participants found that SUI had improved their wellbeing, though for some the personal investment in the role had a negative impact.</li> </ul>

Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Jones and Black (2008)	Service user and student experiences of a teaching session as part of nursing training. In this session, service users talked about their experiences of mental health problems.	Student nurses (n = 30) and service users (n = 8).	Analysed feedback on teaching sessions. Method of analysis not reported.	<ul style="list-style-type: none"> <li>- SUI had “given meaning to their ‘suffering’, reduced self-stigma and enhanced self-respect.” (p.74).</li> <li>- Participants noted that SUI had helped them to develop self-management strategies and that being occupied facilitated a sense of achievement and pride.</li> <li>- “Service user” identity at times brought to the fore, even when not relevant to the situation.</li> <li>- Participants found the experience to be empowering and important in challenging stigma.</li> <li>- Personal benefits reported included improved confidence, mood and self-worth.</li> </ul>
Walters, Buszewicz, Russell, and Humphrey (2003)	Experiences of service users who were interviewed by undergraduate medical students as part of their training.	N = 95 service users completed questionnaire. Follow up interviews also conducted with	Evaluation questionnaires administered to participants. Semi-structured follow up interviews	<ul style="list-style-type: none"> <li>- Many reported they were treated with respect; felt empowered and had something to ‘give back’.</li> <li>- Many reported involvement as useful in making sense of experiences, but some (n = 2) found it distressing.</li> </ul>



Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Honig, Dargie, and Davies (2006)	Experiences of providing training on eating disorders, both immediately after teaching and six months later.	service users (n = 20), tutors (n = 12) and students (n = 14).  Service users who had used adolescent eating disorders services (n = 7) and their parents (n = 9)	completed and analysed using a framework approach.  Questionnaires administered using Likert scales (presented descriptively) and open-ended questions (subjected to thematic analysis).	<ul style="list-style-type: none"> <li>- SUI had positive effects on self-esteem, and this was maintained six months later.</li> <li>- SUI had helped service users to feel more confident; more relaxed around professionals and develop communication skills.</li> <li>- Also helped to develop narratives around their experiences.</li> </ul>
O'Reilly, Bell, and Chen (2011)	Explored goals, challenges and benefits for service users involved in training pharmacy students.	Pharmacy students who had received the training (n = 11) and service users (n = 12).	Focus groups conducted six to eight weeks after teaching session. Content analysis carried out on transcripts, using the constant comparative method to identify key themes.	<ul style="list-style-type: none"> <li>- Influencing large numbers of people's attitudes towards mental health and reversal of traditional professional-service user roles felt empowering.</li> <li>- Reminder that recovery is "going well", and an opportunity to review management skills.</li> <li>- Improved confidence and public speaking skills, though anxiety and paranoid thoughts can present a challenge.</li> </ul>
Harding, Brown,	Experience of	N = 10 service user	Semi-structured	<ul style="list-style-type: none"> <li>- Participants felt their experiential knowledge</li> </ul>

Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Hayward, and Pettinari (2010)	service user representatives on panels for NICE guidelines.	representatives. All were White British; five were male.	interviews that explored how participants perceived the role of scientific data and experiential data in the guideline development process. Grounded theory was used for analysis.	<p>complemented scientific evidence, but felt their experiences nevertheless were less valued.</p> <ul style="list-style-type: none"> <li>- Meetings felt collaborative, but sometimes final decisions seemed to be made by professionals.</li> <li>- Professional jargon was a barrier.</li> </ul>
McDaid (2009)	Participatory action research study exploring service users' experiences of attending service advisory committees in Ireland	N = 20. Fifteen were long-term mental health service users, and five were leaders of advocacy groups (included for triangulation).	Participants were interviewed, focussing on experience or anticipated experience of participation. Data analysed using grounded theory.	<ul style="list-style-type: none"> <li>- Participants identified inequalities and challenges in a range of areas, including feeling nervous, outnumbered or intimidated, stigma and tokenism.</li> </ul>

Author(s)	Study aims	Sample	Data collection and analysis	Relevant Findings
Rutter, Manley, Weaver, Crawford, and Fulop (2004)	Perspectives of multiple stakeholders on SUI in two London NHS trusts.	Sample of service users (n = 13); voluntary sector (n = 9) and staff (n = 27). Demographic information not provided.	Semi-structured interviews conducted and analysed using grounded theory.	<ul style="list-style-type: none"> <li>- Service user groups reported struggling to maintain an independent voice because of involvement with services.</li> <li>- Struggles with frustrations around tokenism.</li> </ul>

## **Literature Review**

Each paper is described in more detail below, with key findings and methodological limitations discussed. Since many of the papers included in this review discussed outcomes on recovery, empowerment and identity interchangeably, it was not possible to organise this review under these three subheadings. Instead, this section will be organised by exploring each level of SUI (research and training, policymaking and service planning) in turn. A synthesis of the overall findings for empowerment, recovery and identity can be found in the discussion section.

All studies identified for review use qualitative methodology or a mixed methodology with a significant qualitative component. A quality assessment framework was developed by combining criteria described by Mays and Pope (2000), and Elliott, Fischer and Rennie (1999). This framework was systematically applied to each paper to judge their quality. Critiques of each paper are described more fully in the body of the text, but a summary of their quality against the framework can be found in Appendix A.

### **SUI across all levels**

The study by Omeni et al. (2014) was the only paper that did not focus on a specific level or type of involvement, but rather explored SUI at all levels (e.g. training, recruitment, running services, commissioning, etc.). The authors carried out a large-scale cross-sectional survey across three NHS mental health trusts. A questionnaire was completed by service users (n = 302) and professionals (n = 143). Participants were asked which areas (if any) of SUI they had been involved in, and to rate and describe qualitatively the perceived impact of their involvement.

From the open-ended questions completed by 97 service users and 67 professionals, a range of benefits of SUI were identified, including being able to have a say and feeling included in decision making (n = 61). Respondents also identified therapeutic benefits (n = 29), in that SUI improved their self-esteem or contributed to their recovery. However, a small number of participants reported that SUI was detrimental to their mental health (n = 5) and nine respondents identified stress and high demands as having a potentially negative effect on the health and wellbeing of involved service users.

One of the major limitations of this study was that it was not clear how experienced respondents were in SUI, or the extent or impact of their involvement. A second limitation is that, because of the survey-based nature of the study, it was not possible to ask follow up questions to find out more about the personal outcomes of SUI. For example, while some participants reported that SUI had negative effects on health and wellbeing, the precise nature of this was unclear. This was exacerbated by the fact that the authors do not provide any quotes from participants or ground their data in examples, which is one of the quality criteria from Elliott et al. (1999).

### **SUI in Research and Training (Meta Level)**

The majority of studies (n = 8) identified for review discussed meta-level SUI across two domains: SUI in research and SUI in teaching. These are described separately below.

#### **SUI in Research**

Four studies (Hutchinson & Lovell, 2013; Moltu et al., 2012; Taggart et al., 2013; Patterson et al., 2014) explored the experience of being involved in research (also known as “participatory action research” or “PAR”).

Hutchinson and Lovell (2013) reported on a 3-year PAR study in which a team of 6 service user researchers interviewed 30 mental health service users about illness identity. The paper focussed on the experience of the service users who had been involved in the research project. Participants described involvement as empowering, as they felt listened to and valued. They described this experience as an “affirmation of their worth as a human being” (Hutchinson & Lovell, 2013, p.646). Participants also felt a renewed sense of purpose and they were “giving something back”, and suggested that these factors contributed to recovery. In addition, since the topic of the research resonated closely with individuals’ own experiences of living with mental health problems, participants talked about how the process of hearing others’ stories was normalising and inspiring, and helped participants to make steps towards their own recoveries.

Hutchinson and Lovell (2013) also made reference to identity. The authors argued that involvement “provided a mechanism for redefining identities, increasing social experiences and regaining control over one’s life” (Hutchinson & Lovell, 2013, p.647). They conceptualised this in a “transformation trajectory” diagram, indicating the shift in participants’ identities from a “cycle of illness” to cycles of inclusion and transformation (Figure 2). One participant noted that they had moved from identifying as a service user to identifying as a researcher, which they viewed as a positive shift.

One of the major limitations of Hutchinson and Lovell’s (2013) paper is that the authors did not make clear what analysis (if any) was carried out on the research data. While the authors indicated that they were focussing on participants’ narratives and cite books on narrative analysis, they also cite books on interpretive phenomenological analysis (IPA), and appear to have built a theory reminiscent of grounded theory. Furthermore, the authors did not provide

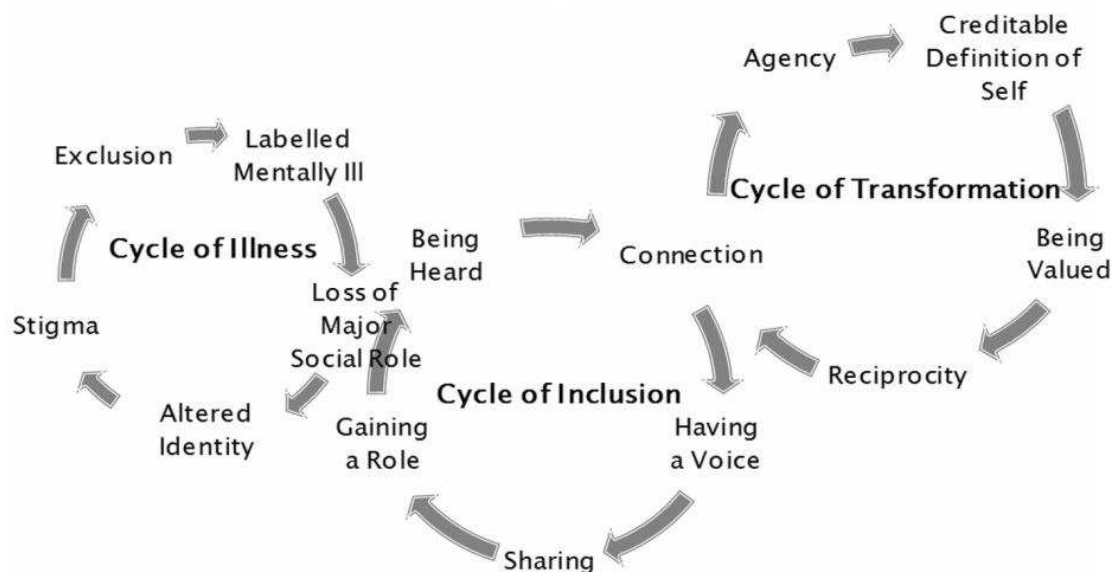


Figure 2. The Transformation Trajectory (Hutchinson & Lovell, 2013)

any information on credibility checks or reflexivity. This lack of clarity makes it difficult to critically evaluate the study using the quality assessment framework (Appendix A).

In another study exploring SUI in research, Moltu et al. (2012) conducted an in-depth study in Norway which explored the experiences of service users who participated in a five-day a teaching programme on theories of science and qualitative methodology. The aims of this were to provide service users with knowledge and to empower them users to participate in a PAR project. Twelve participants were randomly assigned to one of two focus groups, both of which met simultaneously at the end of the teaching programme and 12 weeks later. Data were analysed using a hermeneutic-phenomenological approach to identify themes.

The central findings from Moltu et al. (2012) echoed Hutchinson and Lovell's (2013) transformational trajectory model in that participants developed a positive and valued social identity as a "coresearcher", and suggested that this group identity "makes relating to the world of academic research more secure and less overwhelming" (Moltu et al., 2012, p.1612). Participants also reported that their social identity as coresearchers differentiated them from

academic researchers. This was perceived as a positive thing: coresearchers had a clearer sense of their own unique perspectives, their role within research, and the potential benefits of SUI in research. Participants noted that the research school served to demystify academic research and position researchers' views as one perspective of many, giving them more confidence in the values of their own perspectives.

Participants also described feeling that they needed to remain loyal to their background in order to effectively represent the perspective of people with mental health problems in research. Participants described a risk of becoming a "super user", by becoming too skilled and developing perspectives reminiscent of an academic researcher. They felt that whilst becoming a super user might confer greater influence overall, it would be detrimental to the coresearcher cause and would mean that one would have to step down as a coresearcher.

The study by Moltu et al. (2012) was well-designed and the authors provided a detailed summary of the approach data collection and analysis and evidence of member checking (where preliminary findings are presented to participants for comment). They also commented on awareness of the ways in which their own perspectives might influence the data and of the importance of reflexivity, but did not provide information on their own perspectives and potential biases. Consequently, they did not meet this criterion in the quality assessment framework (Appendix A). Another limitation of the study is that, whilst the authors provided some general information on the group (e.g. gender, age ranges), they did not provide sufficient detail on individuals to situate the sample. The authors acknowledged this as a limitation and argued that this was done intentionally to protect confidentiality.



Taggart et al. (2013) explored the experiences of young people (aged 17-22) involved in a PAR project into stigma. The findings of this project were disseminated via an animated film that was presented to local services, in educational settings, and at a conference. Using grounded theory, Taggart et al. (2013) analysed the transcripts of semi-structured interviews with eight participants, all of whom were accessing a community-based voluntary sector mental health service. The aims of the research were to explore the changes that participants had noticed from participating in the project.

The authors identified changes at multiple levels. As with Hutchinson and Lovell (2013), participants reported a sense of achievement, pride and feeling that they were making a difference. Participants also reported feeling empowered and part of a collective action. This enabled people to have more confidence in speaking publically and complaining about poor quality services. Participants also reflected on how this change had contributed to their recovery. For example, one said that speaking out in a conference was “quite a way to come, for someone who was just sitting at home, not even leaving the front door” (Taggart et al., 2013, p.65). However, Taggart et al. (2013) also found evidence of a negative impact of PAR, as some participants reported that carrying out research in an emotive and personally relevant area could be distressing.

Taggart et al. (2013) paid careful attention to rigour in their study and used strategies such as cross-checking between researchers to check the credibility of findings. They also clearly explained their process of data collection and analysis. However, as with Moltu et al. (2012), Taggart et al. (2013) noted the importance of reflexivity and appear to have taken researcher biases into account when analysing their data, but did not provide any information on the authors’ perspectives or biases.

In a much larger study into SUI in research, Patterson et al. (2014) carried out a survey-based study of service users who were involved in research. Data were collected through online self-report questionnaires. The survey was aimed at a broad target population, defined as any “people with experience of service use in respect of mental health who are involved in mental health research (other than as a participant)” (Patterson et al., 2014, p.68). Participants (N = 166) were thus involved in a diverse range of roles such as paid researchers; postgraduate students whose choice of topic was influenced by experience of mental health problems; or representatives on ethics panels. Findings from the questionnaires included quantitative data, presented as descriptive percentages, and qualitative data from open-ended questions, which were analysed using a framework approach.

Respondents indicated that being involved in research was challenging. It involved considerable personal resources, such as being educated, articulate and assertive while also staying mentally “well enough” to participate. The majority of respondents (68.5%) also agreed with the statement that service user researchers were marginalised in mental health research. Nevertheless, participants reported that they felt empowered by being involved in research (82.6% agreed) and that their participation was valued by academic researchers (49.7% agreed, 28.2% neither agreed nor disagreed).

Respondents also talked about the challenges of their mental health identity being at the fore. Some gave examples of being expected to share their personal experience publicly, or being hesitant to show any signs of distress (even when appropriate in the situation) in case it was interpreted by colleagues as related to mental health problems. Similar to the findings of Moltu et al. (2012), some respondents also talked about the challenges of becoming a super user and the consequent risk of being excluded from the wider service user community.

However, whereas participants in the study by Moltu et al. (2012) suggested that becoming a super user would lead to greater influence within the academic world, participants in the study by Patterson et al. (2014) felt that gaining too much expertise could lead to others questioning their representativeness as service users, thereby reducing their credibility. These findings suggest that SUI in research involves treading a narrow path in order to have both a credible identity as a “representative” service user, and a credible identity as a researcher.

A small minority of respondents ( $n = 14$ ) indicated that SUI had negatively impacted their mental health, often because of the stress of the work, and that this had undermined their confidence. One respondent described how struggling with the work had impacted on their mood because of close links between the role and their identity. However, most ( $n = 80$ ) had found that involvement had improved their wellbeing in similar ways to those described in Hutchinson and Lovell’s (2013) study, with many writing about getting a sense of purpose, greater self-respect and giving meaning to their experiences.

The study by Patterson et al. (2014) generates its findings from a sizeable sample, meaning that the findings are more generalisable than in the study by Hutchinson and Lovell (2013). Furthermore, it meets many of the quality criteria outlined in the quality assessment framework (Appendix A), in that it uses multiple sources of data (qualitative and quantitative) to triangulate its findings and reports data from negative cases (i.e. those respondents who did not agree with the emerging picture of SUI in research). However, some of the roles that participants had in the study do not meet the definition of SUI used in this review, as not all participants were working from a position of “expertise by experience”. For the purpose of this review, therefore, this study must be interpreted with caution.

### SUI in Teaching and Training

Four studies explored the experience of SUI in training professionals and students. In Jones and Black's (2008) study, service users had presented their experiences as part of a mental health branch of a nursing degree course in Wales. The authors analysed feedback from student nurses (n = 30) and service users (n = 8) and found that SUI was seen as overwhelmingly positive. Although one service user acknowledged that it was difficult to speak in front of other people, many found the experience to be empowering, reported a greater perceived value as a person, and said that the experience had a positive impact on their mental health such as improvements in confidence and mood. One service user reported that SUI had inspired them to enrol on a college course, suggesting that the experience facilitated their recovery.

This study, however, has significant limitations and so findings should be interpreted tentatively. Jones and Black (2008) made no mention of data analysis, so it is unclear whether any analysis was carried out or if the study simply provides a descriptive overview of raw interview data. Additionally, while the authors reported that feedback was collected through a written evaluation form, they provided little information on the structure of these forms, or how they were developed. This lack of detail means that the study met few of the quality criteria used in this review (Appendix A).

In another study of SUI in training, Walters et al. (2003) administered evaluation questionnaires to 95 service users who had participated in a mental health teaching programme for undergraduate medical students. Students spent time in GP surgeries and community mental health teams and, as part of their teaching, interviewed someone with lived experience of mental health problems. To explore the questionnaire responses further,

the authors conducted semi-structured interviews with 12 tutors, 14 students and 20 service users who had completed the questionnaire. Service users were selected for follow-up interview on the basis of their attitudes to teaching and demographic information to ensure a wide diversity of participants. Data were analysed thematically using a framework approach. Walters et al. (2003) noted that they reached saturation point with their data at 14 service users but carried out a further six interviews to ensure adequate diversity.

The authors found that service users were generally positive towards the teaching programme, and 62 of the 95 participants reported that they found their own participation valuable. Consistent with findings from Moltu et al. (2012); Taggart et al. (2013); and Hutchinson and Lovell (2013), participants reported that they found the experience empowering and validating, as it helped them to feel like they have something to “give back” to services. Many participants also talked about the benefits of telling their story as a way of making sense of their experiences and developing their narratives, and an opportunity to reflect on their recovery thus far. Some participants reported less positive outcomes, such as finding sharing their stories emotionally distressing or feeling initially nervous.

The study by Walters et al. (2003) appears to be well-designed and careful attention was paid to diversity and data saturation. The study also meets many of the validity criteria used in this review (Appendix A) as the authors paid attention to negative cases, provided evidence of reflexivity and clear information on data collection and analysis methods, meaning that the findings are credible, robust and likely to be generalisable to the wider service user population. However, the authors note that the service users were initially chosen from a highly selected group of people who had been specifically chosen to participate in teaching.

Honig et al. (2006) explored the experiences of training for service users who had used adolescent eating disorders services. Questionnaires were given to all service users ( $n = 8$ ) and parents ( $n = 9$ ) who had been involved in training events in the five years prior to the study. These training events included running workshops at conferences and providing teaching to student nurses. A total of seven questionnaires were returned from service users, and nine from parents. Questionnaires included a number of questions with 5-point Likert scales to rate how they felt about their SUI immediately afterwards and 6 months or more after participation. These findings were presented descriptively. Questionnaires also included some open-ended questions, which were subjected to thematic analysis.

The majority of service users reported that their involvement had a positive or very positive effect on their self-esteem, even more than six months after being involved. Participants felt their involvement had led to positive personal outcomes and, interestingly, no service users indicated any negative impact of involvement. Participants reported outcomes that indicated greater confidence, such as feeling more relaxed and comfortable around professionals and improved communication skills (especially public speaking). Participants also valued being heard and helping others, and felt validated by their participation. Honig et al. (2006) found that sharing their stories helped service users to reflect on their experiences. One participant, for example, noted that they “developed a perspective about the course of events, summarising a difficult phase in [their] life” (Honig et al., 2006, p.267). This is consistent with the findings of Walters et al. (2003), indicating that sharing experiences in teaching settings may offer an opportunity to develop narratives.

One of the limitations of the study is the small sample used to gather quantitative data, and this may partly account for the overwhelmingly positive feedback on the project. Honig et al.

(2006) did not describe the demographic characteristics of the sample, so it was not possible to situate the sample. Additionally, the post-hoc nature of the study meant that people were asked to recall back to how they were feeling at the time they provided training, and this was up to 5 years prior to the study.

Finally, O'Reilly et al. (2011) explored the experience of SUI in training third year pharmacy students in Australia. Service users were invited to talk about their experiences of living with mental health problems and to answer questions. Following this, all students and service users were invited to attend separate focus groups. Five focus groups were conducted, comprising a total of 12 service users and 11 students. Data were analysed using content analysis and the constant comparative method.

Service users felt that sharing their experiences and potentially making a difference to stigma was empowering. Participants also reported feeling more confident and having improved social skills. However, participants felt that rather than directly contributing to their recoveries, SUI was more a chance to reflect, review their management strategies and to affirm their recovery. This differed from participants in some studies already described in this review (e.g. Hutchinson & Lovell, 2013; Taggart et al., 2013). Some service users also found that the role was challenging and had a negative impact. They linked this to their mental health problems, such as feelings of paranoia or social anxiety. This perhaps relates to the findings of Patterson et al. (2014), where SUI was reported to require one to feel "well enough" to participate.

O'Reilly et al. (2011) used focus groups and this means that they shared similar limitations to Moltu et al. (2012): the paper lacked detailed descriptions of participants with which to

situate the sample, and nuanced differences between participants' perspectives could not be detected. Another limitation is that the authors did not mention any credibility checks or reflexivity, and while they noted the data analysis methods, this was somewhat lacking in detail. This renders it more difficult for the reader to form a clear judgement of the rigour of the study.

In summary, SUI at the meta level had a generally positive influence on empowerment, recovery and identity. Many studies in this section found that SUI in training and research was empowering, because it fostered a sense of being heard and “making a difference”; that it contributed to recovery, with participants reporting that their involvement gave them a sense of purpose and confidence; and that it had a positive effect on identity in terms of developing new, positive roles or narratives.

In the next two sections, this review describes SUI at the levels of policymaking and service design. At these levels, service users were working mainly with mental health professionals (rather than with academics, students and educators), and their involvement had the potential to directly influence services. In this context, service users' experiences of, and personal outcomes resulting from, SUI were somewhat different.

### **SUI in Policymaking (Macro Level)**

One paper (Harding et al., 2010) explored SUI at the level of policymaking. They carried out semi-structured interviews with 10 service users who had been involved in NICE Guideline Development Groups (GDGs) for mental health, analysing their data using grounded theory. The aims of the study were to explore the relationships between the group members and the perceptions of scientific data and lived experience in the guideline development process.



Participants reported that lived experience was given a lower priority compared to quantitative research evidence. They nevertheless felt that discussions were collaborative, that their personal experience was recognised and valued by other group members, and described having some power and influence within the group. Some participants felt, however, that there was a lack of clarity around how final decisions were made and at times the consensus appeared to be overturned. Some participants also noted that SUI may have had a negative effect on identity, by comparing themselves unfavourably with the professional GDG members. One described themselves as “little old me that’s had this experience...a long time ago” (Harding et al., 2010, p.255) when compared with the “experts”. Such unfavourable comparisons against others may lead to more negative self-perceptions, as suggested by social comparison theory (Stets & Burke, 2014).

The study paid careful attention to reflexivity, which Mays and Pope (2000) define as an important part of improving the validity of qualitative research. Harding et al. (2010) was the only paper in this review to have explicitly reported on the researchers’ personal experiences, assumptions and epistemological position. However, the authors noted that the study recruited too few participants and so they failed to reach saturation in their data. As such their findings may have been incomplete or unbalanced.

It seems then, that participants in the Harding et al. (2010) study found their SUI to be somewhat empowering in the sense that they felt valued and listened to but that there were limits on their relative power. SUI at this level also had a somewhat negative influence on identity. This contrasts with findings of SUI at the meta level. However, since this was the only paper identified in this review to explore SUI in policymaking, and since Harding et al.

(2010) did not reach saturation, it is unclear how representative the study is of SUI in policymaking more broadly. As such, only tentative conclusions can be drawn.

### **SUI in Service Planning and Service Development (Meso Level)**

Two papers described SUI at the level of service planning. McDaid (2009) reported on a PAR study in Ireland in which people were asked about their experiences (or anticipated experiences) of attending service advisory committees. Participants were 15 long-term mental health service users (referred to as the “Core group”). To improve validity of the research, the study also included five leaders of the Irish user/survivor movement (referred to as the “Triangulation group”) and carried out member checking. These are important criteria in Mays and Pope’s (2000) quality checks, as they allow for corroboration of the researcher’s interpretations.

McDaid (2009) analysed interview data using grounded theory, identifying the “equality of condition framework” (Baker, Lynch, Cantillon, & Walsh, 2004) as a foundation for their analysis. This framework argues that disadvantaged groups (such as people with mental health problems) should be able to achieve greater equality through equal participation in social groups and activities such as democratic decision-making. The equality of conditions framework outlines four dimensions of inequality: power; respect and recognition; resources; and love, care and solidarity.

The overarching finding of the study was that involved service users experienced substantial inequalities and, as a result, service users did not feel empowered. Participants described feeling nervous or intimidated by attending the meeting because they felt out of their depth and did not always understand the jargon used. Participants also talked about inequalities in physical and mental resources such as lacking the energy or capacity to concentrate, or

feeling stressed and anxious about participation. These had a negative impact of SUI on recovery and wellbeing, and made it difficult to fully participate. This resonates with the findings of Patterson et al. (2014), in which participants highlighted the need for considerable personal resources to manage the demands of SUI.

Participants also felt stigmatised by meetings which were dominated by professional interests and tokenism. One member of the triangulation group described a feeling of inferiority because he felt that staff “were only listening...because it was the proper thing to do” (McDaid, 2009, p.469). Some participants described feeling isolated and feeling “like an outsider” (McDaid, 2009, p.470). McDaid (2009) highlighted that in a group of people who can often feel socially isolated and lack emotional support there is a need to build in opportunities for solidarity wherever possible.

In a broader study exploring SUI in service planning, Rutter et al. (2004) explored the perspectives of multiple stakeholders across two London NHS trusts. SUI included involvement in recruitment, attending groups/forums regarding service change and development, and informal consultation of service users by managers. They carried out a total of 49 interviews with multiple stakeholders, such as service users (n = 13); representatives from the voluntary sector (n = 9) and staff (n = 27). They analysed the data using grounded theory.

The paper highlighted feelings of disempowerment across the two trusts. Service users expressed frustration at a lack of power to facilitate change. Some felt that their involvement was “project managed” by professionals, with clear boundaries as to where involvement was expected. Service users reported being invited only to selected meetings and that issues in

which they were involved tended to be left unresolved for a long time, often becoming mired in lengthy negotiation. This perhaps echoes some of the power inequalities between service users and the trusts as highlighted by McDaid (2009). Rutter et al. (2004) also found that while service users and voluntary sector representatives had objectives around empowerment, increasing self-esteem, and developing a collective identity, staff and managers' objectives were exclusively focussed on political or quality aims (e.g. improving services, justifying decisions made). This perhaps sheds some light on the lack of positive personal outcomes in this study.

Identity was also a theme in the paper. Many service user groups reported struggling to maintain their identity as an independent voice because of their working relationships with the trusts. Similar to the findings of Patterson et al. (2014) and Moltu et al. (2012), participants also were involved described the tensions of negotiating an identity somewhere between "service user" and "professional". For example, participants reported feeling that they were expected to act like professionals in meetings, but that the more they developed their confidence and skills, the less representative they were perceived to be by services and professionals.

Rutter et al.'s (2004) paper is large in scope, in that it they interviewed a large number of stakeholders from a large population. However, the authors do not provide information on reflexivity, so it is not possible to situate the findings in relation to the researchers' perspectives. They also do not provide information on credibility checks such as analytic auditing, triangulation or member checking, all of which would strengthen the credibility of the results (Elliott et al., 1999).

SUI at the level of service planning, then, appeared impeded by a greater degree of tokenism and inflexible and unequal power relationships, and few positive outcomes on the dimensions of empowerment, recovery and identity were noted. However, as with SUI at the level of policymaking, the dearth of studies into SUI at this level means that the representativeness and generalisability of these findings is uncertain.

## Discussion

This article reviewed 12 papers, published since 2002, that explored the experience of service users who had been involved in SUI activities at the levels of service planning (meso level), policymaking (macro level), or research and education (meta level). The majority of studies focussed on SUI at the meta level, and only three out of the 12 studies explored SUI at the level of service planning or policy development. Most studies described SUI as having a broadly positive effect on empowerment, recovery and/or identity, but for a minority of participants, SUI seemed to be experienced as a struggle for power, with service users feeling disadvantaged and SUI itself often feeling stage-managed or tokenistic.

There were a number of findings related to concepts of empowerment, recovery and identity, and these are discussed below. While these are discussed separately for clarity, it should be noted that the studies suggested an interrelationship between the three dimensions. This is consistent with the wider literature (Nelson, Lord, & Ochocka, 2001; Wisdom, Bruce, Saedi, Weis, & Green, 2008; Andresen, Oades, & Caputi, 2003).

### **Influence on Empowerment**

All papers but Moltu et al. (2012) make some reference to empowerment. In many cases, SUI was seen as an empowering process because service users felt listened to or respected, or because they felt that they had a voice. There were also some findings which suggested that feelings of empowerment echoed in participants' lives outside of SUI. However, several studies found that SUI could potentially be a disempowering experience, reporting struggles such as their own expertise by experience not being valued, or ultimate decision-making power to be with professionals and services. This is perhaps explained by the findings of Rutter et al. (2004), who suggested that while empowerment was a central aim of SUI for

service users, for services themselves the central aims of SUI were around quality or political outcomes. Such a focus perhaps increases the risks of tokenism, where service users are involved enough to meet political demands but not enough to have a meaningful voice.

### **Influence on Recovery**

The process of SUI appeared to contribute to recovery in several ways. In addition to therapeutic benefits such as improved self-esteem, self-confidence or improved social skills, participants in some studies referred to developing a sense of purpose or a feeling like they were “giving something back”. The effect of SUI on recovery is perhaps most clearly noted in Taggart et al. (2013), where one participant reflected on how SUI helped her to her “get out of the front door”, and in Hutchinson and Lovell (2013), where SUI is described as a process of developing from an “illness narrative” to a narrative of agency, value and reciprocity. These papers highlight the potentially transformative nature of SUI.

However, a small minority of service users found SUI to be detrimental to their wellbeing, largely due to stress, anxiety, the high demands of SUI, or the impact of talking about emotive topics. Other papers talked about how mental health problems themselves affected their capacity to take part in SUI activities. Participants in the study by Patterson et al. (2014), for example, talked about how being engaged in research required them to be “well enough”, and that at times they felt closely scrutinised at by well-meaning colleagues, such that showing distress in any form was not acceptable. The practice implications of this are that service users who have more complex mental health problems or fewer coping strategies may be excluded from SUI.

## **Influence on Identity**

Several papers made reference to the ways in which SUI shaped identity, though three papers explored this in particular detail. Hutchinson and Lovell (2013) and Moltu et al. (2012) found that SUI in research helped service users to develop more positive identities but, in contrast, Rutter et al. (2004) found frustration, inflexibility and tensions between service users and professionals, to which service users responded by distancing themselves from services so that they could campaign against them more effectively.

SIT predicts that members of low-status groups may use various strategies to develop a positive social identity (Tajfel & Turner, 1979; Brown, 1995; Haslam, 2001), and several such strategies appear evident in these papers. If group boundaries are perceived as permeable, SIT suggests that group members may seek to distance themselves from the low-status group (Haslam, 2001). This can be seen in Hutchinson and Lovell's (2013) study, where participants described "lengthening the gap" between themselves and their illness identities (p.647). Another strategy is to emphasise the positive dimensions of their group and rejecting the negative aspects. This can be seen in the study by Moltu et al. (2012), where service users carved out a unique and positive role for themselves that turned their difficult experiences with mental health problems into a positive. A third strategy, particularly employed when the boundaries between groups are perceived to be fixed and impermeable, is to enter into direct competition with the high status group (Brown, 1995; Haslam, 2001). This could be argued to be the case in the study by Rutter et al. (2004).

These findings also provide support for the challenges to social identity described by Tse et al. (2012). Patterson et al. (2014) lends weight to the notion that developing a positive social identity as a service user representative depends to some degree on colleagues having



positive attitudes towards them. Participants in their study reported that this was not always the case, and as a consequence people did not always feel comfortable to be “exposed” as someone with mental health needs. Some studies also highlighted the risk of identifying too closely with professionals. Moltu et al. (2012) point out that such over-identification risks losing one’s roots and thus one’s unique role and other papers highlighted the challenge of being seen as “unrepresentative” if they acted more professionally or with more expertise than was expected of the average service user (Patterson et al., 2014; Rutter et al., 2004). This is consistent with existing literature (e.g. Beresford & Campbell, 1994; Contandriopoulos, 2004; Martin, 2008; Rose et al., 2003).

### **Research Implications**

Several areas have emerged from this review as areas for further research. First, there is notable paucity of research into SUI at the macro and meso levels. It is thus difficult to determine whether the experiences of macro- and meso-level SUI (which tended to be more negative) represent a wider phenomenon or are simply reflections of the services, participants or research aims of these studies. Further research would need to be carried out to determine whether the findings of these papers could be reproduced.

Second, two papers (Walters et al., 2003; Honig et al., 2006) found that service users involved in training valued telling their stories as it helped them to make sense of their experiences of mental health and develop their narratives. There are close links between narratives and identity (Somers, 1994; Singer, 2004), so it is possible that this process of developing narratives through sharing stories would also influence their identity. However, this was not explored in the two papers. Nevertheless, the consistent finding between the two studies suggests that this might be an area for further research.

Another significant gap in the extant literature is in the types of services and service users studied. All of the 12 papers identified in this review related to working age adults or older adolescents, and (aside from Honig et al., 2006) all papers discussed people with mental health problems as a homogenous group. This echoes the findings of Tambuyzer et al. (2011), who noted a lack of research into specific groups such as children, people from ethnic minorities, or other involved service users (e.g. people with learning disabilities or dementia). As noted above, there is some overlap between different groups of people who access services, but there are also sizeable differences.

For example, consistent with SUI in mental health services, SUI in learning disabilities services can be hampered by tokenism, power imbalances and stigma (Chaplin, Halls, Carlile, Hardy, & Joyce, 2009). It is reasonable, therefore, to assume that these barriers affect the personal outcomes for both groups in similar ways. However, unlike mental health service users, people with learning disabilities experience disempowerment through exclusion from a wide range of day-to-day decisions such as choice of activities, food or relationships (Smyth & Bell, 2006). A “learning disabilities” identity is also arguably more impermeable and inflexible than a “mental health” identity (Beart, Hardy, & Buchan, 2005), meaning that SUI for people with learning disabilities may have less influence (or at least a different influence) over identity when compared with SUI in mental health services. People with learning disabilities may also have additional barriers to effective SUI, such as difficulties understanding abstract concepts or complex processes, communication problems or challenging behaviour (Hurtado et al., 2012; Chaplin et al., 2009), and so SUI in learning disabilities services may be substantially different to SUI mental health services.

These differences mean that the degree to which findings from the identified literature are applicable to other service user groups is perhaps limited, indicating that this is an important area for further research.

In summary, then, the following questions could be future research directions:

1. Studies into SUI at levels of at the levels of policymaking or service planning suggest that involvement was often hampered by tokenism and power imbalances, which in turn affected personal outcomes. However, a paucity of studies meant it was not clear whether these findings were representative of wider experiences of SUI at these levels. To what extent are these findings replicable?
2. In what ways does involvement/participation of SUI in training influence narratives, and what are the influences of SUI in training on narrative identity?
3. What are the experiences of SUI for service users other than working age adult mental health service users? For example, how do people with learning disabilities, dementia, and substance users experience different areas of SUI?

## Conclusion

This systematic literature review explored the influence of SUI in mental health services at the levels of research and training, policymaking and service planning on three personal outcomes: empowerment, recovery and identity. Findings from 12 studies suggested that SUI has the potential to have a positive influence on all three of these dimensions, and in particular, SUI in research had strong positive effects on identity. However, a minority of participants reported that SUI was stressful and negatively impacted on wellbeing. These studies suggest that SUI is less empowering if involvement is tokenistic or if service users do not feel valued. SUI is also demanding, stressful and challenging undertaking, and can have a negative impact of service users' wellbeing and recovery if not supported effectively. Finally, SUI can facilitate the development of a positive identity based on narratives of competence and expertise, but this appears to be dependent on others' attitudes towards mental health and SUI. This particularly appeared to be the case in SUI at the levels of policymaking and service planning.

One of the limitations of this review is that it focuses exclusively on SUI in mental health, and it is not clear to what degree the findings generalise to other service user groups, such as people with dementia or learning disabilities. It is reasonable to assume that there are some similarities between these groups, and that people would be expected to benefit in some similar ways, but also fundamental differences that suggest that the ways in which the findings discussed here are unlikely to be generalisable to other groups. This indicates a gap in the extant literature.

## References

- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: Towards an empirically validated stage model. *Australian and New Zealand Journal of Psychiatry*, 37, 586-594. doi:10.1046/j.1440-1614.2003.01234.x
- Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychiatric Rehabilitation Journal*, 16(4), 11-23.
- Ashmore, R. D., & Jussim, L. (1997). Introduction: Toward a second century of the scientific analysis of self and identity. In R. D. Ashmore, & L. Jussim (Eds.), *Self and identity: Fundamental issues* (pp. 3-22). Oxford: Oxford University Press.
- Baker, J. L., Cantillon, S., & Walsh, J. (2004). *Equality: From theory to action*. Basingstoke, UK: Palgrave MacMillan.
- Barnes, M., & Cotterell, P. (2012). From margin to mainstream. In M. Barnes, & P. Cotterell (Eds.), *Critical Perspectives on User Involvement* (pp. xv-xxvi). Bristol: Policy Press.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18, 47-56. doi:10.1111/j.1468-3148.2004.00218.x
- Beresford, P., & Branfield, F. (2012). Building solidarity, ensuring diversity: Lessons from service users' and disabled peoples' movements. In M. Barnes, & P. Cotterell (Eds.), *Critical Perspectives on User Involvement* (pp. 33-45). Bristol: The Policy Press.
- Beresford, P., & Campbell, J. (1994). Disabled people, service users, user involvement and representation. *Disability and Society*, 9, 315-325. doi:10.1080/09687599466780361
- Brown, R. (1995). *Prejudice: Its social psychology*. Oxford, UK: Blackwell.
- Burke, P. J., & Stets, J. E. (2009). *Identity theory*. Oxford: Oxford University Press.

- Chaplin, E., Halls, S. C., Hardy, S., & Joyce, T. (2009). Barriers to user involvement in mental health services for people with learning disability. *Advances in Mental Health and Learning Disabilities*, 3(3), 28-33. doi:10.1108/17530180200900028
- Contandriopoulos, D. (2004). A sociological perspective on public participation in health care. *Social Science and Medicine*, 58, 321-330. doi: 10.1016/S0277-9536(03)00164-3
- Cowan, S., Banks, P., Crawshaw, P., & Clifton, A. (2011). Mental health service user involvement in policy development: Social inclusion or disempowerment? *Mental Health Review Journal*, 16, 177-184. doi:10.1108/13619321111202331
- Crawford, M. J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. (2002). Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, 325, 1263. doi:10.1034/j.1600-0447.2003.00049.x
- Department of Health. (1999). *National Service Framework for Mental Health*. London: Department of Health.
- Doherty, C., & Doherty, W. (2005). Patients' preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. *Journal of Nursing Management*, 13, 119-127. doi:10.1111/j.1365-2934.2004.00498.x
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229. doi:10.1348/014466599162782
- Felton, A., & Stickley, T. (2004). Pedagogy, power and service user involvement. *Journal of Psychiatric and Mental Health Nursing*, 11, 89-98. doi:10.1111/j.1365-2850.2004.00693.x

- Forbat, L., Hubbard, G., & Kearney, N. (2009). Patient and public involvement: models and muddles. *Journal of Clinical Nursing*, 18, 2527-2554. doi:10.1111/j.1365-2702.2008.02519.x
- Fudge, N., Wolfe, C. D. A., & McKeivitt, C. (2008). Assessing the promise of user involvement in health service development: Ethnographic study. *British Medical Journal*, 336, 313-7. doi:10.1136/bmj.39456.552257.BE
- Hamann, J., Leucht, S., & Kissling, W. (2003). Shared decision making in psychiatry. *Acta Psychiatrica Scandinavica*, 107, 403-409. doi:10.1034/j.1600-0447.2003.00130.x
- Harding, E., Brown, D., Hayward, M., & Pettinari, C. J. (2010). Service user perceptions of involvement in developing NICE mental health guidelines: A grounded theory study. *Journal of Mental Health*, 19, 249-257. doi:10.3109/09638230903469202
- Harrison, S., & Mort, M. (1998). Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Social Policy and Administration*, 32, 60-70. doi:10.1111/1467-9515.00086
- Harrison, S., Barnes, M., & Mort, M. (1997). Praise and damnation: mental health user groups and the construction of organisational legitimacy. *Public Policy and Administration*, 12(2), 4-17. doi: 10.1177/095207679701200202
- Haslam, A. S. (2001). *Psychology in organizations*. London: Sage Publications.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health and wellbeing: An emerging agenda for applied psychology. *Applied Psychology: An International Review*, 58, 1-23. doi:10.1111/j.1464-0597.2008.00379.x
- Honig, P., Dargie, L., & Davies, S. (2006). The impact on patients and parents of their involvement in the training of healthcare professionals. *European Eating Disorders Review*, 14, 263-268. doi:10.1002/erv.715

- Hoole, L., & Morgan, S. (2010). 'It's only right that we get involved: Service user perspectives on involvement in learning disability services. *British Journal of Learning Disabilities*, 39, 5-10. doi:10.1111/j.1468-3156.2009.00563.x
- Hopton, J., & Nolan, P. (2003). Involving users in mental health services. *Mental Health Practice*, 6(7), 14-18. doi: 10.7748/mhp2003.04.6.7.14.c1756
- Hurtado, B., Timmins, S., & Seward, C. (2012). The importance of being earnest: Our experience of involving service users with complex needs in staff recruitment. *British Journal of Learning Disabilities*, 42, 36–42. doi:10.1111/bld.12007
- Hutchinson, A., & Lovell, A. (2013). Participatory action research: Moving beyond the mental health 'service user' identity. *Journal of Psychiatric and Mental Health Nursing*, 20, 641-649. doi:10.1111/jpm.12001
- Iyer, A., Jetten, J., & Tsivrikos, D. (2008). Torm between identities: Predictors of adjustment to identity change. In F. Sani (Ed.), *Self-continuity: Individual and collective perspectives* (pp. 187-197). New York: Psychology Press.
- Jones, K., & Black, D. (2008). Involving mental health service users in student education. *Nursing Times*. Retrieved from <http://www.nursingtimes.net/involving-mental-health-service-users-in-student-education/1735557.article>
- Kemp, P. (2010). Introduction to mental health service user involvement. In J. Weinstein (Ed.), *Mental Health, Service User Involvement and Recovery* (pp. 15-29). London: Jessica Kingsley.
- Leary, M. R., & Tangney, J. P. (2012). The self as an organising construct in the behavioural and social sciences. In M. R. Leary, & J. P. Tangney (Eds.), *Handbook of self and identity* (2nd ed., pp. 3-14). New York: Guildford Press.



- Martin, G. P. (2008). Representativeness, legitimacy and power in public involvement in healthcare management. *Social Science and Medicine*, 67, 1757-1765. doi:10.1016/j.socscimed.2008.09.024
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. 320, 50-52. doi:10.1136/bmj.320.7226.50
- McDaid, S. (2009). An equality of condition framework for user involvement in mental health policy and planning: Evidence from participatory action research. *Disability & Society*, 24, 461-474. doi:10.1080/09687590902879064
- Moltu, C., Stefansen, J., Svisdahl, M., & Veseth, M. (2012). Negotiating the coresearcher mandate: Service users' experiences of doing collaborative research on mental health. *Disability and Rehabilitation*, 34, 1608-1616. doi:10.3109/09638288.2012.656792
- Nelson, G., Lord, J., & Ochocka, J. (2001). Empowerment and mental health in community: Narratives of psychiatric consumer/survivors. *Journal of Community and Applied Social Psychology*, 11, 125-142. doi:10.1002/casp.619
- Omeni, E., Barnes, M., MacDonald, D., Crawford, M., & Rose, D. (2014). Service user involvement: Impact and participation: A survey of service user and staff perspectives. *BMC Health Services Research*, 14(491), 1-13. doi:10.1186/s12913-014-0491-7
- O'Reilly, C. L., Bell, J. S., & Chen, T. F. (2011). Mental health consumers and caregivers as instructors for health professional students: A qualitative study. *Social Psychiatry and Psychiatric Epidemiology*, 47, 607-613. doi:10.1007/s00127-011-0364-x
- Patel, S. R., Bakken, S., & Ruland, C. (2008). Recent advances in shared decision making for mental health. *Current Opinion in Psychiatry*, 21, 606-612. doi:10.1097/YCO.0b013e32830eb6b4

- Patterson, S., Trite, J., & Weaver, T. (2014). Activity and views of service users involved in mental health research: UK survey. *British Journal of Psychiatry*, 205, 68-75. doi:10.1192/bjp.bp.113.128637
- Petersen, K., Hounsgaard, L., & Nielsen, C. V. (2008). User participation and involvement in mental health rehabilitation: A literature review. *International Journal of Therapy and Rehabilitation*, 15, 306-313. doi:10.12968/ijtr.2008.15.7.30453
- Renedo, A., & Marston, C. (2011). Healthcare professionals' representations of 'patient and public involvement' and creation of 'public participant' identities: Implications for the development of inclusive and bottom-up community participation initiatives. *Journal of Community & Applied Social Psychology*, 21, 268-280. doi:10.1002/casp.1092
- Rise, M. B., Solbjør, M., & Steinsbekk, A. (2014). Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: A qualitative case study. *International Journal of Social Psychiatry*, 60, 387-395. doi:10.1177/0020764013491739
- Rise, M. B., Solbjør, M., Lara, M. C., Westerlund, H., Grimstad, H., & Steinsbekk, A. (2013). Same description, different values. How service users and providers define patient and public involvement in health care. *Health Expectations*, 16, 266-276. doi:10.1111/j.1369-7625.2011.00713.x
- Rose. (2001). *Users' voices: The perspectives of mental health service users on community and hospital care*. London: The Sainsbury Centre for Mental Health.
- Rose, D. (2014). Patient and public involvement in health research: Ethical imperative and/or radical challenge? *Journal of Health Psychology*, 19, 149-158. doi:10.1177/1359105313500249
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P., & Wykes, T. (2003). User and carer involvement in change management in a mental health context: Review of the

- literature: Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). London: NCCSDO.
- Rush, B. (2004). Mental health service user involvement in England: Lessons from history. *Journal of Psychiatric and Mental Health Nursing*, 11, 313-318. doi:10.1111/j.1365-2850.2004.00728.x
- Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science & Medicine*, 58, 1973–1984. doi:10.1016/S0277-9536(03)00401-5
- Sayers, A. (2007). Tips and tricks in performing a systematic review. *British Journal of General Practice*, 57(542), 759.
- Schneebeli, C., O'Brien, A., Lampshire, D., & Hamer, H. P. (2010). Service user involvement in undergraduate mental health nursing in New Zealand. *International Journal of Mental Health Nursing*, 19, 30-35. doi:10.1111/j.1447-0349.2009.00642.x
- Schulte, S., Moring, J., Meier, P. S., & Barrowclough, C. (2007). User involvement and desired service developments in drug treatment: Service user and provider views. *Drugs: Education, Prevention and Policy*, 14, 277-287. doi:10.1080/09687630701267317
- Simpson, E. L., & House, A. O. (2002). Involving users in the delivery and evaluation of mental health services: Systematic review. *British Medical Journal*, 325, 1265-1269. doi:10.1136/bmj.325.7375.1265
- Singer, J. A. (2004). Narrative identity and meaning making across the adult lifespan: An introduction. *Journal of Personality*, 72, 437-459. doi: 10.1111/j.0022-3506.2004.00268.x

- Smyth, C. M., & Bell, D. (2006). From biscuits to boyfriends: the ramifications of choice for people with learning disabilities. *British Journal of Learning Disabilities*, 34, 227-236. doi:10.1111/j.1468-3156.2006.00402.x
- Somers, M. R. (1994). The narrative constitution of identity: A relational and network approach. *Theory and Society*, 23, 605-649. doi:10.1007/BF00992905
- Stets, J. E., & Burke, P. J. (2014). Social comparison in identity theory. In Z. Krizan, & F. X. Gibbons (Eds.), *Communal functions of social comparison* (pp. 39-59). New York: Cambridge University Press.
- Storm, M., Knudsen, K., Davidson, L., Hausken, K., & Johannessen, J. O. (2011). "Service user involvement in practice": The evaluation of an intervention program for service providers and inpatients in Norwegian Community Mental Health Centers. *Psychosis*, 3, 29-40. doi:10.1080/17522439.2010.501521
- Tajfel, H., & Turner, J. (1979). An integrative theory of intergroup conflict. In W. G. Austin, & S. Worchel (Eds.), *The social psychology of intergroup relations* (pp. 33-48). Monterey, CA: Brooks/Cole.
- Taggart, D., Franks, W., Osborne, O., & Collins, S. (2013). 'We are the ones asking the questions': The experiences of young mental health service users conducting research. *Educational and Child Psychology*, 30, 61-71.
- Tambuyzer, E., Pieters, G., & Van Audenhove, C. (2011). Patient involvement in mental health care: One size does not fit all. *Health Expectations*, 17, 138-150. doi:10.1111/j.1369-7625.2011.00743.x
- Terry, J. (2012). Service user involvement in pre-registration mental health nurse education classroom settings: A review of the literature. *Journal of Psychiatric and Mental Health Nursing*, 19, 816-829. doi:10.1111/j.1365-2850.2011.01858.x

- Townend, M., & Braithwaite, T. (2002). Mental health research - The value of user involvement. *Journal of Mental Health*, 11, 117-119. doi:10.1080/096382301200041524
- Tritter, J. Q., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76, 156-168. doi:10.1016/j.healthpol.2005.05.008
- Trivedi, P., & Wykes, T. (2002). From passive subjects to equal partners: Qualitative review of user involvement in research. *British Journal of Psychiatry*, 181, 468-472. doi:10.1192/bjp.181.6.468
- Tse, S., Cheung, E., Kan, A., Ng, R., & Yau, S. (2012). Recovery in Hong Kong: Service user participation in mental health services. *International Review of Psychiatry*, 24, 40-47. doi:10.3109/09540261.2011.646244
- Walters, K., Buszewicz, M., Russell, J., & Humphrey, C. (2003). Teaching as therapy: Cross sectional and qualitative evaluation of patients' experiences of undergraduate psychiatry teaching in the community. *British Medical Journal*, 326(740), 1-6. doi:10.1136/bmj.326.7392.740
- WHO Regional Office for Europe. (2010). User empowerment in mental health. Retrieved from [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0020/113834/E93430.pdf](http://www.euro.who.int/__data/assets/pdf_file/0020/113834/E93430.pdf)
- Williamson, T. (2004). User involvement: A contemporary overview. *Mental Health Review Journal*, 9, 6-12. doi:10.1108/13619322200400003
- Wisdom, J. P., Bruce, K., Saedi, G. A., Weis, T., & Green, C. A. (2008). 'Stealing me from myself': Identity and recovery in personal accounts of mental illness. *Australian and New Zealand Journal of Psychiatry*, 42, 489-495. doi:10.1080/00048670802050579

**MRP Section B**

**Involving People with Learning Disabilities on Interview Panels for  
Professionals and its Influence on Narrative Identity**

For Submission to *Disability & Society*

**ACCURATE WORD COUNT:**

**8000 (190) words**

## **Abstract**

Identity can be considered to be socially constructed and developed through narratives about ourselves and our experiences. Having socially valued roles may thus facilitate a positive identity. This study aimed to explore how the experiences of service user involvement (SUI) in health and social care services (specifically, being involved in staff recruitment) influenced the narrative identities of people with learning disabilities. Interviews were conducted with seven people with learning disabilities who had been service user representatives on NHS interview panels. These were analysed using thematic narrative analysis as a framework. All described positive narrative identities, but the degree to which SUI featured in the construction of narrative identities varied. Whilst some found the experience transformative, for others it was not an important part of their narratives. The findings suggest that such experiences formed just one of many narratives that participants drew from to construct their narrative identity.

### **Points of interest**

- There is a growing body of literature that suggests that people make sense of their experiences by telling stories (or ‘narratives’) which are embedded in our culture. The narratives we tell, and how we position ourselves within them gives us a sense of who we are. This is known as our ‘narrative identity’.
- This study explores the narratives that people with learning disabilities have about their experiences of being service user representatives on interview panels, and the ways in which these narratives influenced their narrative identities.
- Some participants told narratives about being powerful or a part of the team, and described their experiences as transformative. For others, however, narratives about

being involved in interviews had a lesser influence on narrative identity, or were not significant at all.

- It is suggested that services should pay more attention to the ways in which they involve service users so that involvement is more meaningful.

**Keywords:** learning disabilities; service user involvement; narrative identity; recruitment



## **Involving People with Learning Disabilities on Interview Panels for Professionals and its Influence on Narrative Identity**

Dominant discourses often position the label of ‘learning disabilities’ as ‘toxic’ because it carries considerable stigma (Edgerton, 1967, 1993; Hall, 2004; Paterson, McKenzie, & Lindsay, 2012) and a ‘master identity’ as it overshadows other identities (Beart, Hardy, & Buchan, 2005; Davies & Jenkins, 1997). However, despite the apparently pervasive and negative nature of ‘learning disabilities’ identity, people with learning disabilities often maintain positive identities and feel valued and competent (Finlay & Lyons, 1998; Rapley, Kiernan, & Antaki, 1998).

Much of the research into identity with people with learning disabilities has explored the strategies that people employ to distance themselves from the label (Edgerton, 1967, 1993; Jahoda, Markova, & Cattermole, 1988; Craig, Craig, Withers, Hatton, & Limb, 2002). Other studies have suggested that this constitutes being “in denial” or “invisible to themselves” (Todd & Shearn, 1995, 1997; Edgerton, 1967, 1993). However, these studies have been critiqued because they assume that ‘learning disabilities’ identity is a fixed, taken-for-granted reality (Rapley et al., 1998; Rapley, 2004; Finlay & Lyons, 2005). Through this lens, attempts to construct alternative labels are dismissed as ‘coping strategies’, and the social context of disability (Oliver, 1990; Goodley, 2001) is minimised.

Narrative identity theory addresses some of these limitations, as it emphasises that identity is socially constructed. The theory has emerged from a growing body of literature that suggests that people make sense of their circumstances or actions by constructing stories (or ‘narratives’) that organise and assign meaning to events (Singer, 2004; Bamberg, 2012; Crossley, 2000; Somers, 1994; Murray, 2003). Through this meaning-making process, a

‘narrative identity’ is constructed that creates a sense of continuity between past, present and future (McAdams, 1985; Somers, 1994; Singer, 2004).

The construction of narrative identity occurs in a social context, in that people draw from culturally available plots to construct narratives and use to situate themselves socially (Murray, 2009). Consequently, cultural definitions of ‘learning disabilities’, which largely centre around a medicalised notion of deviance from ‘normal’, have considerable influence on the narratives that people with learning disabilities construct (Gillman, Heyman, & Swain, 2000). However, narrative identity theory regards identity as fluid (Murray, 2003) and rejects the idea of ‘learning disability’ being fixed, since people with learning disabilities are also able to draw on other discourses to construct identities. This can be seen as a process of ‘negotiating identity’ (Rapley et al., 1998; Rapley, 2004). A study reported by Rapley et al. (1998) and Rapley (2004) exemplifies this process of negotiating identity. Through interviews with people with learning disabilities, they found that while participants were very aware of the label of ‘learning disability’ and the consequential prejudices they experienced, participants “took pains to construct versions of self as doing typical, ordinary, activities” (Rapley et al., 1998, p.819) through subtle use of language to privilege other narratives (e.g. ‘typical worker’, ‘public speaker’, ‘helper of others’).

The study reported by Rapley et al. (1998) and Rapley (2004) provides important insights into how people with learning disabilities negotiate positive identities in conversations about everyday situations such as work and relationships. This study seeks to expand on this by exploring how people with learning disabilities negotiate identity when in powerful or empowering positions.

## **Identity and Service User Involvement**

In UK health and social care services, people with learning disabilities have increasingly been perceived as active participants in the services they access, rather than as passive recipients (Atherton, 2007). This has been a nationally recognised aim since the publication of the government White Paper, *Valuing People* (Department of Health, 2001), and people with learning disabilities have been involved in a diverse range of service user involvement (SUI) activities such as strategic service planning (Fyson & Fox, 2014; Dearden-Phillips & Fountain, 2005), staff recruitment (Johnson, Carpenter, & Scarbrough-Lang, 2012; Hurtado, Timmins, & Seward, 2012) and quality improvement (Campbell & Martin, 2009).

There are several reasons to assume that SUI may influence identity. SUI enables people with learning disabilities to have socially valued roles which, according to the principles of Social Role Valorization (SRV; Wolfensberger, 1983) increase visibility and social standing. Indeed, the social roles we assume relate closely to identity (Lemay, 1999) in that they “largely define who we are, what we do and with whom we act” (Wolfensberger, 1992, p.20). It is reasonable to assume, then, that SUI activities can potentially have a powerful influence the narrative identities of people with learning disabilities. Furthermore, there is evidence from related areas such as self-advocacy that giving individuals a more powerful voice has a positive effect on their identity (Goodley, 2001; Beart, Hardy & Buchan, 2004; Caldwell, 2011). However, the ways in which SUI might influence identity is relatively under-researched. While there is some (albeit very limited) evidence that people with learning disabilities find SUI to be a positive experience (Johnson et al., 2012; Hurtado et al., 2012), no studies have explored the relationship between SUI and identity.

### **Aims of this Study**

This project aims to explore the ways in which people with learning disabilities who are involved in service development might incorporate those experiences within the construction of their narrative identities. Involvement in recruitment of new staff for services was chosen as a way of exploring SUI. This was chosen specifically as it is a relatively common form of SUI (Hurtado et al., 2012; Crawford et al., 2003; Rutter, Manley, Weaver, Crawford, & Fulop, 2004). Furthermore, it is considered to be a clear example of SUI and, when effective, is regarded as “the peak of user involvement at an organisational level” (Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2003, p.34). SUI in recruitment is thus a reasonably representative and discrete form of user involvement.

This study had two central questions:

1. What stories do people with learning disabilities tell about being interviewees on interview panels for professional positions?
2. How might these experiences influence individuals' narrative identities?

## **Method**

### **Design**

This study explored the experiences of people with learning disabilities as interviewees through unstructured, face-to-face interviews which were analysed using narrative analysis (NA). A central assumption of NA is that people make sense of experiences by constructing stories (or narratives) that provide “a certain shape, structure or plot to a sequence of events” (Murray, 2003, p.98). NA takes a social constructionist epistemological position (Crossley, 2003), as narratives are considered part of an ongoing process of co-construction between the narrator and listener rather than a reflection of an objective reality. Importantly, NA is a useful method for exploring relationships between experience and narrative identity (Benwell & Stokoe, 2006).

### **Recruitment**

Participants were invited to take part via an NHS community learning disabilities team (CLDT) in South East England. People were eligible for participation if they had ever been on an interview panel for the team as a service user representative. Eight potential participants were identified. These potential participants were contacted by a staff member who knew them well and asked if the researcher could arrange a face-to-face meeting with them to discuss the project. All eight potential participants agreed to be contacted by the researcher. Since one participant was unable to attend a face-to-face meeting (so withdrew from the study), initial meetings were arranged with seven participants.

At the meeting, the researcher explained the study, answered any questions and gave potential participants an information sheet and consent form (Appendix B). Potential participants were encouraged to invite carers, friends or relatives along to the initial meeting

if they wished and were given a period of at least seven days to read through the form, discuss the project with others and decide whether they wanted to take part. A follow-up meeting was arranged, where the researcher checked that they had understood the information sheet, asked participants to sign the consent form and, provided consent was given, commenced interviews.

### **Ethical Considerations**

Ethical approval was gained through the NHS National Research Ethics Service. Measures were put in place to ensure participants understood the nature of the study and consented freely. The information sheet and consent form was created in an accessible format to facilitate comprehension (Appendix B) and, as noted above, participants were given time to think about their decision to consent and encouraged to involve others in their decision-making if appropriate. The researcher ensured that all participants understood the nature of their participation in the project before they signed the consent form and emphasised their rights to decline consent or withdraw consent at a later date.

### **Participants**

Seven people with learning disabilities participated in the study. Five were male, and all were White British. In addition to interviewing for the CLDT, four participants mentioned that they had also been interviewers for jobs in other services such as day centres, social services and residential homes. All participants were able to communicate verbally and spoke English as a first language, although one, Brenda, made use of a sheet of symbols to facilitate her communication (Appendix C). She also requested that a staff member be present the interview to support her as she had some memory difficulties and occasionally found it difficult to understand questions.

## **Procedure**

All participants took part in face-to-face interviews which were audio recorded and transcribed. The mean length of interviews was 52 minutes (range = 27-69 minutes). Each participant was read the same opening statement at the beginning of the interview, and the interviewer used an aide-mémoire during interviews (Appendix D). Participants were interviewed at a place of their choice. Two participants were interviewed at their day centre; two at the local office of a learning disabilities charity of which they were members; two were interviewed at NHS sites and one participant was interviewed at his home.

The interviewing style was based on the “narrative interviewing technique” described by Jovchelovitch and Bauer (2000). This technique involves four stages: setting the context; listening to the main narration without interruption; asking questions using the interviewees’ own language to complete gaps; and concluding the talk with informal discussion. However, Booth and Booth (1996) indicate that interviewing people with learning disabilities presents challenges to “standard” interviewing approaches. Their suggestions to overcome these challenges were incorporated into the interviewing technique. For example, the interviewer adopted a more direct interviewing style; simplified questions and facilitated story development gradually eliminating alternatives and offering participants different possible storylines until one fits. This process is referred to as ‘creative guesswork’ (Booth & Booth, 1996, p.64).

## **Data analysis**

NA can be defined as a family of methods, with no one agreed approach to analysis (Riessman, 2008). In this study, an approach to data analysis was developed from principles

of thematic NA, which explores the content, rather than the structure or performance, of narratives. The analysis method is described below.

Based on approaches recommended by McCormack (2004) the first stage of analysis involved listening to the recordings and reading transcripts several times. McCormack (2004) suggests a process of “active listening”, in which the researcher asks questions of the transcripts, such as;

- who are the characters in the conversation?
- What are the main events?
- How is the researcher positioned?

Initial reflections arising from this process of active listening were noted and were used as a lens through which all further analysis was viewed.

Next, a descriptive overview of each participant’s story was compiled based on their interviews (Appendix E), as described by Murray (2008). This helped to clarify participants’ stories, which were at times fragmented, and prevented important elements being lost within the transcript. The process of re-composing stories risks losing the participants’ voices in favour of the researcher’s story (McCormack, 2004), so careful attention was paid to using participants’ own words and phrasing as much as possible.

In the next stage of analysis, transcripts and overviews were re-read with three particular lenses in mind. First, attention was paid to narrative tone (Crossley, 2000; Murray, 2003; McAdams, 1993) and structure (Gergen & Gergen, 1984, 1986). These give a sense of the overall emotional flavour and temporal structure of the story. Within narrative structures, attention was paid to the trajectories which narratives took. Gergen and Gergen (1984, 1986)



suggest that there are three such trajectories: progressive narratives, which centre on success and advancement; regressive narratives, which involve decline and deterioration; and stable narratives, which describe a steady state.

The second lens was language. McCormack (2004) described this process as attending to what is said, how it is said and what is unsaid but signalled in the text. Because the central focus of the study was identity, particular attention was paid to the language participants used around themselves, others and their relationships.

Thirdly, transcripts and overviews were read with particular attention paid to the narrative characters. Murray (2009) states that narratives are about specific characters who are defined by their actions, beliefs and values, and by their relationships with others. Particular attention was paid to positioning, which is how participants situated their characters relative to one another (e.g. as heroes, villains or victims; Bamberg, 1997). This phase of analysis was aimed at exploring how participants used their narratives in identity formation. These were considered in the context of wider discourses which might have influenced them (Murray, 2003; Murray, 2009).

From these stages of analysis, central narrative themes emerged. These were described and then refined through re-reading transcripts and seeking examples of central themes and then through discussing the data with other trainee clinical psychologists and supervisors. In contrast to a more conventional thematic analysis, where themes usually reflect the content of the interview, the researcher used the stages of analysis described above to generate themes that encapsulated the key plots that were being co-constructed in the interview, and the roles and forms that characters took within narratives.

## Quality Checks

Based on guidelines and quality standards from Elliott, Fischer, and Rennie (1999) and Barker, Pistrang, and Elliott (2002), the researcher used a process of analytical auditing by reviewing the data with another Trainee Clinical Psychologist. Descriptive overviews and identified themes were examined for consistency with the transcripts, overstatements, discrepancies or errors. The researcher also aimed to provide additional contextual information about participants in the results section. This is known as “situating the sample”, which Elliott, Fischer, and Rennie (1999) say is “to aid the reader in judging the range of persons and situations to which the findings might be relevant” (p.221).

Finally, the researcher took steps to own their perspective through reflective diaries (see Appendix F for an abridged summary), conversations with supervisors, and a bracketing interview with another Trainee Clinical Psychologist. This is described below.

### Owning one’s Perspective

For the sake of clarity, this section will be written in the first person.

I am a 32-year old White British man with a long history of involvement with people with learning disabilities (both professionally and personally). I have seven years of NHS experience and was familiar with the team in which I was conducting my research. The way in which I contacted participants (via staff members) and met with many of them at NHS buildings also had some influence on the context of our meeting as it aligned me with the CLDT and identified me as a healthcare professional.

My professional and personal experience has led me to have strong beliefs about advocating for the voices of people with learning disabilities. Related to this, I am particularly interested

in themes of empowerment and power differences between people with learning disabilities and wider society. I hold strong beliefs about the importance of SUI as a form of empowerment but am also concerned about the risks of tokenism. These perspectives have no doubt led me to privilege particular themes during research interviews and data analysis to the exclusion of others.

## Results

An overview of the participants is provided in Table 3 and is provided for the purpose of situating the sample. More comprehensive descriptive overviews of participants' background information and narratives, developed as part of the data analysis, can be found in Appendix E.

### Overall Experience of Being Involved in Interviews

While some participants struggled to remember specific details of interviewing, the procedure of interviews appeared to be broadly similar from the information given. Participants described taking part in whole days of interviewing. Service user interview panels were separate from the staff interview panels, with the exception of Colin, who sat on the same panel as staff the very first time he interviewed (in subsequent interviews, staff and service users were on separate panels).

Three participants (Andrew, Brenda and Colin) described interviewing as tiring. Five (Andrew, Colin, David, Fred and Graham) described feeling nervous as interviewers, particularly the first time they held this position, although the ways in which they experienced and managed their nervousness differed. Six of the seven participants described the overall experience of being involved in interviews as positive. Brenda was the only person who did not share this view. She described the experience as "half and half": while she found interviewing to be good in some respects, she also indicated feeling annoyed when she did not feel listened to by interviewees.

Table 3

Situating the sample: Overview of participants

Name	Age	Gender	Interview location	Contextual information	Experience of interviewing
Andrew	28	Male	Local Mencap	Lives in his own flat. Recently married, works in a charity shop, where he is being trained to open and close the shop on his own and is a member of his local Mencap.	Has been a service user representative on around 25 interview panels over the past 3 years, almost always jointly with Brenda. He was selected to be an interviewer after someone emailed the manager at his local Mencap to recruit service users for interviewing. He said that he knows the role “like the back of his hand”.
Brenda	49	Female	Local Mencap (support worker present)	Lives in a residential service and is a member of her local Mencap (with Andrew). Also attends a day centre, where she particularly enjoys using computers. Has Down Syndrome, and needed some support with communication and remembering things. A member of staff sat in on the interview to support her with this.	Has interviewed “quite a lot of times”. The first time she interviewed it was “a very long time ago”. Has also been an interviewer for her day centre, her local Mencap, and at her residential home. For NHS interviews, she almost always sits on a panel with Andrew.

Colin	59	Male	Office at residential home	Currently living in a residential service. Previously detained under section on a low-secure assessment and treatment centre, where he resided for nearly four-and-a-half years.	Started interviewing about 2 or 3 years ago on the inpatient unit and continued to interview after he was discharged. However, has not been an interviewer for months.
David	23	Male	CLDT office	Lives with his father. Has autism and epilepsy, and has longstanding relationships with many of the CLDT staff, particularly the epilepsy nurse specialist and the psychiatrist. Works at a supported employment scheme and enjoys watching DVDs and playing computer games.	Has been an interviewer more than once, for both the CLDT and for positions at the respite home he sometimes stays at. He always interviews with the same service user, Fred (Participant 6) and is supported by a staff member.
Emily	28	Female	NHS clinical room	Has lived in a newly built supported living service since 2013, but has a difficult relationship with staff there. Has epilepsy as well as non-epileptic seizures and can at times show challenging behaviour towards staff. Works at a supported employment scheme, but also has difficult relationships with staff and service users. Enjoys playing computer games and watching DVDs.	Previously interviewed for the CLDT several years ago. Has also been an interviewer for her supported living service in 2012, when the service was being set up. Found it difficult to recall experience of being an interviewer.

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Fred	59	Male	Office at day centre	Lives in a social services-run residential home with 5 other residents. Goes to the day centre and also attends a supported employment scheme, where he works as part of a team delivering trays of sweets to local businesses. He is also a member of his local Mencap and attends meetings for this. Has been in a relationship for two years. Enjoys painting, playing computer games and going on outings. Does not like to stay at home because he gets bored quickly.	Has been an interviewer for the CLDT on two occasions after the manager his residential home recommended him. Has interviewed once with David, and the other time alone. Also does interviews for social services and said that he has been asked to do interviews full-time there.
Graham	36	Male	Office at day centre	Lives on his own: previously lived with his mother but she died several years ago. Has a sister who he sees regularly, and attends a day centre.	Has been an interviewer at least four times. Had trouble remembering details of the first time because it was a long time ago at the previous CLDT offices (which have now shut). Has been involved in more recent interviews at the new offices.

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## **Narrative Themes**

Table 4 provides an overview of the analysis, including the tone, structure and central themes of participants' narratives. Central themes were drawn out of the data by initially identifying them (Appendix G) and then refining them through re-reading the transcripts and discussion with supervisors (Appendix H). Participants talked about various things in addition to their experience of interviews, such as their work, relationships with others and pastimes. While these narratives provide important contextual detail and give a sense of their narrative characters, narratives specifically about interviewing have been foregrounded for the purpose of this study.

All participants provided narratives that positioned their narrative characters in a positive light. However, there was variation in the degree to which involvement in interviews featured in this construction of a positive narrative identity. Three thematic categories were identified. Colin's and David's narratives were of the transformative effect of interviews, and they described their experiences as having a lasting influence on their narrative identities. Andrew's, Fred's and Graham's narratives described interviews as having a positive impact on some aspects of identity but their experiences did not have particularly wide influence outside of interview settings. Finally, Brenda's and Emily's narratives depicted interviews as not particularly significant in their lives. These categories of narrative are described below, using one participant's voice for illustration. This is similar to other narrative studies (e.g. Williams, 1984), and allowing for more detailed exploration of narratives.



Table 4

## Summary of Narrative Themes

Name	Narrative synopsis	Narrative Tone and structure	Narrative themes
Andrew	A story of competence and independence in many areas of his life	Progressive then stable. Emotional tone of confidence and contentment	Skilled at role Inclusion Pros and cons Life outside of interviews
Brenda	A story of taken-for-granted competence and power. Also about the importance of being listened to.	Stable. Told in a matter-of-fact way	Sense of importance Personal benefits Importance of feeling listened to Indifference to interviews
Colin	Three main phases: hopelessness about life before interviews; the transformative effects of being involved in interviews; feelings of loss and adjustment post-interviewing	Very progressive to start with: from “life’s not worth living” to feeling valued and powerful. Regressive towards the end: “haven’t heard from them in a while”, miss interviewing	Sadness and emptiness before interviews Skilled at interviewing Power and importance Loss and change
David	A story of group membership and feeling part of the team, rather than feeling powerful. Also one of transformation: interviews injected him with confidence.	Progressive and transformational. Became more animated as interview progressed, and this reflected his narrative. Overall tone is a positive one, with a grand ending.	Group membership Transformation and development Interviews as interesting Being generous
Emily	A story of a struggle between autonomy and dependence. Interviews not a strong feature, more engaged with things that directly affect her, such as residential staff and work	Stable. No particular changes as a result of interviews. Narrative tone of anger, sense of feeling oppressed and having to constantly fight her own corner.	Interviews “not really that important” Relationships with others Life outside of interviews
Fred	A story about feeling special. Interviews give him a sense of being an “important chap” and “clever man”.	Progressive at first, but regressive towards the end. Emotional tone is one of pride, but with a tone of sadness at the end.	Skilled role Specialness and importance Anxiety Life outside of interviews

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Graham	A story of doing things on his own, having a say and overcoming nerves.	Progressive. Lots of references to feeling nervous and worried about making mistakes at first, but then felt more confident and competent.	Developing in skill and confidence “Got more say” Independence Good at talking Personal benefits Taking it seriously
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### Interviews as Transformative

Both Colin’s and David’s narratives had a progressive structure and described the experience of interviews as having a significant, positive and lasting influence on their identities. For David, interviewing gave him a sense of group membership and being liked, and his narrative emphasised that he wanted to be seen as generous and kind. Colin described interviewing as giving him a sense of power and importance that was lacking in his life. Colin’s story will be used as an example of this transformational narrative.

#### Colin’s Story

Colin had spent the past four-and-a-half years as an inpatient on a locked Assessment and Treatment unit and had only recently moved into a residential service in the community. He had been an interviewer multiple times whilst he was an inpatient. On the first occasion, this had been part of a large panel consisting of staff and service users, but on all other occasions interviewees met with a service user panel (consisting of Colin, another service user and one staff member), then met with a staff panel.

Colin’s narrative was primarily about feeling powerful and important. He opened the interview with a strong statement that clearly set out the tone and central themes of his narrative:

*Researcher:* ...can you tell me about your experiences of interviewing people for jobs?

Colin: Yeah, it-it-it was, it was good, it, it, it was like being the boss.

R: Yeah?

*C: Yeah, like, it was like being like, like you're the boss and you are employing them.*

He emphasised his power through language. For example, at times in the interview he described himself and his co-interviewer as “the judges”, and used language around being “in control” or “in charge” of interviewees:

*Colin: we had power in our hands to, to employ 'em. Yeah?*

Researcher: Yeah?

*C: Not to employ 'em but not, to judge 'em, yeah?*

R: Mmm

C: Em, and that felt good.

R: It felt good?

C: Yeah.

R: What felt good about it?

C: [sighs] be being in, in control of, of being in control, of, of er, but I can't uh. Being in charge, er, *of, of 'em, yeah?*

Staff were assigned a passive role within Colin's narrative, as they were described as almost always agreeing with his judgment. In this way, Colin's narrative emphasised his power. It appears that by drawing on cultural narratives of being 'the boss' (which one might find in popular media representations such as the TV show *The Apprentice*), Colin was able to subvert dominant narratives about the relative worth of people with learning disabilities and people on locked inpatient units.

Another key theme was that Colin had particular skills which made him well-suited to the role. He talked about being a “good judge of character”, which meant that he could “tell if a person’s bad or not”. Colin said that it was important to ensure that people had the correct skills and experience and weren’t lying about their qualifications, because working in the Assessment and Treatment unit could be dangerous. This emphasised the importance of his role and positioned him as indispensable. Colin told a particular story several times which illustrates this. He described a question of his own invention which he used to decide whether someone was right for the job:

*Colin: like the one person there, he, I asked him a question, yeah? “What, what would you do if a patient got violent and attacked ya?”*

Researcher: Mmm

*C: He turned round and said “I would try and talk to him” and I said “that what”, I just let him carry on and then soon he, soon he went into the other room, I, me and er the other person said “he’d be no good”.*

*R: Right, OK He’d be no good?*

*C: Nah, cos he, he, if patient attacking you, yeah?*

R: Mmm

*C: You, you wouldn’t try t-t-t-, wouldn’t try t-t-t-t-to talk y-y-y-you restrain him.*

*R: OK, OK, So you thought that person would be no good cos he didn’t give the right answer?*

*C: No.*

Later, Colin noted that he had come up with these questions himself, thus emphasising his skill:

R: So [staff member] said what questions to ask?

C: Ye-, yeah, but I threw, but I threw two, I threw, I threw a couple of questions in, yeah?

R: Ah OK.

C: Yeah? At the end of it, yeah?

R: OK.

C: *And I asked, I asked 'em yeah, because I wanted to see, their r-, their reaction.*

R: OK.

C: What, what, what would they do.

Around halfway through the interview, Colin talked about his life before interviewing. The theme here was one of desolation, powerlessness and hopelessness. As well as being on an Assessment and Treatment unit for a long time, his parents had died, and he “just wanted to join them”:

Researcher: After you'd been an interviewer for a while, what did you think about yourself? Did you feel differently about yourself?

Colin: [long pause] Yeah, I felt different about myself.

R: Yeah? In what way?

C: I [long pause], er, I thought life was worth living.

R: OK. Thought life was worth living?

C: Yeah, a-a-at one time I didn't think life was worth living, yeah?

R: OK.

C: But started doing good, yeah? Thought, thought life was worth living.

R: OK.

C: But

R: Because of the interviews?

C: Mmm

R: Yeah. What happened that meant you felt life wasn't worth living?

C: Er, I was hopi-, in hospital, I was in hospital for a long time. Before I done the interviews, yeah?

R: Mmm

C: Started doing the interviews, yeah?

R: Yeah.

C: I didn't have noth-, I was just stuck on the ward.

R: Right.

C: *And I thought "there's nothing for me" then when I was stuck on the ward but soon as I started the interviewing, yeah?*

R: Mmm

C: After first two, two, yeah?

R: Mmm

C: I thought life was worth living.

When viewed through the context of life before interviews, Colin's transformation becomes apparent.

Colin stopped interviewing around the time he moved out of the Assessment and Treatment Unit, and at the time he gave his narrative interview he had not interviewed in a number of months. While he still felt he was someone of value, the main theme of life narrative post-interviewing was one of loss and adjustment. He talked about how he missed interviewing:

Colin: N-Now, I got no, got no, there no interviews, aint done for ages.

Researcher: OK. Do you miss it?

C: Yeah.

R: Yeah? When was the last time you did an interview?

C: Months ago.

R: Months ago? OK. Do you think they will come back to you again when they need to hire people and ask you to do interviews?

C: Yeah, yeah, they will do yeah.

R: OK. How does it feel that you've not done interviews in months?

C: Er, I get low mood sometimes and I just stay in my room.

However, he also talked about how he found other avenues to get a feeling of value and power. He described being involved in a project to “help people [who’ve] got learning disabilities to get a better life”, and said that he had done a good job of this so far. He also talked about how he had been invited by staff to train new service user interviewers, but joked that if he trained them too well they might take that role from him. Finally, he talked about how he was helping another resident at his home to become more independent:

*Colin: ...there client here, yeah?*

Researcher: Mmm

C: *Don't* know, like when we go out on buses, yeah?

R: Right.

C: He don't know where to get off or nothing, yeah?

R: OK.

C: And what, when I go out he ask me if he can go with me, yeah?

R: Yeah.

C: And I take him out, yeah?

R: Yeah.

C: I-I try and get him used to the buses.

R: Mmm. And that helps you to, that helps him out does it?

C: Yeah.

R: Yeah? OK. And does that, is that a time when you feel powerful?

C: Yeah.

R: Yeah? OK. What is it that makes you feel powerful about that?

C: *I'm doing, I'm doing something good there.*

Colin's experience of interviews appeared to transform his narrative identity substantially. Prior to interviewing, his narrative identity was that his life wasn't worth living, but through interviewing he was able to feel powerful and valued. While he experienced the end of his time as an interviewer as a loss, he found other activities and tasks in his life that he incorporated into this new narrative of someone who has useful, important and "doing something good."

#### Interviews as Positive but not Central to Identity

Andrew's, Fred's and Graham's narratives differed from the narrative of a transformational experience described above. While all agreed that being an interviewer was a positive experience, and all agreed that the experience had some influence on their narrative identity, this influence was somewhat limited.

For Andrew, interviews were one of many things that engendered a sense of self-confidence, agency and independence, in addition to his recent marriage, his involvement with the local Mencap and volunteer work. For Fred, being an interviewer was the "best day ever" and made him feel special and important, but it was more the break from his usual routine and the opportunity to do something independent that influenced his narrative identity, rather than anything specific about being an interviewer. Graham's narrative was progressive, in that he described starting out as nervous and worried about making mistakes, and emerged as



confident and skilled. However, he appeared to incorporate his experiences of interviewing into his existing narrative identity as someone who doesn't usually get nervous, who likes talking and who prefers to do things on his own, and he noticed very little difference afterwards.

Graham's narrative provides a clear example of this category of narratives.

### Graham's Story

Graham was a 36-year-old man, living in his own home. He had been an interviewer multiple times and felt "happy and proud" of his involvement. When he was initially an interviewer, he was part of a panel of five service users. Later, he was an interviewer on his own. The focus of his narrative was more on his own experience, with few references to other characters. Graham's narrative had a progressive structure, in that he described a process of feeling less nervous and having more of a say over time.

A central theme in Graham's narrative was the contrast between interviewing as part of a large panel of service users, which Graham described as difficult, to interviewing on his own. Graham described interviewing on his own as "more relaxed". He also noted that "with five of us I might forget what I have to say" and "they [staff] listen to me more when I'm on my own". However, while themes of independence, confidence, skill and 'having more of a say' were evident, Graham's experiences appeared to have very little influence on his narrative identity. When discussing life outside of interviews, he said that he had only noticed a subtle change in himself:

Researcher: ...outside the interview did you feel more confident, kind of, you know, at [day centre] or at home, or outside of interview, or is just in the interview you felt more confident?

G: In the interview.

R: OK. Did it change you at all outside of the interview, did you think, did you notice yourself being different at all?

G: Yeah a little bit.

R: In what way?

G: Er, more friendly.

R: More friendly?

G: Yeah.

R: Yeah? OK.

G: And at erm, and let all the ones go on the bus before me.

R: Sorry?

G: I always [unclear] all the ones who wait for the bus stop-

R: Yeah.

G: get on the bus.

R: You let them get on the bus first?

G: Yeah, first.

R: Yeah? Because of interviews?

G: Yeah.

This was the only difference that Graham had found. Instead of a transformation, then, Graham's experience appeared to confirm existing aspects of his narrative identity. For example, he described his nervousness about interviewing as out-of-character, suggesting that he held narratives that he was someone who does not ordinarily get nervous:

*Graham: ...I'd be nervous.*

Researcher: OK.

G: On the day.

R: Yeah.

G: *And that is a first for me, normally I'm f-, normally fine.*

R: Right. Right.

G: When, on the day thought it, I'd be nervous! [laughs]

R: Yeah, yeah. So you were a bit worried about it at first.

G: Yeah.

R: And then you were nervous on the day.

G: Day. And then when I-

R: And then once it started you were fine.

G: started then I'm fine.

R: Yep. OK, but that wasn't, that's not like you normally, then, so [unclear]

G: No. normally I'm not that nervous! [laughs]

Similarly, Graham indicated that confidence in talking is already a part of his narrative identity, so his progression from having little say to more say was perhaps 'return to the norm':

Researcher: Do you have an idea about why [you were picked to be an interviewer]?

G: *Yeah, why I've, Err I got a little hunch why.*

R: Yeah? What's that? What's your hunch?

G: I like talking! [laughs]

R: [laugh] Right!

G: My hunch is.

R: Cos you like talking?

G: Yeah.

R: Yeah? OK. Do you think they saw some things that you were good at?

G: Yeah.

It appears, then, that Graham assimilated his narrative about interviewing into broader narratives about himself as someone who is confident and good at talking, with few noticeable changes in his narrative identity. Nevertheless, interviewing represented an avenue for doing things independently and an opportunity to perhaps strengthen aspects of his identity that he was proud of.

#### Interviews as Not Significant

For Brenda and Emily, interviews appeared unimportant in their wider narratives. This category of narratives provides a stark contrast to the previous two categories. Both interviews were relatively short because neither expanded much on their experiences of interviewing. As noted above, Brenda indicated being largely indifferent to interviews and found them “half good” but half “annoying”. While she had a great deal of experience as an interviewer and in her narrative was one of self-assurance and competence, the role of interviews emerged more as routine experiences, rather than anything of particular note. For Emily, interviews were not particularly memorable at all. Both tended to steer the conversation towards other aspects of their lives. For example, Brenda talked about how she had missed a computer session at her day centre to meet with the researcher, while Emily became more animated when talking about relationships with others and her interests. Emily’s story illustrates this category well.

#### Emily’s Story

Emily was a 28-year-old woman who had been living in a new, purpose-built supported living service for the past two years. While she had a mild learning disability and was largely able to live independently, she experienced significant epileptic and non-epileptic seizures

that meant that she needed staff support. Her interview had a different tone to other interviews, in that she talked much more about the staff at her service, and did not talk as much about interviewing.

Her recollection of being an interviewer was patchy, but she recalled that she had been an interviewer for the CLDT several years ago. She had also been an interviewer for staff at her current residential service sometime in 2012, before she moved in there. While she did recall that being an interviewer was “good”, her narratives about interviewing were vague and lacking in detail, and she indicated through non-verbal cues that she was uninterested in discussing the topic. She yawned several times when we specifically spoke about interviewing, there were often long pauses in her answers and her responses to questions were very brief:

*Researcher: ...what do you remember of being an interviewer?*

Emily: Erm, [long pause] [yawn] I don't remember a lot actually.

R: No? OK. Can you remember anything about how it felt?

E: It felt good.

R: Yeah? What was it that felt good?

E: Mmm, asking people questions.

R: OK. Why did that feel good?

E: I don't know.

R: OK. But there was something about it that felt good?

E: Mmm

R: OK. [long pause] Can you remember how you got involved in being an interviewer?

E: No. [laughs]

It is possible that Emily struggled to recall details about her experience because of her cognitive impairments. However, she had little difficulty recalling other past events, so it might be that she struggled to recollect interviews because they were less memorable. For example, she talked a lot about her history of changing her shifts around at the supported employment scheme that she had been attending for a number of years.

She also took a more active, vocal role when the conversation turned towards employment or her relationship with staff, which contrasted with her apparent impassiveness when discussing interviews. In this area, her story emerged as one of struggle between her wish to be seen as an autonomous individual in a situation where she unavoidably needed support from staff, and where cultural narratives about her capabilities as a person with learning disabilities positioned her as dependent and incapable. This struggle played out in conversations both within and outside of the recorded interview. In these conversations, Emily positioned herself at first as a victim of oppressive staff members:

Emily: Oh, did I tell you I got a new key worker though?

Researcher: Have you?

E: Yeah.

R: OK. Who's your new key worker?

E: Jane.

R: Yeah?

E: Yeah, I don't get on well with Kelly now.

R: OK. Who's Kelly?

E: Kelly was my, my previous key worker.

R: OK. So Kelly was your key worker and you changed to Jane. Yeah?

E: Mmm.

R: Why's that?

E: Well cos, erm, she was, when I was talking to Kelly on Saturday-

R: Mmm.

E: about my medication, about me taking my medication.

R: Yeah?

E: All that, erm, she was like, a bit rude?

R: OK?

*E: And she said, she was like saying to me "What?" and all that kind of stuff.*

In this situation, she described how she was able to demonstrate her power by having her key worker replaced:

Emily: And I, and I didn't like the way she was talking to me?

Researcher: Right OK, cos she was being a bit rude.

E: Yeah.

R: Yeah?

E: So I said to [the home manager] that it's about time I had a new key worker.

It seemed that these areas were important influences over Emily's narrative identity. Whilst user involvement in interviews is perhaps aimed at empowerment, they appeared less important in Emily's narrative:

*Researcher: ...there's lots of different things that you like to do, but the sense that I'm getting is that being on an interview panel, being an interviewer kind of wasn't, isn't that memorable for you. Isn't the kind of, it's not that big a part of your life really, being an interviewer. Does that sound right?*

Emily: I think so.

R: Yeah? Cos the reason I wonder is because it seems like it's quite hard for you to remember what it was like to be an interviewer.

E: Yeah.

R: Yeah? And I wonder if that might be because it's not really that important so it's not something that sticks in your mind.

E: Well it's probably because it's too far ahead and it's not really that important.

It is not clear why interviews were less important to Emily, but it is possible that it is because they did not have a direct and visible influence in her day-to-day struggle for autonomy so were less central to her narrative. It is likely that she had little contact with the people she interviewed for the CLDT, as these were often senior managers and clinicians that she might not have had any reason to meet afterwards. Similarly, while she was also involved in interviews for her residential service, it appears that her involvement had little direct effect on those who worked most often with her, such as her key workers.

Core features of Emily's narrative identity, then, seem to be around autonomy and independence, which were largely expressed through stories about her relationship with staff. Involvement in interviews did not seem to have a prominent role.



## Discussion

This study used NA to explore the experience of SUI in recruitment, and the ways in which this influenced identity. Consistent with other studies (Hurtado et al., 2012; Johnson et al., 2012), participants in this study were generally positive about their experiences of being involved in recruitment. However, there was some variation in the narratives people had about their experiences, and the influences these had on identity. For some, SUI had a transformative and lasting influence, either through narratives of power or importance, or through narratives of being part of a team. For others, the experience of SUI had had some positive influence but any changes noted were limited to the context of the interview setting or were assimilated into existing narrative identities. Finally, for two of the seven participants, SUI was not memorable or appeared less important in comparison with other aspects of their lives.

For people for whom SUI was a transformative experience, the emergent narrative was powerful. For example, Colin's narrative emphasised a contrast between his life prior to interviewing and his life afterwards. Consistent with role theory and the study reported in Rapley et al. (1998) and Rapley (2004), Colin drew from other culturally-defined roles to construct a narrative of power and competence. While the experiences of three participants were less transformative, this does not mean that involvement in interviews was less important. Since narrative identity is constructed through an accumulation of narratives that are combined to form a sense of continuity and consistency, experiences of power, autonomy or competence are needed in order to maintain a positive narrative identity. For example, Graham's narrative identity as someone who is confident, good at talking and independent may have been present but less salient without his experiences of interviewing (or indeed without the opportunity to share his narrative).

### **Contribution to Extant Literature**

At its broadest, this study provides evidence that narrative identities for people with learning disabilities are complex and actively negotiated. While SUI seemed to play a role in construction of identity for some participants, it appears that it was just one narrative of many that participants could draw from. This supports the arguments of some researchers (e.g. Rapley et al., 1998; Rapley, 2004; Finlay & Lyons, 2005) that a “learning disabilities” identity is not fixed or pervasive. This study also sought to further the research reported in Rapley et al. (1998) and Rapley (2004) by exploring how people with learning disabilities negotiate identities when placed in roles specifically intended to be both empowering and socially valued. The findings indicate that the empowering nature of the role itself is less important in constructing positive identities than whether experiences are meaningful for the individual. For the participants in this study, such meaning emerged from pride in their skills, relationships with others or voluntary and supported employment. This challenges a perhaps paternalistic assumption that providing socially valued roles for people who are devalued will inevitably bestow a more positive identity, as suggested by role theory and SRV (Wolfensberger, 1983; Lemay, 1999), and suggests that efforts towards normalisation and SRV (or at least efforts applied in a “top down” fashion) has a smaller impact on individuals’ identity than might be expected.

### **Limitations**

While efforts were taken to maintain a high quality of research through the use of reflexivity, owning one’s perspective and credibility checks (Elliott et al., 1999), several limitations were identified.

First, it could be argued that the findings of the study are not representative of the wider learning disabilities population, as all participants were White British, living in a similar

geographical area and had taken part in interviewing for the same NHS trust. Additionally, the fact that all participants had been involved in the relatively complex task of interviewing meant that they were all verbally able and had more mild learning disabilities. However, it should be noted that generalisability is not necessarily an aim of NA. Instead, NA studies (as with many qualitative methodologies) contribute to and extend broader knowledge by exploring how preconceived notions (in this case theories of identity) occur in everyday life, and highlight the wider context (Riessman, 2008).

Another limitation of this study was that, due to time restrictions, narratives were collected in a single interview, meaning that the researcher and participant may not have had sufficient time to build a rapport and the stories may not have been fully told. While efforts were taken to ameliorate this, such as by meeting participants for an introductory pre-interview meeting, this may have affected the richness of the narratives elicited. This is particularly pertinent given that some interviews were relatively short. Moreover, there was insufficient time to meet with participants after data analysis for respondent validation, where the participant offers feedback on the researcher's interpretation of the data. This is considered by some to be the strongest credibility check (Lincoln & Guba, 1985). Despite using other credibility checks, the data may not have been as authentic a reflection of the participants' voices as it could otherwise have been.

There was also a risk of leading participants as questions were perhaps more direct than would be used for more articulate participants and there were unavoidable power imbalances in interviews. This was perhaps a particular risk for Brenda, as she also utilised a symbol sheet (created by the researcher) and had a support worker present who, despite only intervening when needed, changed the context and possibly the narrative Brenda told. Whilst the researcher aimed to own their perspective through a research diary, supervision and

bracketing interviews, it is perhaps inevitable that the researcher's voice is more privileged when conducting research with inarticulate participants (Booth and Booth, 1996).

### **Practice Implications**

Since most participants indicated that involvement in recruitment was a positive experience, this study provides support for SUI in learning disabilities services. However, this study also highlights that the ways in which people experience SUI is complex. In some cases, it could be argued that service users are involved in recruitment in ways which make the experience less meaningful for those involved. This study highlights the need for greater consideration of whether involvement is meaningful for the service user, and how SUI could be made more meaningful.

SUI appeared to be implemented in an informal, unplanned way, such as by recruiting service users by chance or availability. Through greater consideration of individuals' circumstances, services may be able to approach people for whom SUI may be most meaningful. For example, people who are most excluded may find SUI more transformative, as the experience of inclusion may be more contrasting when compared with people who already have other valued roles. This may mean that services need to consider how to include those with complex needs, challenging behaviour or more severe disabilities, which is inevitably more challenging (Hurtado et al., 2012). Services may also need to pay attention to the experience of service users after SUI. In the present study, some participants were told that they would be contacted when needed for interview panels in the future, but had not spoken to anyone in months. While service users were, for the most part, able to reconcile this, this may have longer-term implications on identity. Since identity can be considered to be a continual process of construction, a lack of follow-up by services might foster more negative narratives (such as of obsolescence), particularly in people who may have fewer valued roles.

Finally, this study highlights that people with learning disabilities construct narrative identities from a range of areas which might be idiosyncratic, and not necessarily through roles which might be considered ‘socially valued’. Services should thus perhaps be flexible and personalised in the ways in which they support service users so people with learning disabilities have the opportunity to develop positive narrative identities through engaging in their own choices of activities.

### **Future Research**

To the author’s knowledge, this was the first study into the relationship between SUI and narrative identity. Participants in this study drew from a wide variety of experiences to construct narrative identities but there are multiple narratives that could be influential. This research explored a specific experience, but SUI in recruitment is an infrequent activity that may feel remote from people’s lives. Exploring how narrative identity is constructed everyday experiences, such as work, relationships or interests may provide important insights into how people with learning disabilities construct positive identities.

There was also a noticeable contrast in narratives about SUI in learning disabilities when compared with experiences of SUI in related fields. In adult mental health, for instance, experiences of SUI had a political flavour: service users were aware that their role had implications for the visibility of people with mental health problems as a whole and discussed struggles with tokenism, stigma and power imbalances (e.g. McDaid, 2009; Rutter et al., 2004). This was notably absent from narratives in this study, and only one participant, Andrew, explicitly commented on involvement as a political act (noting that “there was a point when [NHS trust] did not listen to anyone...but they’ve got better now” and “they’ve got to listen to take our point of view across”). It is possible that political discourses were absent from narratives in this study because of the context of the interview or the focus on

identity. Nevertheless, the ways in which people with learning disabilities relate to discourses of power and the implications of this on SUI is an interesting avenue for future research.

## Conclusion

This study set out to explore the ways in which people with learning disabilities who have been involved in recruitment for health and social care construct narrative identities. The findings highlight that for people with learning disabilities, construction of a positive identity is a complex negotiation and perhaps not as straightforward as a process of using strategies to distance oneself from a “toxic identity” (Edgerton, 1967, 1993). While for some SUI in interviews represented a fundamental transformation, the findings suggest people with learning disabilities are able to draw from other culturally-defined roles and narratives to make sense of a wealth of experiences, and through these narratives can and do seem to create positive identities. Through this lens, SUI represents just one aspect that people with learning disabilities can choose to draw from in identity construction. It is perhaps presumptuous, then, to view SUI as more than this. While SUI can be considered to be a right and a valued social role, it might not automatically bestow a positive identity on people.

## References

- Atherton, H. (2007). A history of learning disabilities. In B. Gates (Ed.), *Learning disabilities: Toward inclusion* (5th ed., pp. 43-66). Philadelphia, PA: Elsevier.
- Bamberg, M. (1997). Positioning between structure and performance. *Journal of Narrative and Life History*, 7, 335-342.
- Bamberg, M. (2012). Narrative analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbook of research methods* (Vol. 2, pp. 85-102). doi:10.1037/13620-006
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology* (2nd ed.). Chichester, UK: John Wiley & Sons.
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18, 47-56. doi:10.1111/j.1468-3148.2004.00218.x
- Benwell, B., & Stokoe, E. (2006). *Discourse and identity*. Edinburgh: Edinburgh University Press.
- Booth, T., & Booth, W. (1996). Sounds of silence: Narrative research with inarticulate subjects. *Disability & Society*, 11, 55-69. doi:10.1080/09687599650023326
- Caldwell, J. (2011). Disability identity of leaders in the self-advocacy movement. *Intellectual and Developmental Disabilities*, 49, 315-326. doi:10.1352/1934-9556-49.5.315.
- Campbell, M., & Martin, M. (2009). Reducing health inequalities in Scotland: The involvement of people with learning disabilities as national health service reviewers. *British Journal of Learning Disabilities*, 38, 49-58. doi:10.1111/j.1468-3156.2009.00562.x
- Craig, J., Craig, F., Withers, P., Hatton, C., & Limb, K. (2002). Identity conflict in people with intellectual disabilities: What role do service-providers play in mediating stigma?



- Journal of Applied Research in Intellectual Disabilities, 15, 61-72.  
doi:10.1046/j.1360-2322.2002.00101.x
- Crawford, M. J., Aldridge, T., Bhui, K., Rutter, D., Manley, C., Weaver, T., . . . Fulop, N. (2003). User involvement in the planning and delivery of mental health services: A cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*, 107, 410-414.
- Crossley, M. L. (2000). *Introducing narrative psychology: Self, trauma and the construction of meaning*. Buckingham, UK: Open University Press.
- Crossley, M. L. (2003). Formulating narrative psychology: The limitations of contemporary social constructionism. *Narrative Inquiry*, 13, 287-300. doi:10.1075/ni.13.2.03cro
- Davies, C. A., & Jenkins, R. (1997). 'She has different fits to me': How people with learning difficulties see themselves. *Disability & Society*, 12, 95-109.  
doi:10.1080/09687599727498
- Dearden-Phillips, C., & Fountain, R. (2005). Real power? An examination of the involvement of people with learning difficulties in strategic service development in Cambridgeshire. *British Journal of Learning Disabilities*, 33, 200-204.  
doi:10.1111/j.1468-3156.2005.00360.x
- Department of Health. (2001). *Valuing People: A New Strategy for Learning Disability in the 21st Century*. London: Department of Health.
- Edgerton, R. (1967). *The cloak of competence*. Berkeley, CA: University of California Press.
- Edgerton, R. B. (1993). *The cloak of competence (Rev. ed.)*. Berkeley, CA: University of California Press.
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229. doi:10.1348/014466599162782

- Finlay, M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability & Society*, 13, 37-51. doi:10.1080/09687599826902
- Finlay, W. M., & Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation*, 43, 120-134. doi:10.1352/0047-6765(2005)43<120:RTLASC>2.0.CO;2
- Fyson, R., & Fox, L. (2014). Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning. *Disability & Society*, 29, 239-254. doi:10.1080/09687599.2013.776491
- Gergen, K. J., & Gergen, M. M. (1986). Narrative form and the construction of psychological science. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct* (pp. 22-44). New York: Praeger.
- Gergen, M. M., & Gergen, K. J. (1984). The social construction of narrative accounts. In K. Gergen, & M. Gergen (Eds.), *Historical social psychology* (pp. 173-189). Hillsdale, NJ: Erlbaum.
- Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society*, 15, 389-409. doi:10.1080/713661959
- Goodley, D. (2000). *Self-advocacy in the lives of people with learning difficulties*. Buckingham, UK: Open University Press.
- Goodley, D. (2001). 'Learning difficulties': The social model of disability and impairment. *Disability & Society*, 16, 207-231. doi:10.1080/09687590120035816
- Hall, E. (2004). Social geographies of learning disability: Narratives of exclusion and inclusion. *Area*, 36, 298-306. doi:10.1111/j.0004-0894.2004.00227.x

- Hurtado, B., Timmins, S., & Seward, C. (2012). The importance of being earnest: our experience of involving service users with complex needs in staff recruitment. *British Journal of Learning Disabilities*, 42, 36-42. doi:10.1111/bld.12007
- Jahoda, A., Markova, I., & Cattermole, M. (1988). Stigma and the self-concept of people with a mild mental handicap. *Journal of Mental Deficiency Research*, 32, 103-115.
- Johnson, P., Carpenter, K., & Scarbrough-Lang, S. (2012). Involvement of service users in the recruitment of staff. *Learning Disability Practice*, 15(2), 22-25. doi:10.7748/ldp2012.03.15.2.22.c8967
- Jovchelovitch, S., & Bauer, M. W. (2000). Narrative interviewing. In M. W. Bauer, & G. Gaskell (Eds.), *Qualitative researching with text, image and sound: A practical handbook* (pp. 57-74). London: SAGE Publications.
- Lemay, R. A. (1999). Roles, identities, and expectancies: Positive contributions to Normalization and Social Role Valorization. In R. J. Flynn, & R. A. Lemay (Eds.), *A quarter-century of Normalization and Social Role Valorization: Evolution and impact* (pp. 219-240). Ottawa, Canada: University of Ottawa Press.
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage.
- McAdams, D. P. (1985). *Power, intimacy and the life story: Personological inquiries and identity*. New York: Dorsey.
- McAdams, D. P. (1993). *The stories we live by: Personal myths and the making of the self*. New York: Guildford Press.
- McCormack, C. (2004). Storying stories: A narrative approach to in-depth interview conversations. *International Journal of Social Research Methodology*, 7, 219-236. doi:10.1080/13645570210166382
- McDaid, S. (2009). An equality of condition framework for user involvement in mental health policy and planning: Evidence from participatory action research. *Disability & Society*, 24, 461-474. doi:10.1080/09687590902879064

- Murray. (2008). Narrative Psychology. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (2nd ed., pp. 111-132). London: SAGE Publications.
- Murray, M. (2003). Narrative psychology and narrative analysis. In P. M. Camic, J. E. Rhodes, & L. Yardley (Eds.), *Qualitative research in psychology: Expanding perspectives in methodology and design* (pp. 95-112). Washington, DC: The American Psychological Association.
- Murray, M. (2009). Telling stories and making sense of cancer. *International Journal of Narrative Practice*, 1, 25-36.
- Oliver, M. (1990). *The politics of disablement*. London: MacMillan.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25, 166-176. doi:10.1111/j.1468-3148.2011.00651.x
- Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge: Cambridge University Press.
- Rapley, M., Kiernan, P., & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of 'being intellectually disabled'. *Disability & Society*, 13, 807-827. doi:10.1080/09687599826524
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. London: Sage Publications.
- Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P., & Wykes, T. (2003). *User and carer involvement in change management in a mental health context: Review of the literature: Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*. London: NCCSDO.
- Rutter, D., Manley, C., Weaver, T., Crawford, M. J., & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult

mental health services in London. *Social Science & Medicine*, 58, 1973-1984.  
doi:10.1016/S0277-9536(03)00401-5

Singer, J. A. (2004). Narrative identity and meaning making across the adult lifespan: An introduction. *Journal of Personality*, 72, 437-459. doi:10.1111/j.0022-3506.2004.00268.x

Somers, M. R. (1994). The narrative constitution of identity: A relational and network approach. *Theory and Society*, 23, 605-649.

Todd, S., & Shearn, J. (1995). Family secrets and dilemmas of status: Parental management of the disclosure of learning disability. Cardiff: Welsh Centre for Learning Disabilities, Applied Research Unit.

Todd, S., & Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability & Society*, 12, 341-366. doi:10.1080/09687599727218

Williams, G. (1984). The genesis of chronic illness: Narrative reconstruction. *Sociology of Health & Illness*, 6, 175-200.

Wolfensberger, W. (1983). Social role valorization: A proposed new term for the principle of normalization. *Mental Retardation*, 21, 234-9.

Wolfensberger, W. (1992). A brief introduction to Social Role Valorization as a higher order concept for structuring human services (2nd Rev. ed.). Syracuse, NY: Syracuse University, Training Institute for Human Service Planning, Leadership and Change Agency.

**MRP Section C**

**Appendices and Supporting Material**

**Appendix A: Framework for quality assessment**

Adapted from Mays and Pope (2000); and Elliott, Fischer, and Rennie (1999)

Paper	Reflexivity /Owning one's perspective	Situating the sample	Grounding in examples	Providing credibility checks	Coherence	Accomplishing general vs. specific research tasks	Resonating with readers	Clear exposition of data collection and analysis	Attention to negative cases	Fair dealing
Omeni et al. (2014)		✓	✓		✓	✓	✓	✓	✓	✓
Hutchinson and Lovell (2013)		✓	✓		✓	✓	✓			
Moltu et al. (2012)			✓	✓	✓	✓	✓	✓		✓
Taggart et al. (2013)		✓	✓	✓	✓	✓	✓	✓		
Patterson et al. (2014)		✓	✓	✓	✓	✓	✓	✓	✓	✓
Harding et al. (2010)	✓	✓	✓		✓	✓	✓	✓	✓	✓
Jones and Black (2008)			✓		✓	✓	✓			
Walters et al. (2003)	✓	✓	✓		✓	✓	✓	✓	✓	✓
Honig et al. (2006)			✓		✓	✓	✓	✓	✓	✓
O'Reilly et al. (2011)			✓	✓	✓	✓	✓	✓		✓
McDaid (2009)	✓	✓	✓	✓	✓	✓	✓	✓		
Rutter et al. (2004)			✓		✓	✓	✓	✓	✓	✓

## Appendix B: Information Sheet and Consent Form

### Information Sheet and Consent Form

This is an information sheet for you to keep. It has information about me and my project. If you need help to read it, please ask me or someone you know.

#### Part I: Information Sheet



#### Who am I?

My name is Leigh Emery and I am a Trainee Clinical Psychologist.



I work at a university called “Canterbury Christ Church University”.



I am doing a research study. I would like to find out what it is like for people with learning disabilities to be on interview panels.



I have two supervisors to help me with my research. Their names are Kate Foxwell and Jennifer Jackson.

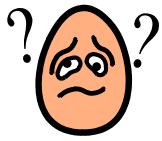


I am going to give you information and invite you to be part of a research study. If you do not wish to take part, you do not have to.



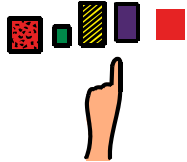
You can keep this form. You can talk about anything in this form with other people if you want. You can also talk to other people before you decide if you want to take part in the study. You do not have to decide now.





There may be some words you don't understand or things that you want me to explain more about. Please ask me to stop at any time and I will explain.

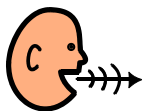
### Why am I doing this research?



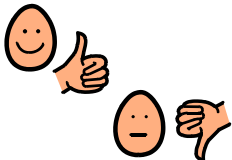
People with learning disabilities sometimes get asked to help professionals choose new staff to work in their teams. They sometimes get asked to be on interview panels as an **interviewer**.



Interviewers meet with a person who is applying for a job.



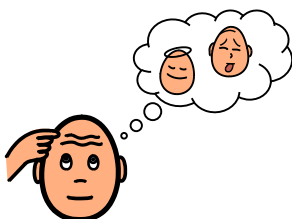
They might ask questions and listen to the answers from the person who is applying for the job.



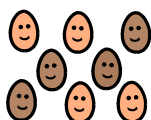
Afterwards, they might need to say who they liked and who they didn't like. They might need to say who they liked the best.



This is a very important job. People with learning disabilities don't often get to do very important jobs.



I would like to talk to you because you have been an interviewer. I want to find out what it was like for you. I want to find out if it was a good thing or a bad thing. I also want to find out if it changed the way you think about yourself.



I will also talk to other people who have been on interview panels.

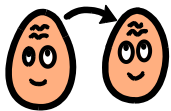


### **Do I have to do this?**

You don't have to be in this research if you don't want to be. It's up to you.



If you decide not to be in the research, it's OK and nothing changes.



Even if you say "yes" now, you can change your mind later and it's still OK.



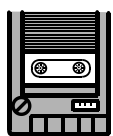
### **What is going to happen to me?**

I would like to meet with you to talk about your experience of being on an interview panel. I would like to hear your story and ask questions about it.

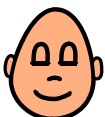


We might also talk about other things about you, like your activities, where you live and your friends and family.

I might meet with you more than once.



I would like to record the interview using a recorder. After the interview, I will write out the interview onto paper – this is called a **transcript**.

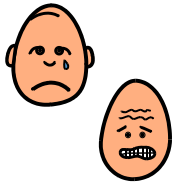


### **Is there anything good that happens to me?**

Sometimes people enjoy talking about their lives and being listened to.

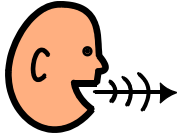


This research might also help us to understand what it's like to have learning disabilities. This might help other people in the future.



### Is this bad or dangerous for me?

This probably won't be bad for you. Sometimes, though, you might end up talking about something that might make you feel sad or worried.



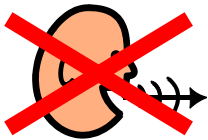
If you do feel sad or worried, you can talk to me about it.

### Do I get anything for being in the research?

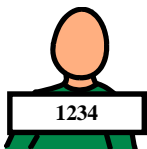


No. You do not get anything for being in the research, but if you have to spend money to meet with me (like a bus fare) then I will give you that money back.

### Confidentiality: Is everybody going to know about this?



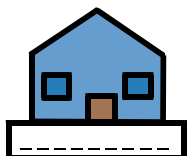
We will not tell other people that you are in this research, but you can tell someone if you want to.



Any information about you will have a number on it instead of your name.



Only the researchers will know what your number is and we will lock that information up with a lock and key.



When I write the transcript I will take out your name and any other personal information like your address or where you work so no one who reads it will know who you are.



I will keep the recordings of our interview in a safe place on a computer with a password. Only Jennifer, Kate and I will be able to get to these recordings.



When the research is finished I will destroy the recordings that I have made. I will keep the transcripts for 10 years and then will destroy them too.

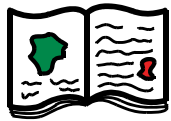
### **What will you do with the results?**



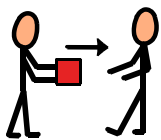
I will write the results into a long report. I might write some of the things you say into the report, but I will not say who said them.



I will give a copy of this report to my university so that they can mark it. A copy of the finished report will go to the library at the university.



I would also like to give the report to a “journal”. This a type of magazine for scientists and researchers. Other people who are interested in the work we are doing can then read about it.



If you would like me to, I can meet with you when we have finished the research and tell you about what we learnt. I can also give you a copy of the report if you want me to.

### **Who can I talk to or ask questions to?**



You can talk to anyone you want about this research.



If you choose to be part of this research I will also give you a copy of this paper to keep for yourself. You can ask a friend, carer or family member to look after it if you want.



You can ask me questions about this research. You can also speak to Kate Foxwell about the research.



You can phone either me or Kate on 0333 0117070



Do you have any questions now?

### PART 2: Certificate of Consent



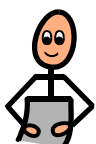
I understand that I will be interviewed to find out about my experiences of being on an interview panel.



I understand that this interview will be recorded.



I agree that some of the things I say might be used in a report. These will be anonymous so no one will know who said them.



I have read this information (or had the information read to me).



I have had my questions answered and know that I can ask questions later if I have them. I also know I can change my mind if I want to.



I agree to take part in the research.

**Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

**For carers - If participant cannot write or is otherwise unable to sign:**

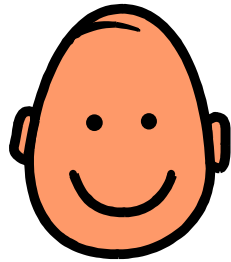
I have witnessed the accurate reading of the consent form, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

**Name:** \_\_\_\_\_

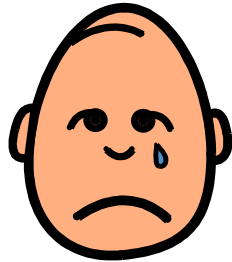
**Signature:** \_\_\_\_\_

**Date:** \_\_\_\_\_

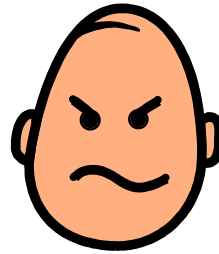
Appendix C: Symbol sheet



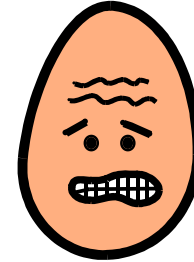
Happy



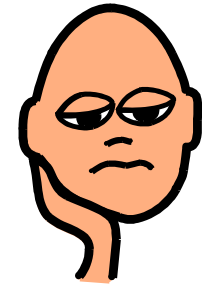
Sad



Angry



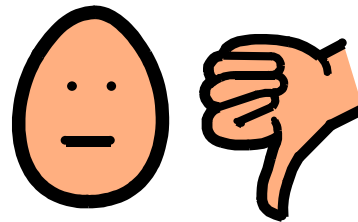
Worried



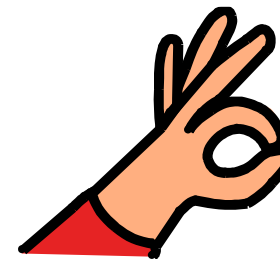
Bored



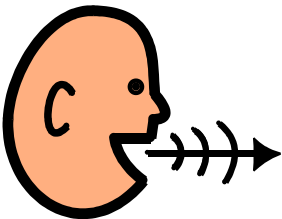
Good



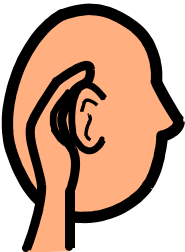
Bad



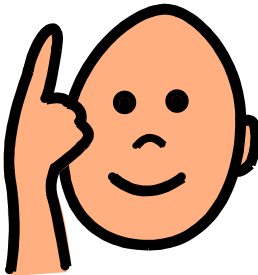
OK



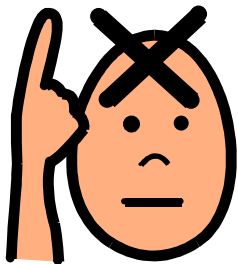
Talk



Listen



Understand



Don't

understand



## Appendix D: Aide-mémoire Used in Interviews

### Interview Schedule

*NB: Since I will be using a narrative methodology, I will aim for the interview to be unstructured aside from an opening statement and question. The additional questions below will be largely to help clients if they get stuck or if (as a result of their disabilities) they find the nature of the task difficult. They also provide an idea of the type of questions I might ask for the benefit of the ethics panel. These questions will not be used for every participant.*

#### **Introductory statement and opening questions (to be given to all participants):**

I am interested in the times when you have been an interviewer for Salomons/NHS jobs. I would like to hear what happened and what it was like for you.

Tell me about your experiences of interviewing people for a job/course.

#### **Prompt questions for participants who move off-topic frequently, or who find abstract concepts, open-ended questions or sequencing difficult:**

- How did you get involved in the interviews?
- Why do you think you were chosen?
- How did you prepare for interviewing people?
  - What did you do to get ready?
  - Did you wear special clothes?
  - Did you practice asking questions?
  - Did you talk to other people about it?
- What happened last time you were an interviewer?
- What was it like being on an interview panel?
  - Was it boring/scary/exciting/tiring/interesting?
- What was it like after the interview?
- How did you view yourself after you were an interviewer?
  - Did you feel proud/good/ashamed?
- How were you picked to be an interviewer?
- How did you feel about being picked to be an interviewer?
- What were the good things about being an interviewer?
- What were the bad things about being an interviewer?
- What happened after the interview?
- How did you tell people who your favourite person was?
- What were the other interviewers like?
  - Did the other interviewers listen to you?
- What were the interviewees like
- What did you think about the experience?

- Would you tell other people that they should get involved in interviews?

**Additional topics that I may cover:**

*NB: The questions in this section are more of an aide-memoire for me as the interviewer. These might be used to provide some contextual information, or as a neutral discussion topic for building rapport with participants.*

- Living arrangements
  - e.g. “Where do you live?”; “Who lives with you?”
- Daily activities/employment
  - e.g. “What do you do with your day?”; “Do you work or go to day services?”; “What do you like to do in your spare time?”
- Significant people in their life
  - e.g. “Tell me about your family and friends.”

## **Appendix E: Overviews of All Participants' Narratives**

NB: All names of people and places have been replaced by pseudonyms to protect confidentiality

### Andrew (Participant 1)

Andrew is a 28 year old man who lives in his own flat. He recently got married, works in a charity shop and is a member of his local Mencap. He has been a service user representative on around 25 interview panels over the past 3 years, almost always jointly with Brenda (Participant 2). He said that he knows the role “like the back of his hand”. He enjoys interviewing every time he does it.

He was selected to be an interviewer after someone emailed the manager at his local Mencap to recruit service users for interviewing. Andrew said that he didn't know why he was selected to be an interviewer the first time, but thought his name was picked out of a hat. After this first occasion, he felt he was called back because he was so good the first time. “Now they can't stop calling us,” he said.

The first time he interviewed was as part of a group of about 6 people. He found this quite hard because the whole group were expected to interact with the interviewee. He also said that he did not feel comfortable because didn't know all of the people on the panel. Overall, however, he found the initial experience of interviewing “interesting and also a little bit scary” because he didn't know what he needed to do. He likened this to starting a new job: you're not sure what the outcome would be and whether you'd be sacked or working the next day. After the first occasion, he felt that he was really listened to by staff at the trust. He commented that this was a good thing because at one point the trust never used to listen to the opinions of people with learning disabilities, but now they are listening to their points of view

more and more. He didn't realise how good the staff there would be at listening to his point of view. Over time, he felt that being listened to has meant his connection with the staff has got "stronger and stronger".

Nowadays, interviews are conducted with just two service users on a panel, which he prefers. There is also a staff panel, which interviewees also have to go to. They only interview for one day: on one occasion they interviewed for 2-3 consecutive days but Andrew said that this was "hard work" and "tiring". He described the typical process of interviewing. Before the interviews, he and his colleague, another person with a learning disability, sort out the questions they'd like to ask. This depends on the type of role that is being recruited. Some of the questions are the same each time, but if the questions don't match the role being recruited to, then Andrew and his colleague get their heads together and come up with a new question. These questions get checked with their support worker and with the job description. For example, if a job description mentions the word "support" then they will try to ask a question that fits it in.

Sometimes participants are asked to give a 5-minute presentation on a particular subject that has been in the news recently, such as the birth of Prince George, or on a work-related question such as "what would make a good manager?" In these presentations, Andrew and his colleague's role is to sit and listen and interact with them if interviewees need them to.

They have a couple of practices and find out practical information like what time they'll be starting and finishing. On the day, they dress smart but casual. They arrive, sort out the room and seating arrangements, sort out their paperwork and then a few minutes later the first interviewee comes in. Their support worker is in the room and writes down the answers that interviewees give. After each interview, Andrew and his colleague have a 45-minute break.

They spend about half-hour scoring and evaluating each of the answers that the interviewee gave. Scores are out of 5. Andrew's favourite question is "if I come to you and tell you something private, would you tell anyone?" and he gave examples of a 5-point and 1-point answer. For the remaining time, Andrew and his colleague relax, get a drink and freshen up. Lunch is also provided by the trust.

At the end of the day they speak to the other panel, which consists of staff and they all score the interviewees to decide who came out on top and who came out on bottom. They talk about how well the interviewee had done, and how well they'd done on any computer tasks (if these were part of the interview). Then the staff ask Andrew and his colleague how well the interviewees had done in their session.

Overall, Andrew finds the experience of being an interviewer "fantastic." He said that he found being an interviewer "quite big" because he feels like he is "the boss" or a member of staff "for that one special day". He is given a key fob to let him in and out of doors and gets paid minimum wage. However, he said that it felt a bit boring the next day because it feels like it's "back to reality". He talked about some of the challenges of the role. For instance, he said that some interviewees "think...they know how it all works and they like to take charge. You can't just shout out and say 'You're taking charge'". Andrew said that instead, he usually allows them to take charge and then knocks down their scores and makes a note that they tended to take charge. He also said that meeting new people, listening to the same presentations and answers to questions can get a bit tiring after a while.

Andrew talked about an occasion when he was approached in the street by someone he interviewed. She started asking him "How come I didn't get the job?" Andrew didn't know

what to do in this situation and so lied and said that he had never been an interviewer. He said that this was annoying as he didn't like lying. Nowadays he's aware that the trust policy is to say that he is not able to talk about interviews.

Andrew said that he finds being an interviewer has helped him to be more opinionated, more self-confident and more upfront. However, he talked about other things in his life which have increased his confidence, such as his work with Mencap, his recent wedding, getting his own flat and his work in the charity shop. At the charity shop, he is currently being trained to be a key holder, so that he can keep the shop open when the manager isn't around. This includes things such as fire and first aid training and learning how to rotate the clothes. He likes this work but prefers the fact that he gets paid for interviews, as getting money for his work makes him feel good.

### Brenda (Participant 2)

Brenda said that she has interviewed quite a lot of times. The first time she interviewed it was a very long time ago. Last time she interviewed, it was for a clinical psychologist. As well as interviewing at the NHS trust, she also interviews for the day centre and learning disabilities charity she attends, and at her residential home. The first time she interviewed was for the day centre. Brenda said that she was chosen because she is "very good at being an interviewer".

Brenda makes sure she has a shower before interviews and dresses up "posh". She usually wears black and silver, or red and white clothes. She said that she thinks it is very important to "dress smartly...and get there on time". She practices asking questions with her support

worker, who also attends the interviews. She comes up with the questions herself, and her support worker types them. She also chooses which questions are asked. She showed me some sheets of paper with the questions that she asks written on them. Questions are about things like cooking, writing shopping lists, going for a blood test and communication.

When she interviews, she asks questions about the things the interviewee is like to see if they're good for the job. Afterwards, she and Andrew (participant 1) tell the interviewees to go outside and wait until they've finished interviewing. After interviewing, they tick a sheet to say if they thought the person was good or bad. Brenda felt that the best interviewees "listen to you", but she doesn't give jobs to people who seem bored or worried. Sometimes they talk to the other panel, who ask questions about who she liked and didn't like. Brenda really felt listened to in these discussions, and felt she had a say in who was hired. After this she goes home. Brenda said that she feels tired the next day.

Overall, Brenda felt that being an interviewer is "about half-and-half" – half good and half bad. Interviewing and giving people jobs makes Brenda feel "happy and good". She also likes getting paid and playing on the laptop between interviews (Brenda's favourite pastime is using computers. She missed computer time at her day centre to meet with me, and mentioned this twice). She is more indifferent to aspects of interviewing such as meeting new people and listening to them ("alright I suppose"). Brenda said one of the things she doesn't like about being an interviewer is that some interviewees don't listen and say "pardon" all the time. This makes her feel annoyed.

Being an interviewer doesn't appear to influence how Brenda feels about herself. When asked if she thought interviews made her feel good or bad about herself, she said "it's alright" in an

indifferent tone. She usually keeps the interviews quiet and doesn't really talk to others about them. However, she was very clear that she is very good at being an interviewer, and she appeared proud of this.

### Colin (Participant 3)

Colin started interviewing about 2 or 3 years ago but he hasn't done it for a long time. He occasionally had difficulty remembering some of the details. He started interviewing while he was an inpatient at an assessment and treatment centre, where he resided for nearly four-and-a-half years. He carried on interviewing after he was discharged. Colin said that he was chosen because he is a "good judge of character".

The first time Colin interviewed someone it was for a nurse's position because someone was leaving. This was on a panel alongside staff members. He said that he was nervous the first time, but staff said that he did so well that they wanted him and another service user to be on an interview panel on their own. Nowadays, interviewees still have to go to another room to meet with the staff, but interviewees see Colin and the other service user first. Colin said that he and another service user were "the judges". Staff came in and asked what they thought and went by their judgement. On situations where the staff panel thought the interviewee was good but the service users disagreed, they usually went with the service user panel's views and didn't offer the job to that person.

Colin does little preparation for interviews. He doesn't practice on the day, and the paperwork is prepared by staff. He does, however, wear a suit when he interviews because he was asked to dress smart. Asking questions was the best thing about being an interviewer. During interviews, he asked a few questions such as "what experience do you bring to the



job?” and “why do you want this job?” These questions were selected by a staff member, but Colin threw a couple of his own questions in at the end of the interview. Afterwards he never really talked to others about doing the interviews.

Colin was particularly keen to talk about a particular question that he made up, “what would you do if a patient got violent and attacked you?” Colin said that asking his question was important because it helped to check people out and make sure they were qualified. He said that one woman started crying when he asked this question, which isn’t good. He told a story about one interviewee who said that he would try and talk to the patient, which Colin did not think was a good answer, as they should get help, press the alarm or try and restrain the person. He said that this told him that the person would be no good for the job. As soon as he left he and the other interviewer spoke to the staff and said told them. The main panel, who had also interviewed him, agreed with their opinion. Colin said that this event showed that he’s “got a good judge of character” and “can tell if a person’s bad or not”. This is a skill that he’s developed since doing the interviews.

Part of Colin’s task during interviews was to “judge” the people. He said he was looking for staff that could explain themselves clearly. He said that some people didn’t look at you, and this was no good. He said “if they don’t look you in the eye...that mean they’re nervous”.

Colin said that that when interviewing he looked for “equalities”, “professional experience”, someone who was a “good listener” and “good with people with learning disabilities”. He said that some people had some experience but maybe hadn’t worked for a while which shows you that they haven’t got the skills. Others had “sense...but didn’t have the experience”. He also said that it was important to be careful because they might be “fibbing” about their experience. Colin emphasised that it was important to find someone who was

suitable because “patients can get violent sometimes.” He illustrated how dangerous the role could be with an example of a situation that he got bitten by another patient while he was in the hospital.

Colin could not think of a single bad thing about being an interviewer, although he found it tiring to interview all day. He said that being an interviewer made him feel “like being the boss” and “in charge of the company”. He felt like he had power in his hands to decide who got the job, and that felt good. He said that he “felt different about [him]self” afterwards, because he “thought that life was worth living”. Colin explained that before doing interviews he’d been stuck on the ward and felt there was nothing for him. He’d also lost his parents and “just wanted to join them”. However, as soon as he started interviewing he thought life was worth living. Colin put this down to having judgement over other people.

Colin said that he missed doing interviews now, as he’d not done them for months. He still keeps busy nowadays but sometimes gets a low mood and just stays in his room. He believes that staff will call him when they need him to do interviews, but that they must just not be hiring at the moment.

Nowadays, he helps people with learning disabilities “to get a better life” and has done well so far with that. There aren’t many parts of his life where he feels powerful, but he gave an example of helping a fellow resident to use the bus. He said that he is also attending “special meetings” about something, but made it clear before and during the interview that he was not allowed to talk about what these meetings were about. These things help him to feel that life is worth living. He feels powerful here because he feels that he’s doing something good.

Colin hasn't interviewed in a while but has been asked if he could teach new service users to interview. However, he joked that if he trained them too well they'd take their jobs! He hasn't heard anything about this training role yet, but it's a relatively recent development.

#### David (Participant 4)

I interviewed David on the fourth floor of Brook House, the office block that houses the NHS community learning disability team (CLDT) and the social services learning disability team. This is also where he conducted his interviews as a service user representative. There was a thunderstorm at the time I interviewed him, and David was frequently distracted by the thunderclaps and lightning flashes during interviews. He said that these gave him "the creeps".

David has been an interviewer more than once, for both the CLDT and for positions at the respite home he sometimes stays at. He always interviews with the same service user, Fred (Participant 6) and is supported by a staff member. The most people he's ever interviewed in one day is fourteen. He said that he interviews every week on Thursdays, and interviews take place at Brook House in an L-shaped room which is very warm. David said that he likes Brook House because it is tall and has various other businesses working from the office block, and it is within walking distance of his house. He knows the people in the team well and has known them for a long time. He says that his psychiatrist is a "funny guy" and that he once saw his epilepsy nurse's motorbike. He also called the receptionist a "funny lass" and mentioned that she had made him a latte, which he drank during our interview.

David told the story of the first time he interviewed. He was asked to take part by a member of the community learning disability team (CLDT) to take part. The staff arranged a date

through his parents. On the day, he walked to Brook House with his dad, saw Fred and then they “cracked on” with the interviews. David felt “really, really, really inspired” when he was selected to be an interviewer. It felt good to be picked and that he wanted to do more of it.

They interviewed five or six people. David was “half nervous, half OK”, and he said that feeling nervous on the first day was the worst thing about his experiences of being an interviewer. The most nerve-wracking part was the first few hours when he was getting prepared for the interviews by getting the questions out and the drinks sorted. After preparation was complete, they waited in the room for the interviewee to arrive and everybody introduced themselves. After this, David said that he “really got into it” and was “steady as a rock”. David and the other service user asked two questions each, which the interviewee answered “straight on.”

Questions are chosen by the staff, but David and Fred swap the questions around sometimes. David gave an example of a question he asked: “why do you want to work with someone with learning disabilities?” He said that their role as interviewers was to “listen to the answer, take it in and store it there”. They then ask any other questions they might have, which David calls “spare questions.”

At the first interview, interviewees gave information about places they’d worked and the type of work they’d done in the past, in detail. They were also asked to give a presentation on Invictus Sports, the recent athletics event devised by Prince Harry for people in the armed forces who got injured in the war in Afghanistan. During this presentation interviewees brought artefacts of the games, gave out handouts and showed clips of the games. David said that he still had one of the handouts at home. At the end of the interviews, someone said

“thank you for showing us this and have a nice day”, and then the interviewee went outside and waited.

It was then time for lunch. The team had provided food which they ate in the interview room. The team had provided David’s favourites: egg and cress sandwiches, prawn cocktail flavoured crisps and coffee. At the end of the day he said he felt that he wanted to burst with excitement, and that he “nailed it”. On his second week of interviewing, they interviewed thirteen people. He said this was “brilliant” and that he was “definitely steady as a rock.”

David described what happens after interviews. They score interviewees out of five across several ‘targets’. After scoring, they think about who is suitable for the job, and who needs to be more equipped. David and the other service user have a “little debate” with the staff about who was best for the job. The staff team then decide who gets the job.

David is usually generous with his scoring, and talked about how this was important to him. On one occasion he gave a lady all fives because he liked pretty much everything about her and she “impressed” and “stunned” him. In particular, he liked that she gave simple, straight answers. Fred gave her a mixture of scores because he was “in the middle”, but David is “not that harsh” and usually gives someone higher scores than Fred. There has never been a time when he has given a very low score, and even if they were really bad he’d still give them a score of two. He told a story of an occasion when someone was disorganised and forgot their handouts. However, he was kind and gave her a four all the way down.

Last time David and Fred interviewed, they were supported by a speech and language therapist. In the past a home manager has helped them for social services interviews. Staff are

there to help Fred to ask questions if he was struggling, but David has no problem asking the questions. When asked about who he thought was the better interviewer, he said that he feels he is “one step ahead” of Fred, which feels good, although said that he is “with him, not against him”.

David thinks that the whole idea of SUI in interviews is “smart” and “brilliant”, and feels that whoever came up with the idea of interviewing people is a “smart person”. He feels that taking part is a good thing because he likes being part of giving people paid jobs that they need. He said that he likes everything about being an interviewer and is not aware of a thing that he doesn’t like. He would encourage other to get involved in interviewing. He also thinks that being part of the team for the day is “really, really good.” He told a story about an occasion where he interviewed with the manager of his respite service and then went upstairs afterwards to have lunch with her in the office area. He is not usually allowed upstairs in the office area, and this was the first time he had been there. It was also the first time he had ever eaten lunch with the manager. David said that these two things (being part of the team and having lunch with the manager) were the two best things about being an interviewer. He now feels like the team all the time.

David talked about the importance of pay because it enables him to buy things he likes, such as repairing his chain for his dog tag, computer games, DVDs and CDs. He said that he recently cracked the screen of his mobile phone and had to pay £150 to repair it. His dad controls his money to help him to save up “for holidays and stuff like that”. However, his phone was insured. David said that he was paid £25 last time he was an interviewer, but on other occasions has been paid as much as £35. He feels this is really good money. He also gets money from a supported employment scheme, his DLA and from interviewing.

David said that he felt proud after he had been an interviewer, and it made him hold his head up “Like an ostrich”. He struggled to describe the feeling verbally, so instead mimed being injected by something then suddenly standing up straight, moving his hands in a “come here” gesture and saying “bring it!” He repeated this mime several times. This appeared to be demonstrating that being an interviewer ‘injected’ him with confidence, energy and a feeling that he could handle anything. He said this feeling lasted a long time, and he still has passion inside him now from the very first time he was in interviewer. He said that “it stayed with me...it got a hold of me”. He described it as “like a feline has been brought back from the darkness”, but that it felt “good dark”, like “power, passion” or an “ultimate feeling”.

#### Emily (Participant 5)

It took two attempts to interview Emily. On the first occasion we had arranged to meet but she got into an argument with her staff and so did not turn up. She got quite upset because her home manager said that she needed to be accompanied by a staff member when she came to our appointment, despite being independent enough to use public transport on her own and wishing to meet with me alone. It was unclear why staff had decided this. She got very angry about this and started to show some challenging behaviour on the bus. We therefore had to reschedule our interview to a few weeks later. She arrived at this interview alone. Emily was quite tired in our interview and yawned frequently. However, she said that she was “alright” to do our interview.

Emily found it quite difficult to remember much about being an interviewer because it had been a long time since she had done it and “it’s not really that important” to her. She did remember that being an interviewer was “quite good” and “felt good”. She could not recall

how she had become involved in being an interviewer, but she had been an interviewer quite a few times. As an interviewer she met with quite a lot of people and had to ask “all sorts of questions” and then said who she liked and didn’t like. The last time she was an interviewer was at least two years ago, when she was still living at her old residential service. She also had some recollection of interviewing for NHS jobs at the community learning disabilities team.

Emily recalled that she did a series of interviews for jobs for care staff at her current residential service, Perry Avenue. This was a newly built service. Some staff at Perry Avenue, including the manager, were previously working another residential service and were transferring to Perry Avenue, but a number of new staff were also hired before the service opened. Emily moved into the service in January 2013, although she was originally meant to move in before Christmas 2012. She did not know why there was a delay.

All of the new residents of Perry Avenue were interviewees, as well as one staff member from Emily’s previous residential home, who was helping. Interviewing was quite hard because they had to get “the right staff”. Emily said that the right staff were nice, and so it was quite a big responsibility to pick staff as the wrong staff “wouldn’t be very nice.” However, she thought she picked OK.

Emily said that she now has a new key worker, Helen, as she didn’t get on well with her previous key worker, Claire. Claire had been Emily’s key worker for about a year. She became her key worker after the last one left. On the Saturday prior to our interview, Claire was talking to Emily about taking her medication. Claire was a “bit rude” and kept saying things like “what?”, and Emily didn’t like the way she was talking to her. Emily therefore



spoke to the manager, who said that it was about time she had a new key worker. Emily felt that it was better that her and Claire stayed well clear of each other, although Claire does still have to support her. Emily didn't know how she felt about that. Emily hadn't interviewed Claire. She also hadn't interviewed Helen, as Helen wasn't around while the service was being set up. However, she thinks she interviewed the manager.

Emily does other things outside of interviews. She does her shopping on a Wednesday and occasionally goes to a local Costa or a bowling alley with another resident. She sometimes sees her family – she went to a garden centre the day before our interview with her sister, and went food shopping with her dad. Emily's dad recently bought her a new desktop computer to replace her laptop, which broke so her dad had to take it away. Emily watches DVDs, uses the internet and plays music. She also plays games such as “Purple Place” (a game where you make cakes) and mah-jong.

Emily has worked at a local supported employment scheme for several years, but has given up half her days because she had problems with a particular service user and a staff member there. She said that she kept arguing with the staff member, and had problems with the service user earlier this year because he kept talking about relationships inside of work. One of the rules of the supported employment scheme is that service users aren't allowed to talk about relationships inside of work because it upsets people. Emily said that his talking was distracting and was disturbing her from her work because she couldn't concentrate.

Since Emily started, she used to change her days “a hell of a lot” under a previous manager – she started working one day per week, then went up to three days, then dropped to two days and then increased to three days. Now people are getting fed up with her changing her days

all the time. Emily said she can't really change her days again because the manager of the supported employment scheme won't let her.

Emily's mum and an old member of staff believe that Emily is getting a bit bored at the supported employment scheme now, and email thinks that's "a bit" true. She would like to change jobs, but doesn't know what's out there. She would like to work at a local Sainsbury's, but she would have to do day shifts because she can't do nights or evenings, as her dad doesn't allow her to come home in the dark.

#### Fred (Participant 6)

It took some work to organise a meeting with Fred. We had originally arranged to meet at an NHS site, but his staff team were reluctant to facilitate him meeting with me because it was on a day when he should have been at his day centre. This was resolved after I discussed it with the home manager. Unfortunately, on the day of the meeting, the home's car broke down so a meeting had to be rearranged. This time, Fred was happy to meet at his day centre. We were placed in a room where medicines are stored. During the course of the interviews, we were disturbed three times by staff members.

Fred lives in a social services-run residential home with 5 other residents. Fred goes to the day centre on Mondays and Thursdays. He also attends a supported employment scheme on Tuesdays and Wednesdays, where he works as part of a team delivering trays of sweets to local businesses. He has Fridays off but likes to keep busy because he gets bored when he stays at home.

Fred says that the supported employment scheme is “not bad but it’s not good.” The main problem is that it’s a small place with quite a few people, so there’s no room. Fred wants to sit on his own and do his own thing, but “everyone’s on top of you”. He finds the day centre more relaxing. At the day centre, Fred usually sits and does artwork with his girlfriend, who he thinks is “very pretty” and likes being with. They’ve been together for two years, and “haven’t separated yet”. He likes to do artwork at the day centre but he also likes to get smartened up and go and do different things. Fred used to go to Brook House to do art and craft such as painting and collage, and did all of the artwork that was on display in Brook House. Staff were trying to make sure he did more there, but it was cancelled because there wasn’t enough money. Fred feels disappointed about this because he wants to do other things at Brook House.

He has been an interviewer Brook House on two occasions. Staff let him do the interviews because he knows what to do and others don’t. This makes him an “important chap.” In order to be a good interviewer, you need to be able to listen without shaking, keep calm and be relaxed. The best things about interviewing are dressing smartly and doing things on his own. Fred dresses smartly every morning (on the occasions we met he was always wearing a suit and tie), but when he interviewed, Fred had a shower and wore a special outfit because it was a special day. He wore a black jacket and trousers, white shirt and black tie. He dresses smartly because he feels that it to make interviewees look at him across the table and not feel nervous. Fred makes his own way to and from the interviews using a cab and pays for it by himself. He makes sure he gets there on time. Doing his own thing in this regard makes him feel good.

Fred was initially picked to be an interviewer specifically because staff thought he would be good for the role. His manager (the manager at his residential home) recommended him to someone. She then asked Fred if he would like to do it and he said yes. He was pleased to be picked and was really excited and happy on the day. He also does interviews at the civic centre. When he did interviews there, they asked him if he wanted to do interviews full-time because he was really good at his job, and Fred accepted.

The first time he interviewed at Brook House, they interviewed four people. Interviews took place in a “special room” on the second floor, and staff and service users sat on the same panel. Fred interviewed jointly with David (Participant 4), and they took it in turns to ask questions. Interviews took place across four days, on Mondays and Tuesdays between 12 and 3. Interviewees gave presentations on “disabled Olympics” at Crystal Palace, which he found very interesting. Fred described a female interviewee’s presentation and interview. Fred said that it was a really good day and he enjoyed it. She was not offered the job, but Fred said that it was very interesting and enjoyed asking questions.

He was a bit shaky at first and was scared of being in the same room as the other interviewees, and felt hot and dizzy. While interviewing he spilt coffee all over the table by mistake, because he was feeling nervous and his nerves jumped in his arm. Fred also got a bit giddy and shaky towards the end of interviewing because it was hot in the room. He gets giddy spells now and then when he gets too nervous, but feels fine afterwards. He had to stop interviewing to eat some dinner. He felt better afterwards but it “would’ve been bad” if he’d carried on. He came back to finish interviewing the same day, but interviewed only two people. The fact that it was too hot and he came over giddy was the worst thing about being an interviewer.

Fred was distracted by David's behaviour during interviews and didn't want to do them with him. He said that David was "putting the people off" by asking "silly questions" like "what's your favourite hobby?" or "what's your favourite job?" He was also cracking his knuckles, biting his fingers, "fidgeting all over the place" and swore at a woman. The staff member who was supporting them told David off, and David had to leave the room for a little while. Fred, on the other hand, asked "proper questions" like "how would you like to work with disabled people?" As a result, interviewees gave Fred a "proper answer". He said that he was able to act differently from David because he was "keeping calm." The staff looked also "looked after" Fred more than they did with David, and said that Fred was more polite than David.

Interviewees were nervous, and started shaking and trembling. After interviewees left, he had to give interviewees points according to how good or bad he thought they were. After scoring participants, Fred said that the staff at Brook House said how well he did. Two of the women at Brook House said that he was so good that they were taking him out for dinner. They took David too. He said interviewing was the "best day ever" because he got free coffee and dinner. One of the staff members wrote something down about how good he was, which she passed on to his home manager. His home manager said "You're a clever man." Staff at Brook House also rung up the staff at his home and said how good he was. The staff at his home said "well done". The amount of praise he received made him feel "very happy." Doing interviews makes him feel clever and proud of himself. He said his "heart feels like it's excited." The thing that makes him feel most proud is sitting and listening to people. He said that interviewing was the best job he'd done as it was "interesting", "exciting to do" and he got paid £20 for doing it. When staff made him a coffee, they allowed him to walk

round Brook House with them to make it. This was a part of Brook House that he is not usually allowed to enter, so it was strange. Fred has “a load of friends” in Brook House, such as the secretaries. He has also met the manager of Brook House and had a conversation with him about where he lives.

On the second occasion, a staff member at Brook House called his home manager and asked if he would like to do it, and he said yes. He was interviewing because someone in the team was going on maternity leave. Interviews took place in a big room at the end of Brook House, with a big table that everyone sat around. This time, they interviewed four or five people and, unlike the first interview day, the staff and service users sat in different rooms. David was not able to attend on the second day of interviewing, so Fred was the only service user representative. The questions were different this time, and the answers he received were “very clear.” One of the interviewees used a tablet to give a presentation on her favourite hobbies and sports.

Afterwards, Fred went away and the staff gave interviewees marks and selected who they were going to give the job to. One had a score of 25, and another a score of 40. Staff marked down their scores on paper, and Fred was very pleased because the one he picked was selected. The successful candidate was quite young but she was good. Although Fred was not directly involved in the final decision, he felt listened to. He said that he felt more listened to because he was on his own, and generally prefers to do things on his own because it makes him feel better.

It felt boring after interviewing and Fred wanted to carry on. He was not happy when he had to go back home as he wanted to do more. Fred said that he hadn't done interviews in a while

and is not sure if they'll do some more this year. This feels "boring", and he wishes he could do more interviews. If he is needed to do interviews again he would, and staff said they would phone him (either at home or at work) when they need him.

Outside of work, Fred does various things. He goes food shopping, does his own shopping for Christmas and goes on outings. He recently went on a chair lift across the River Thames but dropped his camera and smashed it. He said that just slipped out of his hand and it wasn't his fault, but he had to get a new one.

Fred likes playing computer games like Solitaire, Candy Crush and Super Mario. He has a Wii, but it's "going wrong". He also has an Xbox but no longer wants it because he has got bored with it. He is hoping to sell the Xbox and Wii to buy a DS. Fred also likes to attend the AGM at his local Mencap, and it is his job to attend several Mencap meetings in the region. He usually meets a group of people at the local Mencap office and then they all go to the meetings together by bus. He enjoys sitting and listening there, but sometimes gets bored. Of all of the things he does, he thinks that interviewing is the best because it keeps him busy and makes him feel good. Fred also likes taking part in research, and said that if I needed him to do more interviews for my study he would.

#### Graham (Participant 7)

Graham lives on his own. I knew from conversations outside the interview that he used to live with his mum, but that she had died in the last few years. He has a sister who he sees regularly, and he attends a day centre, which is where our interview took place.

Graham said that he liked interviewing and it made him happy to do it. The best thing was meeting new people, which was easy and fun, but a little bit hard the first time he did it. Graham is sometimes, but not always good at meeting new people. He could not think of a bad thing about being an interviewer.

He had been an interviewer at least four times. He started interviewing at the old CLDT offices, as part of a panel of five service users. He'd also been asked to interview after the CLDT moved to new premises, but this time he was asked to do it on his own. One of the posts he interviewed for was a psychologist. He found that part of the role was to calm people down so they could talk. He talked to interviewees about the job and asked why they want the job and why they want to be a psychologist. People gave "all different things" for answers, although Graham could not remember specific examples.

He had trouble remembering details of the first time he'd interviewed because it was a long time ago, at the previous CLDT offices (these have now shut). He said that he thought he was approached by Bob (a staff member at the CLDT), but it may have been another staff member. When he was asked to be an interviewer, Graham thought "Why me?" but jokingly said that he had a hunch that he was selected because he likes talking.

He was a bit "scared" and "worried" about interviewing, and was nervous on the day. Interview day was really nerve-racking, and his hands shook, but that when interviewees came into the room his hands calmed down. He said that because interviewees were calm in the seat, he got "calm at the same time". He likened this to how calm I was when I walked in. Talking to other people was therefore "easy". He managed to do the interviews without forgetting anything and without making mistakes.



Graham took interviewing quite seriously and wanted to get it right. He prepared for the interview day by practising all through the night (until he went to bed), then in the morning read through the notes again before he went in. Graham said that with him things can go “in one ear and out of another”. He can sometimes know what he needs to say the night before, but in the morning he might forget, which is why he needed to practise some more in the morning. Practise involved doing a load of talking and learning how to read the paper notes that listed what he needed to say to interviewers. He practised on his own. He needed to take his time to read through it, in case he forgot what to say on the day. He wore his posh clothes (shirt and tie), and, unlike Bob, did not wear jeans. No other service users seemed to dress up. He said that he made himself “a bit more posher” [sic] to help the people he was with to calm down with him.

He wasn't sure why he was nervous at first but thought it was because it was the first time he'd done interviews and because he never met the people involved in the interviews. He found that all the other times he'd done it he was “fine”. Graham said that being nervous was “at first” because he's not normally nervous, although it depends on who he's with and who's doing it too. When asked who it's easier to do interviews with, he said that it “doesn't matter”.

There were five service users on the interview panel. One member of CLDT staff was also there to look after them. Interviewees met with the service user panel first, and then went to a main panel, which consisted of two staff members. He couldn't remember specific questions that they asked, but could remember that he asked one question that he always asked: “why they want the job for” [sic]. He thought he interviewed three people all in one day, which felt

OK. Graham thought that all of the interviewees were good, and didn't know if he thought one was the best. After interviewing, the five people on the interview panel got the names of the interviewees and talked amongst themselves about them. They gave points to each interviewee, then a staff member went back to Bob to talk about it and see how many people they wanted to hire. Bob and the staff decided amongst themselves who they wanted to give the job to. They made this decision either on that day or the day after. Graham said that it didn't matter to him that the final decision was made by the staff, but he felt he had a little bit of say in who was chosen. He said that he felt listened to and that the opinions of the service user panel were taken on board. Overall, he thought being an interviewer was a good thing for all of the service users.

After the CLDT team moved premises, Graham interviewed on his own, rather than as a panel of five service users. He said that knew what he needed to do and say so didn't need to practise. The first time he did this, Bob picked him up from his house and took him to the new premises (Brook House). They then had a cup of tea or coffee and then started interviewing. He said that he was nervous when he walked into the new building, because it was the first time he had seen it. He was also a little nervous in case he said something wrong or forgot what he needed to say, but generally found it found it much easier. Interviewing on his own felt more relaxed, so Graham was able to laugh at himself and anything else. Interviewees were calm themselves and all three of them laughed through the interviews. Graham said that this is good for them all, especially himself. He said that even with the laughing and more relaxed atmosphere, he still got the same answers about why they wanted the job.

The interviews had the same structure as in previous interviews. Graham was on a panel with a staff member. Interviewees met with the panel that Graham was on, and then afterwards sat outside waiting for the main panel. While interviewees were waiting, Graham and the staff member talked about the interviewee on their own. They had a list of names of people coming in, and they gave interviewees points which they wrote in a box alongside their names.

When all of the interviews were finished, Graham and the all of the staff (including the main panel) went back to the office together to see how many points interviewees had and to talk about who they liked. This differed from being on a panel with four other service users because they weren't involved in the final discussion about who would get the job. At the meeting, they sometimes agreed on whom they liked best, but other times they didn't. When there was not agreement, they looked at the points and gave the job to whoever had the most points. Graham said that it felt easy to give jobs to people. Graham felt more involved when he was on his own. He felt that he had more say; staff listened to him more and asked his opinions.

When there were five service users they didn't laugh. He found it harder to do interviews with four other service users was hard because they had to take turns to say what they needed to say. Graham joked that this was especially hard for him because he can't stop talking and so found it hard to stop to allow others to ask their questions. On his own, because he was asking all the questions, this was easier. Asking questions with four other service users also meant that it was easier to forget what he had to say, whereas on his own he "always go[es] through [his] head more". He prefers interviews where interviewees, he and staff all say what their names are. While they do always give names with five of them, this is hard.

Graham was told that he was selected to interview on his own because staff pulled his name out of a hat. He was selected for subsequent interviews on his own because he had done it before. After interviewing on his own, Graham felt pretty good about himself. He used words such as “easy”, “fine”, “happy and proud”. He was happy that he had done it right, and it was easier to do interviews the second time. He doesn’t mind doing it again. Graham would recommend interviewing to other people, but if they do it they need to do it right and practise what they need to say.

Graham said that he felt a bit more confident in himself after being an interviewer, although this was only limited to interview situations – he does not feel more confident at his day centre, for example. He had noticed that he is a little bit “more friendly” since being an interviewer, and told a story about how he often lets others get on the bus before him, especially when it is cold or raining. In the summer he always walks. In part, he put this change down to talking to people in interviews. He talked about his experience of being an interviewer with his mum, but not with anyone else, but wasn’t sure why.

## Appendix F: Abridged Research Diary

29 November 2012

Today was the research fair, so it seems like a good time to start my research diary. Seems really early to be planning about my MRP, but I suppose it's good to get the ball rolling. Some of the projects sounded really good, but I already had a few ideas of my own. My last supervisor had recommended that I get thinking about my MRP before I even started the course, so I suppose it's been playing on my mind a little. I'll have to give it more thought.

11 December 2012

I have been thinking a lot about my research idea and have narrowed it down to one of two: either looking at the decision-making process around CTOs, or something about involving people with learning disabilities in interviews. These might seem like wildly different topics, but I'm quite interested in power imbalances.

I've really got thinking about CTOs after a client on my current placement who has recently been placed on a CTO, and from discussions in the weekly team meeting, there was a clear and shared impression of him being a high risk of harm to himself. I'm interested in the processes that lead teams to place some individuals on CTOs but not others.

With regards interviewing, I got the idea after discussions with my old supervisor. We often had long, critical discussions about involving people with learning disabilities in interviews. Sometimes it feels that people with learning disabilities are involved because it seems like a good idea, but I can imagine that sitting in an interview and hearing lots of technical information being discussed that I don't understand might feel isolating.

I've not thought out the nuts and bolts of how this idea might be researched as yet, but I'm going to approach some potential supervisors to flesh it out. Haven't yet decided which one I'll do.

4 February 2013

I've been back and forth about my decisions for which research project to do. After various conversations with colleagues and potential supervisors, I've decided to go with exploring people with learning disabilities and interviews. Although the CTO project is interesting, I have really struggled to find a supervisor and to whittle the topic down into a manageable question.

My current thinking is that I will do a discourse analysis on the experiences of interviewing from perspectives of service users and services. It seems like service user involvement has a lot of power dynamics at play and it would be interesting to unpick these a little.

1 March 2013

Had a meeting today with my external supervisor. She's suggested doing a narrative analysis instead of discourse analysis. This seems to make sense. Through our discussions, it feels like

understanding the discourses around service user involvement is important, but before we can look at that question, we first need to ask “what’s it like to be involved in interviews?” Narrative analysis suits this better.

22 March 2013

I’ve been thinking a lot about whether to do discourse analysis or narrative analysis, and a lot of reading around the two approaches. I think narrative analysis is the way forward. Still not 100% sure on my research question yet, but I’m interested in the idea of narrative identity – the ways in which we construct our identity from our narratives. Seems like this might be a fruitful avenue for research.

31 May 2013

I’ve submitted my MRP proposal document. I’m pretty happy with how the project is shaping up.

19 June 2013

Had my MRP proposal review today. They seemed to like the project in general but I need to work on the language I’m using. Qualitative is relatively new to me, and I think I’m being too positivistic with my language. Some of the comments seemed a little tricky. I intentionally kept my interview schedule brief because I wanted to have totally unstructured interviews to avoid leading the interviewee too much and therefore shaping the interview. This, to me, is how narrative interviews should be. However, the reviewers thought differently. I argued the case but I think that I will need to develop the interview schedule a little.

5 July 2013

Just found out that my internal supervisor is leaving! I’m quite sad about this. We get on very well and I was looking forward to working with her. From the perspective of my project, I guess it’s good that she left early in the process rather than at a critical stage. However, since my external supervisor is also going on leave in later this month, I’m feeling a little abandoned!

19 July 2013

Had my MRP proposal amendments rejected. They want an even more detailed interview schedule! I’m feeling quite frustrated about this, but I’m meeting with my external supervisor (A new one – she’s covering for my main external supervisor while she goes on maternity leave) on Thursday and can talk about this.

9 September 2013

Approval given! I now have to fill out the NHS ethics form. Feeling quite daunted at the prospect.

31 October 2013

Met with my new internal supervisor for the first time. It’s tricky having to change supervisors while in the midst of my NHS ethics but I think it will be OK.

16 November 2013

I've just submitted my REC form for NHS ethics. This has been a long a stressful process! The good news is that the turnaround for proportionate review is fairly quick, so I should be able to get on with recruitment fairly soon. From conversations with my external supervisor, I don't think I'm going to have too much trouble with recruitment. There are already at least half a dozen service users who have been interviewers and who would probably be willing to participate. With any luck.

3 December 2013

Had feedback from the REC. They are requesting some amendments but nothing too daunting. They seemed concerned with capacity to consent and with providing information. Both seem very reasonable points. I'll address these and resubmit as soon as possible.

16 January 2014

Ethics approval has been given. Now I need to start recruiting.

17 February 2014

I've just received an email to tell me that my internal supervisor will be changing again because a staff reshuffle. I must admit I'm quite frustrated about this, but I suppose it's happening at a good time – I've got ethical approval but I've not yet started recruiting.

24 April 2014

I met with my new supervisor today. I feel I need to start making getting going with recruitment now, and this meeting has been a helpful nudge.

29 May 2014

Today I carried out a pilot interview with a service user who had had some experience of interviewing. It was really helpful to do this. I don't feel too confident about my capacity to do narrative interviews as I have this notion that there is a special technique that I'm not sure I understand. However, during the interview it felt entirely natural and comfortable. I think I'm feeling more confident after this interview, but I've agreed to give a portion of the recording to my internal supervisor so she can listen to it and offer me feedback.

5 June 2014

Attended a meeting today to start recruitment in earnest. This was a Service User Involvement meeting at the NHS trust I used to work at. I used to attend this meeting and I know most of the people there. They were very helpful and have several people in mind as potential participants. It was interesting to talk about my project with people other than supervisors. I'm still not sure I fully understand narrative analysis, but these conversations help me to think more about it. It was also interesting to attend this meeting again, as it reminded me of why I started this project in the first place.

18 July 2014

I had a bracketing interview today with another trainee. This was really helpful. She asked lots of very incisive questions that helped me to really delve into my position and think about what I might bring to the interview. I don't think I'd quite realised how strong my views on the rights of people with learning disabilities are, and how passionate I am about inclusion and involvement. I am more aware that I have a particular interest in power (it's reminded me that this was the reason I got into this project in the first place!), which is a perspective I might end up bringing to the interview and data analysis. I need to be aware of this when I go into interviews.

1 August 2014

Interviewed my first two participants today – Andrew and Brenda. I interviewed them at their Mencap office. Andrew came across as quite a playful and funny man. He made a lot of jokes, particularly after the interview. I found it difficult to interview Brenda. She favoured closed questions and struggled to recall things. She was a middle-aged woman with Down syndrome and I suspect she was in the early stages of dementia, and she sometimes struggled with questions that involved “what” or “why”. Brenda was accompanied by her support worker during the interview. This was helpful, and the support worker was good at stepping back and only intervening when Brenda appeared to be struggling, but I wonder if this changed the context a little and therefore the narratives that Brenda told.

Particular points that resonated with me in the interviews were that Andrew made a comment about being given a key fob and feeling important but then “coming down with a bump” after interviews because it was back to ordinary life. I've not thought of this before, but being involved in interviews is quite an infrequent occurrence, and this made me wonder about how that is experienced. He certainly sounded a little sad about this, and I wonder how other participants will describe this. I also noticed how enriching the experience was for him. Andrew has a lot going on in his life – he's married and he's becoming a supervisor in the charity shop he works at. The interviews nevertheless seemed important, particularly because Andrew and Brenda were paid minimum wage. This had a symbolic importance and felt like a “real job”. Both described this as one of the most important positives of SUI. However, as with many people with learning disabilities, there was a problem around not being able to work too many hours because they will lose their benefits. Andrew and Brenda's money for doing interviews has to be held by Mencap and paid to them at £15 per week. This is something I've always found absurd. Perhaps that says a lot about my position regarding rights and inclusion for people with learning disabilities.

I was also struck by the role of the support worker in interviews. She said that she used to sit next to the service users but found that people were often talking to her rather than to Andrew and Brenda. Consequently, she now sits behind interviewees, but interviewees seem to get confused about this and still turn around to try and talk to her directly, mistaking her for part of the interview panel. Brenda talked about her frustration at people who do not speak directly to her, and this emphasised that interviewing can have a negative side that I don't think is always appreciated by services, who seem to see SUI as an overwhelmingly positive thing to do.



After the interview I sat with Andrew, Brenda and the support worker and we talked informally for a while. One of the themes of this post-interview discussion was about professionalism. Andrew was talking about how in the interview you have to be serious and ask questions. The support worker mentioned that Brenda has a lot of empathy with people who seem to be nervous or struggling in interviews, so when interviewees don't answer the question properly, Andrew tends to be quite serious and professional, whereas Brenda tends to want to console interviewees. Andrew also said that sometimes interviewees don't read the interview paperwork properly and bring presentations on memory sticks instead of printing them and bringing paper copies. They get frustrated because they thought they would have access to a laptop. It seems that he positioned himself as competent and smart relative to interviewees who were sometimes described as disorganised.

We also talked about why Andrew and Brenda were specifically selected to be service user representatives. The NHS trust that approached Mencap and asked them to recommend a couple of people. Their support worker said they are in different "groups" – I'm not sure what that means but assume it means that they don't spend that much time together outside of interviews.

Overall, I found interviewing Andrew and Brenda a really interesting experience. It was perhaps a little too heavily focussed on the practicalities of interviewing, rather than their experiences. I will need to be careful of this in future interviews.

8 August 2014

Today I interviewed my third participant, Colin. As I arrived for the interview, Colin was about to walk out of the door. Despite speaking to him the previous week and asking staff to make a note of our appointment in the home's diary, no one reminded Colin that I was coming. I was a bit annoyed with the staff because of this.

I think I might have come into this interview thinking (naively) that Colin's interview would be broadly similar to Brenda's and Andrew's. To be honest, he told me an awful lot, which not only added weight to my early hypotheses but also made me think about other things I'd not yet considered. I was really struck by Colin's description of feeling powerful during interviews – he mentioned feeling "like the boss" or "in charge". I was also really struck by was that he had a story that he'd told three times. It seemed very important to him. This story was about a question that he'd introduced himself that he used to determine who was suitable for the job. It took me until the third mention of it before I really noticed this and asked follow-up questions about it. Maybe this was because I initially thought "I know this story, no need to tell me again." However, I realised that this was an important story to him and so followed it up.

I was also struck by way he talked about "life being worth living" after interviewing. I felt quite sad when he talked about his life before interviews, and he talked about feeling depressed and perhaps suicidal in the past. I think I hesitated about this and wasn't sure how far to go down this route of inquiry. Colin has set boundaries about things he didn't want to

talk about from the outset. He didn't want to talk about his current job as it was "secret", so at times it felt like we were dancing around the topic. On reflection, it felt that Colin had a great deal of control over the conversation.

I really noticed that I was specifically looking for narratives this time and this seemed to enrich the interviews. Rather than discussing practicalities of interviewing, I asked more questions like "what happened when...?" and "what did you do next?" This seemed to encourage Colin to tell his story from a more experiential perspective.

22 August 2014

I met with my internal supervisor today. It was a really useful meeting. We discussed the interviews I'd done thus far and had a conversation about the pilot interview I did a few months ago. It was really helpful to get some feedback, even if I'd already completed a few interviews. I think that the main thing I'll take from this discussion is that my interviewing style is better than I think it is, but that if anything I need to relax more. She noted times when I seemed to hesitate during the interview, and when I seemed to want to ask a question but didn't. When we discussed this, it seems that I am anxious about leading people too much and so I'm not allowing the conversation to flow naturally. I need to remember that narratives are co-constructed, so I need to have more input by asking questions to elaborate. Otherwise I may lose out on some of the richness of the narratives.

19 September 2014

I've been able to get in touch with two participants and arranged to meet with them next week for initial meetings. Both seem very keen to meet.

9 October 2014

I've now completed four interviews. Today I met with David. I really enjoyed meeting with him! I was particularly struck by how he warmed up as the interview progressed. Towards the end of the interview he became particularly energetic and was using mime and gestures to emphasise how strong he felt after being an interviewer. Interviewing seemed to be a very powerful experience for him. He described it vividly as something that gave him an injection of confidence that stuck with him long after he had finished.

I really noticed how he situated himself relative to the team. When I met him in the waiting room he was laughing and joking with the receptionist, who had made him a coffee. This was unusual, and demonstrated that he knew the team well. He also talked fondly of the people he knew. This also seemed to be a theme within interviews – I was particularly struck by a comment he made about how one of the best things about interviewing was that he got to eat lunch with the manager. He spoke about this with a kind of reverence, and it made me think of someone on a cruise liner talking about having dinner with the captain. It also brought to mind the culturally symbolic importance of "breaking bread" and I wondered whether the fact that he told a story of breaking bread with a team member signified his equal status with the team.

I was also aware that, unlike Colin, David was not concerned with feeling powerful. He said that the staff made the final decision on who was employed, and was fine with that. This contrast made me aware that David's experience was more about being part of the team and being friendly. While this was no less important or positive for him, it was a different experience and narrative.

16 October 2014

It's been a very frustrating day. I've been doing a lot of travelling and not been able to meet with any of my participants, despite having two booked in today.

One of my participants, Emily, didn't turn up today because she got quite upset and in the end went home. She was upset because, despite being able to travel on public transport independently, the home manager had insisted that she be accompanied by a member of staff to attend our meeting. Emily was that she got very angry on the bus. She phoned me and my supervisor several times to express her anger. While she wanted to meet with me, she said that she didn't want to come today because the member of staff was with her. Emily appears fiercely independent, and so she seemed upset at the idea of having to be accompanied. I was left feeling quite frustrated - it seemed that staff were telling her she needed to be accompanied by a staff member without good reason, and I felt this was not OK. In many ways this felt like she was denied her rights. I'm not sure what is going to happen next, but hopefully we will be able to meet at some point.

I also had difficulties with the staff team of another of my participants, Fred. I spoke to him on the phone yesterday and we had agreed to meet next Thursday. However, his staff team were perhaps being a little obstructive and difficult. During a conversation with a staff member yesterday, I was told that they weren't sure they could facilitate a meeting between Fred and me. The staff member said that this was because of staffing issues, but this seemed to be because they were being protective of him. I can empathise with this but nonetheless feel frustrated.

She suggested I speak to the home manager. I did so today – she said that he had to go to the day centre on Thursdays. However, she also said that he often tries to get out of going to the day centre because he finds it boring. I pointed out that I had given Fred a choice of dates, and he had chosen the Thursday so I wanted to try to respect his decision. The manager said that she would try to sort something out. I was perhaps a little blunt in this conversation, but I think I was frustrated because I thought that staff were perhaps being a little inflexible. I was annoyed because he had capacity to make decisions about meeting with me, had consented to meet with me and had chosen the date he wanted to meet.

I think the last couple of days have really got me reflecting on my position with regards to people with learning disabilities. I'm a fairly strong proponent of the rights of people to make a choice. To my mind, if a service user has made a choice to meet with me then it should be the role of staff to facilitate this as much as possible. In these cases, it felt like staff were being unnecessarily obstructive. Perhaps this is something that lies behind my wish to do this

research. I believe in the rights of people with learning disabilities to be involved in all aspects of daily life, and this has perhaps led me to question the role of SUI. The sense I have so far is that while some value it hugely, there also appears to be a flip side to this about going back to a relatively mundane life. I need to be aware of this because I'll be bringing these biases and perspectives to interviews and data analysis.

31 October 2014

Just finished interviewing Emily. What a tough interview. It felt like she was keen to meet with me because she wanted to get involved in the project, but that she didn't really have much that she wanted to say about her interview experience. She couldn't really remember her involvement and I got a strong sense that it wasn't really a significant experience for her. She struggled to recall what it was like, and couldn't really recall what she did other than that she asked questions.

Her narrative of being an interviewer was quite limited, but I suppose that's telling in and of itself. Every time we talked about interviewing, she got more quite, brief and vague. However, if we talked about other things like work, staff members or family, these were clearly more important to her. For example, she talked a lot about people who she doesn't get on with and got more animated. It seems that these things were more important in her construction of her identity, but interviewing just wasn't part of it.

With hindsight, I feel like I could have asked more pressing questions or chased avenues such as what it was like to interview her manager, but also got a sense that she wasn't interested in talking about interviewing and so I didn't feel invited to continue the conversation.

6 November 2014

Today I interviewed Fred. This has been a difficult interview, not because of Fred, but because of the constant interruptions. We met at Fred's day centre, and although I asked for a private room to conduct the interview, we were put in the room that also housed the meds cupboard. It was very noisy and we were interrupted on three occasions by people who wanted to get into the meds cupboard, and this really interrupted the flow of the conversation. However, we managed.

Fred was smartly dressed in a suit, and made a point that he always likes to dress smartly. He also made a point of this in interviews, and stressed that he takes interviewing seriously, unlike his co-interviewer, David. I also really liked the point that he made right at the end about being an "important chap". This felt like the overarching summary of his story – interviewing makes him feel important. My initial thoughts are that there are two things happening in his interview. First, being an interviewer seemed to be just one of many things to do in order to keep busy. He liked to get out of the house and be helpful, but had lots of other things in his life for this. Interviewing did give him a sense of value, however. He stressed that everyone said that he did a good job and seemed very proud of himself.

Second, like Andrew, Fred seemed to gain a lot from feeling part of the team. He talked fondly about knowing the secretaries and being able to access parts of the office that others

couldn't. I sensed that he seemed to be distancing himself from other people with learning disabilities and emphasising his specialness in this way. However, I'm not sure if there was anything specific about interviewing that generated this feeling.

Fred's narrative also had a bittersweet note, in that he said that he never wanted interviewing to end. He seemed to hint that he was a little disappointed because he'd not been called back in a while but didn't appear to want to say it directly and rock the gravy boat. Perhaps he didn't want to say a mean thing about the service, but I really felt he looked disappointed. Fred is not the first participant to have this reaction to interviewing, and I'm realising that interviewing is inevitably a sporadic and infrequent activity. I'm not sure that services are necessarily taking this into account.

20 November 2014

Unfortunately, one of my potential participants has had to drop out. He said that he works most days and only gets his weekly shift pattern a few days in advance. This has meant that despite multiple attempts we have been unable to find a mutually convenient date.

Throughout these conversations I've been struck by how inflexible his work appears to be and how worried he seems about requesting a day off. It doesn't seem fair that he gets his shift patterns at such short notice as he's unable to plan anything for the following week. It's made me wonder whether this would happen if he didn't have a learning disability, and it's crossed my mind that from my position of relative power (as an educated, intelligent man) I would be able to say that this is not good enough and demand more notice for my shifts. I suppose I would also feel more able to leave the job if I was unhappy, but I'm aware of how difficult it is for people with learning disabilities to secure employment.

11 December 2014

Just finished interviewing Graham. I feel like I was doing a lot more work in this particular interview, and perhaps a little more leading in my questions. For example, I may have made assumptions about how he was feeling and asked closed questions that might have been leading. I feel that this was necessary with Graham, however, as without these questions he tended to stick with answers like "it was easy" or "I was nervous". I wanted to discuss the nuances of his experience, and so I felt I needed to ask more direct, closed questions to delve into this. This isn't ideal for a narrative interview, but it seemed unavoidable.

Graham seemed to really enjoy being an interviewer. I didn't get the sense that he valued it as a piece of user involvement or anything identity-changing or life-changing. It was more something to that was enjoyable to do. Unlike other people he didn't really talk to anyone about his experiences, and his narrative did not seem to be about being a boss, importance or decision making. There appeared to be something about how he found it better when he had more of a say in interviewing, but that was more subtle. This was interesting because it felt like a slightly different angle on the experience. This might be a good starting point for thinking about narrative themes.

8 January 2015

Now that Christmas is over, it's time to really crack on with my write up. I've been worrying about deadlines a lot recently, and I think I can allay some of that anxiety by getting some work done. I've made a start on Section A: I have identified my papers and developed my question. I'm looking into the experiences of service user involvement from the perspective of service users. I've been really surprised to discover that there are no papers at all that explore this for people with learning disabilities. I suppose that says a lot about how people with learning disabilities are positioned in society – it's not the first time that I've found a dearth of research with people with learning disabilities. Perhaps that's part of the reason I wanted to do research with this client group.

19 March 2015

Met with my external supervisor to go through my data. I have now finished my analysis of the transcripts. This has been a long, arduous process and I've struggled because I feel I want to do justice to the stories that people have told. After discussing this with my supervisor, I think this might be because of my own biases about wanting to hear the voices of people with learning disabilities and to make others hear them too. However, I have a tight word count, and so just don't have the room to tell all seven stories fully. It's been quite a dilemma – I can either tell all seven stories but keep them very brief, or tell just a few stories to illustrate my findings and try to use the extra space to really do them justice. I think I might opt for the latter, but this feels uncomfortable because I feel that I'm essentially silencing some of my participants by not telling their stories. I'm not sure I can win either way.

The meeting itself was an extremely helpful space for me to air this dilemma. It has also helped me to really tie together the narratives. There seem to be three types of narrative, and I think I'm going to use this as the basis for my results section. I've got the next month off placement, so I can really concentrate on my write-up.

8 April 2015

I've finished my Section B draft. Now I can concentrate on amending Section A and then I will pull the whole thing together. I'm feeling relieved at having got this done, but I know I still have a long way to go before I can relax.

16 April 2015

Just adding the finishing touches to the document before I get it bound tomorrow. I'm not sure I've ever committed this much time and energy to a single project. I'm quite proud of the finished article!

### **Appendix G: Initially Extracted Narrative Themes**

Andrew

Narrative tone – Progressive – emotional tone of relaxed confidence, contentment

Type of story - One of competency and independence – embodiment of Valuing people/SRV

Themes:

- **Competence and expertise** – First time was hard because I didn't know anyone I know role like the back of my hand, done it many times. I have memorised some of the questions. Told story about how he determines who's good for role. They called me back because I was good, managing challenges of the role.
- **Inclusion** – at one point trust didn't listen, now they do. Importance of connection between staff and service users, and having more SUI. Political connotations.
- **Agency** – he and colleague get heads together to come up with questions, tailor interviews to roles, etc.
- **Power** – feels like the boss. However, ultimately powerless as called up by staff?
- **Group membership/valued role/social identity** – given key fob, gets paid. Talks about role as “job”, others as “colleagues”
- **Loss** – for one special day but then back to reality
- **Negative aspects**– didn't know what to do at first when approached in street
- **Personal changes** – more opinionated, self-confident and upfront.
- **Interviews as just one factor of many** - marriage, job, Mencap all have a role in identity. Speech pace picks up when talking about his volunteer work. McAdams (1987) “Identity is a life story”, i.e. not just based on one event.

### Brenda

Narrative tone – Stable. Told in a matter of fact way.

Type of story – A story about the importance of being listened to? Taken-for-granted competence and power?

Themes:

- **Competence** – very experienced and “very good at being an interviewer”; comes up with questions herself and chooses which questions are asked. Very clear on this, as if it’s taken for granted. Perhaps clashes with my own prejudices, as assumed that she might not feel competent?
- **Important role** – dresses posh, has a shower. Important to get there on time, practise
- **Power** – language used (e.g. “we tell people to go and wait outside and wait until we are finished”; “we don’t give them the job”), don’t give jobs to people who seem bored or worried. Positions self as powerful compared to interviewees
- **Listened to** – staff on other panel listen to what she has to say, feels she has a say in who is hired. Some interviewees don’t listen, say pardon all the time. This annoyed Brenda and was a key theme – good people (e.g. the staff, good interviewees) listen to her, bad ones don’t. Contextual – is this because I’m listening and asking questions?
- **Personal benefits** – access to laptop, getting money
- **Indifference to interviewing** – “It’s alright I suppose”; “about half and half” – half like it, half don’t.

### Colin

Narrative tone – Very progressive at start. From “life’s not worth living” to valued role and power. However, less progressive towards end – not heard from them in a while, etc.

Type of story – Three main components to story: a bleak life before interviews; the transformative effect of being involved in interviews (this is a story of gaining power, competence and value); feelings of loss and adjustment post-interviews.

Themes (divided into phases):

- Life before interviews:



- **Sadness and emptiness**- 4 ½ years in assessment and treatment unit after parents died. Life not worth living, nothing for him. Suicidal.
- Being involved in interviews:
  - **Competence/skill** –staff said he was so good they asked him to do it on his own. Some questions set by staff, but he always throws a couple of questions in that he made up. Sense of owning the role
  - **“good judge of character”** – needs to check that they have the qualifications they say they do, whether they have the appropriate skills, asks his question about what they’d do if someone showed CB. Feeds this back to staff, who often agree with him. Talked about what he looks out for in an interviewee
  - **Power** – he and co-interviewer are “the judges”. Staff went by their judgement. “Like being the boss”; “in charge of the company”. He is a much needed part of the team, couldn’t do it without him. Real decisions made by him, staff role is to hire whoever he tells them to
  - **Importance of role** – emphasised negative consequences if the wrong person was selected, e.g. that they would not be able to manage challenging behaviour
- Life after interviews
  - **Loss** – Miss it, not done it for months. Waiting to hear from staff. Was asked to be trainer but not heard anything more about that either.
  - **Adjustment**- Finds other things: secret meetings, helping people with learning disabilities to “get a better life” (Positions self as competent relative to other people with learning disabilities). Coincides with moving from assessment and treatment to community.

David

Narrative Tone –Progressive and transformational – as our interview progresses he becomes more animated and confident – mirrors his narrative. Positive story with grand ending

Type of Story – One of group membership – being part of the team is more important than having a sense of power. Also one of transformation – interviews infused him with something powerful and positive

## Themes

- **Group membership** – “I like this place”. Talks about staff he knows, and about how the receptionist makes him drinks. Language puts him on equal footing – e.g. “he’s a funny guy” = informal, colloquial. Also talks about how he ate lunch with the manager (cultural importance of breaking bread) and accessed parts of the building usually off limits to service users. Sense of being privileged when doing this. Being part of team and having lunch with manager = best parts of interviewing. Also positive about the trust – they provided food, came up with a “very smart” way of interviewing.
- **Power** - Staff make decisions but this is OK – not about feeling powerful. Always positions self as “we”, not “I”
- **Interviews as transformative** – Felt “really really inspired” by interviews; “bring it” or “ultimate” feeling; like a feline coming out of the shadows; talked about how the feeling stayed with him. Going quickly from feeling nervous to steady as a rock. Passive role at first – I turned up, things were set up around me. But more active role as narrative progresses
- Interviews as positive experience – Whoever came up with them is really smart, getting paid means I can buy things
- **Being generous** – Always scores interviewees highly, especially relative to other SU. Told story of time when someone forgot handouts but still gave her high score. This

seems more important in narrative than selecting the right person, a dominant feature for Colin – narrative around who gets job is far more vague

- **Competence** – Steady as a rock. Staff there for Fred, not him: “I have no problem asking. “One step ahead” of Fred. Language used = helping staff to “work it out”, i.e. that he has the answers
- **Interviews were interesting** – Talked about Invictus games, kept handout

### Emily

Narrative Tone – Stable – nothing really changes as a result of interviews. Emotional tone: someone oppressed by others and constantly having to fight her corner. Anger?

Type of Narrative – Story of autonomy vs. dependence, but interviews not a strong feature as perhaps less directly relevant to her life. Draws power from supported employment and relationships with staff instead, as these have immediate relevance.

Themes:

- **Interviews “not really that important”** - Hard to remember interviews, but said that the experience was good. Narrative around experience vague – asking “all sorts of questions”. Especially pertinent as she interviewed very senior staff. Seeming less interested in discussing it - Yawning a lot and giving shorter answers. Talked a lot more animatedly about other interests, such as computing
- **Relationships with staff and other service users** – New key worker, didn’t get on with previous key worker. Role of interviews to make sure you get “nice” staff. Difficulties getting to interview because of staff. Staff and service users often portrayed as villains in narrative. They’re rude or break rules – positions self by comparison as not rude and obeys rules. Listens to managers and authority.

- **Relationship with family** – In contrast to fraught relationship with staff, unequivocally does what family says – e.g. story about Sainsbury’s or about PC. Therefore identity as independent but family member
- **Autonomy vs. dependence** - Tension between independence and role of staff in supporting her. Tensions most seen when discussing relationships: who she gets on with, who she listens to, who she gets into power struggles with. Power struggles: seeing me on her own vs. with a staff member; people being rude or confrontational (find sections of transcript); changes in working days.
- **Work** – Changes in days, getting a bit bored. Would like to work at Sainsbury’s.

### Fred

Narrative Tone – told with a sense of pride, but bittersweet tale. Progressive at first but regressive towards end.

Narrative Type – A story of being an “Important chap” and a “clever man”. Focus is on being well-regarded by staff and being told that he has done a good job.

Themes:

- **Independence** – Likes interviews because it is something to do on his own – best thing about being an interviewer is getting out of the house and “doing things on my own”. Struggles with supported employment because there’s no room and so you can’t do your own thing. Makes his own way to interviews in a cab. Felt more listened to on his own, and prefers to do things alone.
- **Skill/competence** – Knows what to do with interviews when others don’t. Offered a full-time job because he was so good. Staff made ultimate decision
- **Professionalism** - Positions other interviewer as unprofessional – putting people off, swearing, whereas Fred asks “proper questions” and gets “proper answer”.

- **Interviews as a “special day”** – Wearing a special outfit and having a shower.  
Interviews took place in a special room. Staff took them out for dinner, got free tea and coffee.
- **Positive aspects of interviewing** – really interesting, enjoyed asking questions, had an interesting presentation
- **Important chap** - Staff “looked after” him more than they did with David. Other characters very minor in narrative. Also likes getting involved in other SUI things like research: seems to be a source of identity to do things with staff that other people with learning disabilities don’t. Lots of friends at Brook House. Got access to parts of office not usually available to them. Met manager and had conversation with him. Seems to differ from David’s narrative in that it’s more about “look how important I am” than “I’m a part of this group”.
- **Praise** - Was picked because staff thought he would be good, and was recommended by manager. Staff said that Fred was more polite than David. Staff told his home how good he was, and his manager said that he was a “clever man” (?distancing self from LD identity). Praise makes his “heart feel like it’s excited”
- **Anxiety** – Bit shaky at first and because it was hot in the room he felt hot and dizzy. Spilt his coffee. This was worst thing about being an interviewer.
- **Wanting to do more** – Felt “boring” after interviewing. Wanted to carry on, and staff said they would phone him if they needed him, but they’ve not yet got in touch. Also made it clear to me directly that he is still available
- **Life outside of interviews** – other sources of identity, such as girlfriend and involvement with Mencap (views this as a job). Pays computer games and does arts and crafts.  
Interviews seen as separate from these things – these are his day-to-day experiences, but

interviews are “best day ever”. (e.g. calls Supported employment and day centre “work” but is clear that interviews are something different).

### Graham

Narrative Tone – Lots of references to feeling nervous. Progressive – Started quite anxious and worried that he was going to make mistakes, but emerged from narrative as competent and confident

Type of Narrative – Story of being independent, being heard and overcoming nerves.

Themes:

- **Developing competence and confidence** – 3 progressions:
  - Nerves - started out very nervous, but led towards mastery of his nerves. Said that he’s not the kind of person who gets nervous, but was a bit nervous at start of interviews. Interviewees not nervous when they walked in and this helped to calm him down. He also helped others: Part of his role was to calm people down so they can talk. He dressed smartly to help to calm other interviewees down (positions self as more confident than other SUs). Feeling scared and nervous at first, hands shaking. Nervous the first time he went to new building, but this was because he’d never been there before.
  - Competence - started needing to practice a lot but didn’t need to practice the second time because he knew what to do. Wanted to get it right and spent lots of time preparing the first time. Aware that he can forget things, so practiced all night and in the morning.
  - “Got more say” – didn’t have much say to having lots of say. Valued being heard by staff, and found he was listened to more when on his own as he was part of post-interview meeting. This seemed more important than how much influence he had over decision. However, staff made final decision and

Graham was fine with this. He referred to the staff panel as the “main panel”, positioning SU panel as lesser panel.

- **Independence**

- Doing things on my own is better than doing things as part of a group - Feels more listened to, more relaxed and task was easier. Preferring it on his own is mentioned multiple times. Also few references to other characters in narrative.
- Being part of a group is a barrier - Part of group seen as barrier to all three progressions, e.g. I was nervous because I didn't know rest of people and it was harder to laugh; I was more likely to make a mistake because of having to take turns so more likely to forget something; I had less say because there were so many of us

- **Good at talking** – suspects he was chosen because he likes talking. Said that he is usually good at talking to people. Struggled with group interview because of taking turns. Key identity point: I'm good at talking.

- **Content unimportant** – Unlike other participants, the precise details (e.g. what interviewees were like, what questions were asked, who got job) less memorable or important.

- **Personal benefits** –being in interviews left him feeling happy and proud that he had done it right. Has noticed he is a bit more friendly since interviewing and lets people on the bus before him.

- **Taking it seriously** – Emphasised importance of practising so as not to make mistakes. Dressed “posher” – suit and tie, even though others didn't. Seems this might be about not letting staff down.

**Appendix H: Table Outlining Refinement of Initial Themes**

Table A1

Initial and Higher Order Themes from All Interviews

Name	Initial themes	Higher Order themes
Andrew	Competence and expertise	Skilled role
	Agency	
	Feeling powerful	
	Group membership	
	Inclusion	Inclusion
	Negative aspects of role	Pros and cons
	Positive aspects of role	
Brenda	Loss	Interviews in context of life outside interviews
	One factor of many	
	Competence	Sense of importance
	Important Role	
	Power	
	Importance of feeling listened to	Importance of feeling listened to
	Personal benefits	Personal benefits
Indifference to interviews	Indifference to interviews	



Colin	Sadness and emptiness before interviews	Sadness and emptiness before interviews	
	Competence and skill “Good judge of character”	Skilled at interviewing	
	Power Importance of role	Power and importance	
	Missing interviewing afterwards Adjustment after interviewing	Loss and change	
	David	Part of the team	Group membership
		OK with staff having power	
Interviews as transformative		Transformation and development	
Competence			
Role of interviews in identity			
Interviews as interesting		Interviews as interesting	
Being generous		Being generous	
Emily	Interviews as “not really that important”	Interviews “not really that important”	
	Relationships with staff and other service users	Relationships with others	
	Relationship with family		
	Autonomy vs. independence		
	Work	Life outside of interviews	
	Other interests		

Fred	Skill/Competence	Skilled role
	Professionalism	
	Likes doing things on his own	
	Interviews as a “special day”	Specialness and importance
	Positive aspects of interviewing	
	“Important chap”	
	Praise	
	Anxiety	Anxiety
	Wanting to do more	Life outside of interviews
	Life outside of interviews	
Graham	Nerves	Developing in skill and confidence
	Competence	
	“Got more say”	“Got more say”
	Independence	Independence
	Good at talking	Good at talking
	Personal benefits	Personal benefits
	Taking it seriously	Taking it seriously

**Appendix I: Example Coded Transcript**

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**Appendix J: Ethics Panel Approval Letter**

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**Appendix K: Research Ethics Committee End of Study Form**

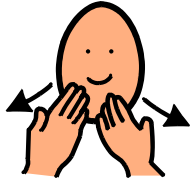
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**Appendix L: Summary Report for Research Ethics Committee**

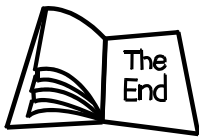
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## Appendix M: Summary Report for Participants

Dear XXX,



Thank you for taking part in my research project!

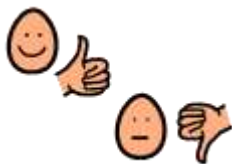


I have now finished my project. I am writing to tell you what I found out.

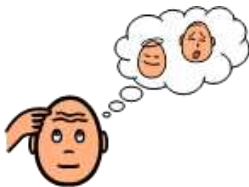
### What I did



I talked to seven people with learning disabilities. I asked them lots of questions about being an interviewer. You were one of the people I spoke to.



I asked you what you liked and what you didn't like about being an interviewer



We talked about whether it changed the way you think about yourself.

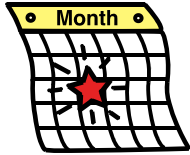


The way you think about yourself is called your **identity**.

## What I found out



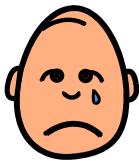
Almost everybody said that being an interviewer was good. One person said it was half good and half bad.



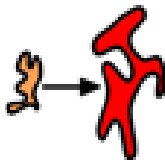
Some people said that interviewing was a special day.



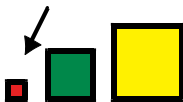
Some people said that being an interviewer made them feel very important. Some said they felt powerful. Some also said they felt part of a team.



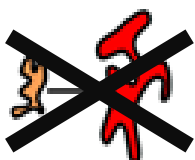
Some people said they felt sad afterwards because they missed being an interviewer.



Some people said that being an interviewer changed the way they think about themselves.



Some people said it only changed them a little bit.



Some people said it didn't really change them very much. They couldn't really remember being an interviewer or there were other things that were more important to them.



## What does this mean?



Some people think that if you have a learning disability then your disability is the main part of your identity.



But I found out that there are many things that make up someone's identity. Learning disabilities is just a little part.

## What can services do differently?



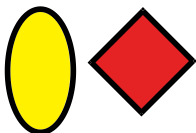
People like being interviewers so services should always have people with learning disabilities on interview panels.



But maybe services could think more about how to make interviewing better. They could pick people who don't get to do important things very often. This might help them to have a positive identity.



Services could also think about how to involve people in more things so that they don't feel forgotten after they've been an interviewer.



Services should remember that everybody is different. They need to think about what is important to each person's identity and support them to do it.



That way, more people can have positive identities.

## What happens next?



I have written what I found out in a long report. I have given a copy of this report to my university so that they can mark it.



I will also give the report to a “journal”. This a type of magazine for scientists and researchers. Other people who are interested in the work we are doing can then read about it.



I have not used your name in my report. That information is private.



Thank you again for taking part in my research project. If you have any questions you can speak to me on **0333 0117070**. You can also speak to my supervisor, Kate Foxwell, on the same number.

Yours sincerely,



Leigh Emery

## Appendix N: Author Guideline Notes for Disability & Society

Retrieved on 15 April 2015 from

<http://www.tandfonline.com/action/authorSubmission?journalCode=cdo20&page=instructions>

### Manuscript preparation

#### 1. General guidelines

- Manuscripts are accepted in English. Any consistent spelling and punctuation styles may be used. Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Long quotations of 39 words or more should be indented without quotation marks.
- A typical manuscript will not exceed 8,000 words including tables, references, captions, footnotes and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.
- Manuscripts should be compiled in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).  
Please supply all details required by any funding and grant-awarding bodies as an acknowledgement in a separate Funding paragraph as follows:  
For single agency grants  
This work was supported by the <Funding Agency> under Grant <number xxxx>.  
For multiple agency grants  
This work was supported by the <Funding Agency #1> under Grant <number xxxx>; <Funding Agency #2> under Grant <number xxxx>; and <Funding Agency #3> under Grant <number xxxx>.
- Abstracts of 100-150 words are required for all manuscripts submitted.
- An additional and separate summary headed 'Points of Interest' must also be uploaded and should be between 100-150 words (maximum) describing in plain English the importance of your work for lay readers. We suggest you aim to do this in 4 or 5 bullet points. The name(s) of the author(s), and a short note of biographical details, the address where the work was carried out, and the full postal and email address of the author who will check proofs and receive correspondence and offprints should be included, as a cover sheet. All pages should be numbered.
- Each manuscript should have 2 to 6 keywords .
- Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here .
- Section headings should be concise.
- All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a

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- All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.
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- Authors must not embed equations or image files within their manuscript
- For further advice on the submission procedure please email [h.j.oliver@sheffield.ac.uk](mailto:h.j.oliver@sheffield.ac.uk)

## 2. Style guidelines

- Description of the Journal's article style.
- Description of the Journal's reference style.
- Guide to using mathematical scripts and equations.
- Word templates are available for this journal. If you are not able to use the template via the links or if you have any other template queries, please contact [authortemplate@tandf.co.uk](mailto:authortemplate@tandf.co.uk).

### Guidelines for the Current Issues Section of the journal

For some years we have incorporated this section into the Journal and we are seeking further contributions on any issue related to disability. The Current Issues section is ideally suited to articles which seek to raise the voices of those who are seldom heard in academic journals and we welcome articles which air controversies and contentions and which stimulate discussion and debate.

Contributions will typically be:

- between 1000 and 2000 words in length, though picture based submissions may also be accepted
- related to a current issue in the lives of disabled people and/or an issue that has recently been raised in the journal
- interesting

It can be:

- controversial
- challenging
- a response to previous articles in Current Issues or Book Reviews

It need not:

- contain references
- conform to the criteria required for academic papers in the Journal
- be peer reviewed

It must not be:

- libellous
- grinding personal axes
- personally insulting or malicious in intent

If you are interested in writing a piece or know someone who is, please contact:

Professor Alan Roulstone  
University of Leeds  
Centre for Disability Studies  
School of Sociology & Social Policy  
Leeds  
LS2 9JT  
Email: a.roulstone@leeds.ac.uk

### **Guidelines for the Student Perspectives Section of the journal**

From 2014 Student Perspective papers will be Free to Access offering new authors a powerful and important opportunity to promote their work. Student Perspective papers undergo the same rigorous peer review as other submissions to the journal.

#### **THOSE ELIGIBLE TO SUBMIT:**

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#### **SUBMISSION CRITERIA:**

- Authors should follow all instructions for submitting a peer-reviewed paper to Disability & Society
- Pay attention to the Journal's policy on language
- All submissions must be uploaded as Student Perspectives in the ScholarOne system
- The paper should not be a straight reproduction of work produced for academic assessment

#### **Books for review**

Books for review should be addressed to Hannah Morgan, Department of Applied Social Science, Lancaster University, Bowland North, Lancaster, LA1 4YL, UK

Tables and captions to illustrations: Tables must be typed out on separate sheets and not included as part of the text. The captions to illustrations should be gathered together and also typed out on a separate sheet. Tables and figures should be numbered by Arabic numerals. The approximate position of tables and figures should be indicated in the manuscript. Captions should include keys to symbols.

### **3. Figures**

- Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.
- Figures must be saved separate to text. Please do not embed figures in the manuscript file.
- Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).
- All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labelled (e.g. Figure 1(a), Figure 1(b)).
- Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.
- The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

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Authors are encouraged to submit animations, movie files, sound files or any additional information for online publication.

- Information about supplemental online material

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