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Doctoral Thesis

Exploring the experiences and perceptions of people with learning disabilities

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Word Count Statement

Thesis section	Main Text	Appendices (tables, figures, references)	Total
Abstracts			576
Thesis	278	**-**	
Literature Review	151	**-**	
Empirical Paper	147	**-**	
Literature Review	7998	8570	16550
Empirical Paper	7968	3981	11951
Critical Appraisal	3955	628	4583
Ethics Section	3669	6923	10592
Totals	24161	20089	44250

Thesis abstract

In the first chapter, a systematic literature review explored the experiences of people with learning disabilities (LD) transitioning from long-term, residential care to community-based alternatives. Socio-political changes over the decades have resulted in many people with LD experiencing change to their accommodation and care. Qualitative research exploring these experiences for people with LD was reviewed, adopting a meta-ethnographic approach. Nineteen papers were included in the review, and subsequently analysed and synthesised. Two over-arching themes regarding people with LD's experiences of residential transitions were identified; From trauma to the unknown; and Striving to belong. The findings highlighted the impact of moving on people with LD, therefore theoretical and clinical implications were discussed.

The second chapter presents the findings of an empirical paper, which explored the experiences and perceptions of people with LD who have been diagnosed with a 'personality disorder' ('PD'). Under Transforming Care, more people with LD and complex needs are likely to move to the community. Therefore, the experience of receiving and living with a 'PD' diagnosis was investigated in people using current, community-based services. Eight people were interviewed, and the data analysed through use of Interpretative Phenomenological Analysis. Four super-ordinate themes were developed: Knowledge is power – Diagnosis as the domain of professionals; Understanding difficulties through a trauma lens; The stigma of diagnosis – Feeling different, seeking acceptance; and Taming the 'beast' inside – The journey towards regaining control. Clinical and research implications were discussed.

In Chapter 3, a critical appraisal compared the findings of the two papers, whilst exploring the rationale for the research, the concept of 'PD', and the impact of Transforming Care on

people with LD. Methodological considerations and implications for clinical practice were

also discussed.

Declaration

This thesis represents research activity completed between March 2018 and August 2019 undertaken for the Doctorate in Clinical Psychology at Lancaster University. The work presented here is the author's own, except where due reference is made. The work has not been submitted for the award of an academic qualification elsewhere.

Name: James Taylor

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Chapter One: Literature Review

Experiences of transitions from long-term care for people with learning disabilities: A

meta-ethnography

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Word count: 7998 (Max 8000 excluding figures, tables, references and appendices)

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Abstract

A significant minority of people with learning disabilities (LD) will experience multiple changes to their living accommodation and the care they receive. These changes have often occurred due to social and political movements or policies such as 'deinstitutionalisation' and Transforming Care. Despite the complexity and possible impact of transitions to community-based care, the experiences of people with LD who undergo these moves are underrepresented in the literature. A meta-ethnographic method was used to systematically review and synthesise experiences of people with LD leaving more restrictive, long-term care for community-based alternatives. Nineteen articles were retrieved from database searches. Two over-arching themes, with additional sub-themes, were developed: (1) From trauma to the unknown; and (2) Striving to belong. Implications for clinical practice were made, including ways to provide support during transitions, increasing autonomy and community integration in people with LD and raising awareness of stigma.

Keywords: meta-ethnography, learning disabilities, transitions, moving, experiences

The term 'learning disability' (LD) will be used throughout this paper, as this is the accepted terminology used within UK services. It is acknowledged that internationally there has been a significant shift to the preferred term of 'intellectual disability'. It is also acknowledged that every person is individual, and experts-by-experience may adopt or relate to different terminology. The desire for use of alternative language within a social model of disability framework is recognised (Department of Health [DoH], 2010). However, as there is no agreed consensus of terminology within this group, 'LD' will be used throughout.

Transitions

'Transition' can refer to any change in life, whether that be physical or environmental, or a more psychological or social change (Tanner, Glasby, & McIver, 2014). Transitions require personal adjustment, and may significantly affect a person's roles, routines, beliefs, and relationships (Parkes, Pyer, Ward, Doyle, & Dickens, 2015). They can elicit excitement and opportunity, or uncertainty, anxiety and loss (Schlossberg, 1981). This review aims to explore the experiences of transitions from long-term care to the community for people with LD. Some experience many residential transitions over their lives. Therefore, the context of why people experience transitions will be reviewed first.

Deinstitutionalisation

During the twentieth century, people with LD and additional needs would often live in large-scale institutions, which were segregated physically and socially from the community (Mansell & Beadle-Brown, 2010). Institutions became increasingly over-crowded and under-funded; providing unacceptable living conditions and ill-treatment towards their residents (Fakoury & Priebe, 2007). Subsequently, there has been a significant shift towards closing institutions and offering community-based support. This 'deinstitutionalisation' movement reflected a widespread trend since the 1960s across countries including the United Kingdom, United States, Canada, Australasia, and Scandinavia (Chowdhury & Benson, 2011). This

paper adopts a UK focus in terms of context, policy, and clinical practice. UK inpatient beds

have reduced from 33,000 in 1987 to under 3,000 (NHS England, 2015). An important

principle of '*Valuing People*' (DoH, 2001) was to enable people with LD to have greater

independence, social inclusion, control and choice in their lives, including over their

accommodation and support.

Where do people with LD live?

'Deinstitutionalisation' resulted in many people leaving institutions for community,

residential settings. Due to economic difficulties and anxiety about their release, not all

people with LD received appropriate support, often leading to re-hospitalisation (Martin &

Ashworth, 2010; Simpson & Price, 2010). A significant minority require intensive support,

with an estimated 33% of all people with LD living in residential care (National Development

Team for Inclusion, 2010). Community provision mainly consists of supported group homes

for up to eight people, or 'supported living' where individuals have more choice over their

accommodation and staffing (Mansell & Beadle-Brown, 2010). However, there remains a

lack of appropriate community provision (Mansell, 2006), resulting in people being

supported in unnecessarily restrictive settings. This can include limiting a person's

movement, liberty or freedom via locked doors, limited access to living spaces, seclusion,

restraint, and over-medication (Emerson & Einfield, 2011).

The closure of institutions led to higher referrals of people with LD to prison settings

(Hutchinson, Hummer, & Wooditch, 2013), with approximately 6,000 people with LD in

prison currently (Ideas Collective, 2015). People with LD are over-represented in the

criminal justice system within the UK and internationally (Fazel, Xenitidis, & Powell, 2008;

Talbot, 2008). It is estimated 7% of people in prison have a LD compared to 2% of the

general population (Warner, 2018). Approximately 10% of prisoners due for release have a

LD (Dias, Ware, Kinner, & Lennox, 2013). Approximately 61% of people with LD are

reconvicted within a year of their release, with factors relating to poor housing, social

isolation and unemployment highlighted (Loucks, 2007). Ex-prisoners with a LD return to

prison at more than twice the rate of 'non-disabled' equivalents (Holland & Persson, 2011).

If people with LD require assessment for additional needs, they may live in forensic

or mental health hospitals (Slevin, McConkey, Truesdale-Kennedy, & Taggart, 2008). These

are often out-of-area, and people face long admissions, delayed discharges or unplanned

transitions due to lack of specialist placements (Holland, Clare, & Mukhopadhyay, 2002;

Parkes et al., 2015; Reed, Russell, Xenitidis, & Murphy, 2004). Admissions are unnecessary

for some who may benefit more from community-based support (Purandare & Wijeratne,

2015). Out-of-area placements restrict money required for local services (Barron, Hassiotis,

& Paschos, 2011). Ultimately, some people with LD therefore transition between different

contexts.

Transforming Care (TC; DoH, 2012) was the response to exposure of systematic

abuse and mistreatment at Winterbourne View, a long-stay LD hospital. People with LD can

receive inappropriate levels of care, restriction and length of admission during inpatient stays

(DoH, 2015). TC aims to help people move from hospital by reinvesting money from the

closure of all LD specialist beds into robust community services (NHS England, 2015).

However, discharge to services not yet fully funded or implemented has resulted in

readmissions (Taylor, McKinnon, Thorpe, & Gillmer, 2017). People with forensic needs

may be diverted to prison or independent sector beds (Taylor et al., 2017). Therefore, various

transitions between different contexts occur for some people with LD.

Better quality of life in the community?

Community living after 'deinstitutionalisation' has been associated with

improvements in social skills, adaptive behaviours, and reductions in 'challenging behaviour'

(Emerson & Hatton, 1996; Young, Sigafoos, Suttie, Ashman, & Grevell, 1998).

Improvements in quality of life (QoL) through community participation and social activities and contact have also been reported (Chowdhury & Benson, 2011). However, environment changes alone do not guarantee better QoL for people with LD (Kozma, Mansell, & Beadle-Brown, 2009). People with higher levels of adaptive functioning have more positive outcomes than those with more 'complex' difficulties (Kozma et al., 2009). Transition requires each individual to draw upon their skills, abilities and personal resources to adjust to new surroundings (Parkes et al., 2015). There remain challenges to the level of community integration people with LD can attain, with many feeling socially isolated within the community they live (Chowdhury & Benson, 2011; McConkey, Abbott, Walsh, Linehan, & Emerson, 2007). They still experience stigma, discrimination, social exclusion and disempowerment (Scior, 2011). In addition, 'transinstitutionalisation' suggests people may move to similarly restrictive community alternatives (Drake, 2013). Therefore, transitions may either enhance or reduce people's QoL depending on current personal, contextual and environmental factors. Focusing on each individual's ability, need and awareness of the community is required. The structure and quality of support provided should be considered, as maintaining historical beliefs and practice can impact on people's wellbeing (Bigby & Fyffe, 2006). Staff practice is thereby vital in building supportive relationships and promoting independence (Kozma et al., 2009).

Review Aim

The lives of many people with LD are subject to a variety of significant changes to their accommodation, support and independence. Repeat transitions can increase emotional and behavioural difficulties for people with LD or reinforce previous life experiences of uncertainty and unpredictability (Hamilton, Sutherland, & Iacono, 2005; Parkes et al., 2015). Successful transitions are important for people's well-being and to reduce a "revolving door" culture in services. People with LD are experiencing more complex transitions; therefore

further investigation into their experiences is warranted (Woodman, Mailick, Anderson, & Esbensen, 2014). This review aims to explore the experiences of people with LD and 'complex' needs transitioning from more restrictive, long-term placements (i.e. institutions, secure hospitals, forensic settings) to community-based options (i.e. group homes, independent or supported living). It does not explore transitions from family homes or independent living. Within this review, 'complex' difficulties incorporate 'challenging behaviour', mental health and/or forensic-related needs. It will investigate the psychological and social impact, alongside the environmental change. Head (2017) completed a similar review exploring transitions from home, hospitals and forensic settings. Transitions were potentially challenging, distressing and worrying for people with LD; however, with increased control over the transition, it marked a time of significant growth and development. This review differs in focusing solely on the perspectives of people with LD themselves. A more transparent and stringent methodology for qualitative synthesis is adopted.

Method

Design

The review adapted the three stage method of Britten et al. (2002) for qualitative health research: (1) a systematic literature search, (2) critical appraisal of the papers' quality, and (3) data synthesis via a meta-ethnography approach (Noblit & Hare, 1988). Guidelines in enhancing the reporting of qualitative synthesis were also consulted (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

Eligibility Criteria

Papers were included in the current review if they: (1) included participants with LD diagnoses; (2) were published in English; (3) were published in a peer-reviewed journal; (4) employed a qualitative or mixed methodology; (5) themes were identified; (6) participant quotes were highlighted; (7) people experienced a transition as an adult (18 years old or

older); and (8) the article detailed transitions from long-term care to less restrictive, community alternatives.

Papers were excluded if: (1) the research used only quantitative methods; (2) participant quotes were not highlighted or information was presented as case studies; (3) the same sample appeared across different papers, with similar research aims and themes; (4) the sample reflected different presentations (e.g. LD and 'mental health') without differentiation; (5) articles documented experiences of transitions from other contexts (e.g. family home) without differentiation; and (6) 'grey literature' including books, literature reviews, theses, or position papers were excluded due to a lack of peer review. Eligibility criteria were discussed within the research team.

Search Strategy

To identify relevant studies for inclusion, a search strategy was devised using the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) framework (Cooke, Smith, & Booth, 2012). Search terms were initially identified by hand, before adding terms with similar meanings found in the thesaurus of each database, in order to meet the requirements of each individual database. A validity check of the final search strategy was reviewed by the dedicated librarian for the department. Four databases were searched (within the titles or abstracts) during April 2019; CINAHL, Medline, PsycINFO, and Web of Science. To minimise the risk of missing relevant papers, no limitations regarding year or full paper availability were placed on the search. As transitions have been researched since the 'deinstitutionalisation' movement started in the 1960s, it was determined searching from the inception of potential journals would encapsulate all relevant data. Table 1 details the search terms used, which were combined with the Boolean operator 'AND'. The operator 'OR' was used between the search terms used in the Design, Evaluation and Research Type

due to overlap between these areas. Quotation marks and truncation methods were also employed.

The initial search identified 4417 potential studies for inclusion in the review. The search results from each database were imported into EndNote X9, combined, and duplicates removed. A review of the titles and abstracts of the remaining 3078 studies, taking into account the eligibility criteria, resulted in 17 studies being identified (see Figure 1 for the selection process). Backchaining via searching the references and citations of included studies identified two additional studies, retrieved via Google Scholar. Therefore, 19 studies were found to meet the inclusion criteria for the review. Some articles were excluded due to being published in non-peer reviewed journals, themes could not be identified, or they reported ethnographic or narrative case studies. Some articles provided poignant first-person accounts (Banham, Garrett, McClean, Strydom, & Hassiotis, 2003; Boodle, Ellem, & Chenoweth, 2014). Studies were also excluded when the context of the transition differed between participants, and the findings were undifferentiated (Bond & Hurst, 2010; Salmon et al., 2019). Studies that included this distinction were included (Cattermole, Jahoda, & Markova, 1990; Jahoda & Markova, 2004). Articles by Ellem (Ellem, 2012; Ellem, Wilson & Chui, 2012) and Booth (Booth, Booth, & Simons, 1990; Booth, Simons, & Booth, 1989) used the same sample, highlighting similar themes. One paper by each author was chosen, based on which had the most relevance to the research question.

Quality Appraisal

Following identification of the final studies from the systematic search, the papers were quality appraised. This involved reading and re-reading all identified studies. The Critical Appraisal Skills Programme (CASP; Public Health Resource Unit, 2006) for qualitative research was used to assess the quality of each paper. The CASP consists of 10 criteria: two questions for screening eligibility and eight relating to methodology, ethics,

analysis and implications. A three-point rating system, as described in Duggleby et al. (2010), was used to calculate a score between one and three for each of the eight CASP questions in every study. A score of one point was given to papers that offered little or no discussion of a topic, score of two given if some justification was given, and a score of three given to papers who fully addressed the question. Therefore, the overall quality of each study was based on a maximum score of 24 points (see Table 2). The author made notes during the initial appraisal, whilst another colleague familiar with the CASP provided a further quality check of the scores for several studies. Discrepancies were discussed and resolved. The majority of papers were identified as good in quality. No articles were ultimately excluded based on scores, to reduce the potential for excluding valuable qualitative data (Barbour, 2001).

Analysis and Synthesis

Meta-ethnography (Noblit & Hare, 1988) is an interpretative approach to qualitative data, aiming to produce new insights and interpretations that go beyond the data of any individual study. As this review explored limited documented experiences of people with LD leaving long-term care, it will be able to contribute to the theoretical understanding of residential 'transitions'. Firstly, the papers were read several times each to become familiar with the content. All themes relevant to the research aim were identified from the results/findings section of each paper. 'First-order constructs' relating to data provided by participants and 'second-order constructs' relating to authors' interpretations were entered into Excel. Findings of each study were then translated into one another to identify commonalities or discrepancies, and eventually the development of over-arching themes. Studies were arranged in chronological order, with themes from the first study compared to those in the second. The resulting synthesis was then compared to the next paper, until all nineteen papers and over-arching themes were identified. Finally, the over-arching themes

were reviewed by the research team to check how well they captured the original data and themes from each study (see Table 3 for a detailed approach).

Results

Description of the Synthesised Papers

The search strategy identified 19 studies for inclusion in the final analysis (see Table 4 for study characteristics). All studies used interviewing as part of the data collection, with the majority using a semi-structured approach ($n = 12$). One paper used a focus group rather than individual interviews (Burns, Silberman, & McCann, 2010). The majority of the studies were conducted in the UK ($n = 14$) with the remaining papers from Australia ($n = 3$), New Zealand ($n = 1$), Czech Republic ($n = 1$), and Ireland ($n = 1$). One paper used a sample from Australia and the Czech Republic (Strnadova & Evans, 2012). Sample sizes ranged from five to 196 participants, including one large, long-term follow-up study (Forrester-Jones et al., 2002). Sample size and demographic information were not reported for two studies (Burns et al., 2010; Fish & Lobley, 2001). Overall, the known experiences of 586 people with LD were reported. The majority were interviewed directly, with their own words contributing to the themes. However, the exact number of people involved is unclear. The age range (where reported) is between 20-69 years old, with a mix of gender and 'severity' of LD. The exact splits of these demographics are unknown. Settings people relocated from consisted of 'long-term hospitals', institutions, forensic units and prison. Data analysis methods included: unspecified qualitative analysis methods ($n = 7$), Content Analysis ($n = 4$), Thematic Analysis ($n = 4$), Grounded Theory ($n = 2$), Interpretative Phenomenological Analysis ($n = 2$), and Narrative Analysis ($n = 2$). Regarding quality of the final studies, CASP scores ranged from 12-24 (out of a possible 24), with a mean score of 18.7. This is similar to the findings of Duggleby et al. (2010), suggesting the overall quality of the papers is good. The quality of

papers shows an increasing trend throughout the years, possibly due to the advancement of formalised qualitative research methodologies and reporting guidance.

Experiences of Transitions

Synthesis of the data produced two over-arching themes: (1) From trauma to the unknown; and (2) Striving to belong. Sub-themes were identified and are individually described (Table 4 details the contribution of papers to themes).

Theme 1: From Trauma to the Unknown

An over-arching theme emerged relating to the difference people with LD experienced between their old placements and their new lives within the community. Transitions appeared to give people opportunity to reflect on how their new environment may represent the potential for a new start. Reflecting on negative past experiences within care helped people contextualise the change to their lives, and a fear of returning to hospital. However, transitions themselves appeared to bring difficult feelings regarding loss and uncertainty. Despite some negative experiences of long-term care, people missed relationships they had built with staff and other residents in care. This theme is split between two subthemes: (1) Leaving the trauma behind, and (2) Thrust into the unpredictable unknown.

Subtheme 1.1: Leaving the trauma behind. This subtheme highlights how people were happy to leave hospital care. People with LD would often compare previous placements to their new settings, with the majority preferring their current way of living: "No, I love it here; I couldn't get here quick enough […] don't mention that place (hospital)!" (Walker, Ryan, & Walker, 1995, p. 252). Living in hospital with other residents who were 'noisy' with "all different problems" appeared to pose a threat to their wellbeing (Williams, Thrift, & Rose, 2018, p. 137). Experiences of abuse from other residents reinforced the preference to remain in the community, due to fear of returning: "Someone hit me once […]

he whacked me in the face. Bite my ear once […] I was really frightened […] I don't want to go back there again" (Brown, Dodd, & Vetere, 2009, p. 220). Others experienced feeling controlled and abused by staff, limiting their dignity and capability:

> I just didn't like it, the staff were rude. The staff weren't very nice to me. They used to hurt me when they were showering me. They wouldn't let me shower on my own. And I told them I could do it myself. (Head, Ellis-Caird, Rhodes, & Parkinson, 2018, p. 67)

Moving to community settings had a significantly positive impact on one person's overall life: "Community is not as bad as (hospital). There is more environment, more space to move around in. Life has changed" (O'Brien, Thesing, Tuck, & Capie, 2001, p. 79). The importance of space highlights how hospital restrictions impact on people's expectations in life. Moving away from the difficulties experiences and environments of long-term care made significant changes to people's lives, allowing them to break away from the past: "When I left there, I left all that behind me. That's the way I felt. I said to myself, when I leave the hospital, I'll forget all about the hospital. I don't even tell people I've been there" (Jahoda & Markova, 2004, p. 725).

Subtheme 1.2: Thrust into the unpredictable unknown. This subtheme explores the feelings of uncertainty and unpredictability regarding the move itself. There was a sense of initial hesitation over transitions, with some feeling worried about leaving a familiar environment. Uncertainty over how the 'outside world' had changed occurred for people leaving prison: "When you come out for the first time, been there a long time, it's a bit scary you know. It's a bit risky" (Ellem, 2012, p. 133). Feelings of worry intensified for people unaware of their impending move, reflecting the lack of involvement and communication over transitions:

> They were talking about it and I was passing by them and they were saying "girls will
>
> go away". I turned around and said "where?" They said, "Nowhere", so […] I asked
>
> her why they are keeping a secret that we have to go away, that they should tell us.
>
> (Strnadova & Evans, 2012, p. 76)

This often occurred within prisons, with some experiencing unexpected, immediate release:

"The other security guard, he said ''Mr Mario P, your time is up'' (Ellem, 2012, p. 131). The

amount of unpredictable transitions experienced elicited a sense of uncertainty over the

future: "Yeah, you just don't know what you're going to be dealing with. That's kind of a

frightening thought" (Strnadova, 2019, p. 61). One participant highlighted how advanced

planning and support during transitions reduced levels of worry:

> When I found out I was moving, it was a bit scary. The staff where I was living
>
> brought me here. And I didn't want them to leave. But I met [Support Worker] and
>
> she was really nice […] I knew her, and that made me feel a bit easier because I knew
>
> somebody already here. The new staff came to the hospital I was in […] and got to
>
> know 'em. (Head et al., 2018, p. 67)

Loss of previous relationships appeared to impact on people's initial evaluation of the move,

as trusted others were a rare source of familiarity and support: "I don't see them no more"

(Booth et al., 1990, p. 92). This appeared linked to an initial sense of insecurity, rather than

the move itself: "I wasn't happy here at first because I missed the people at the institution.

I'm really glad I came now though" (Fish & Lobley, 2001, p. 105).

Overall, there were more positive consequences to the move than negative. The

majority of people would make the move again, despite any uncertainty: "I didn't want to

move at first because I was afraid but I'm glad I did make the move" (McConkey,

McConaghie, Mezza, & Wilson, 2003, p. 85). Although people missed previous

relationships, the majority did not want to return to their previous lives.

Theme 2: Striving to Belong

The second over-arching theme investigates people with LD's search for a 'normal

life', which the move into community settings appeared to give people hope of achieving.

Firstly, people appreciated more freedom and ordinariness to their lives, which allowed a

process of rebuilding their identity, independence and sense of belonging to occur. Despite

this, barriers within services and the wider community impacted on people's ability to feel

truly integrated. This theme is split into three subthemes: (1) 'Ordinary' is extraordinary; (2)

Re-establishing control and independence; (3) "Will I ever fit in?"

Sub-theme 2.1: 'Ordinary' is extraordinary. A common theme to emerge from the

papers related to people's freedom to do 'ordinary' things after moving from long-term care.

Freedom was represented by fewer restrictions, having more space and privacy, and being

able to complete everyday activities. However, restrictions still remained in place for the

majority of people; therefore, only a sense of 'normality' was experienced.

The majority of people with LD across all papers described a sense of freedom that

comes from moving to community-based accommodation, linked to both a physical freedom

and sense of choice. Objects such as keys were a powerful reminder of the new sense of

freedom people who were restricted in long-term hospitals now had: "You can do what you

like—go out. I've got my own key so I can come and go as I please" (Forrester-Jones et al.

2002, p. 746). This allowed people to use local amenities such as shops, parks, churches,

pubs and social clubs. Freedom of choice was represented in an ability to complete daily

activities outside of restrictions and routines, such as showering, increasing people's sense of

dignity: "Anytime I like. One morning, one after dinner, one night" (Booth et al., 1990, p.

90). An even greater sense of independence was instilled in people who moved to

independent living, reflected by a lack of requirements from others: "We're free to do what we want, anything we like. We're free. In other words we don't get told what to do" (Karban, Paley, & Willcock, 2013, p. 90).

Building upon the positives of moving to community services, the idea of having personal space and privacy was an important aspect of many papers. People's sense of privacy and dignity had often been restricted by strict routines, other people and physical security measures, however there was now a sense of privacy when living in more community-based settings: "You have your own space, and then you have your own bedroom, and no one comes into your room without your permission" (Sheerin, Griffiths, de Vries, & Keenan, 2015, p. 272). Some people highlighted the contrast in privacy and dignity between hospital and community settings: "In hospital, I had to share with four other girls and one kept wetting her bed and staff used to come in and wake us up too" (Forrester-Jones et al., 2002, p. 745).

The move to the community opened up new opportunities to learn new or maintain previously learnt skills. People with LD discussed the ability to choose and complete everyday chores such as cooking or cleaning, giving a sense of achievement: "Yeah I love cooking. I can cook my own meals […] I like doing my own washing, my own self […] I like keeping the place clean" (Sheerin et al., 2015, p. 272). Freedom allowed people to demonstrate their competence in areas such as self-care and personal hygiene, whereby previously they were reliant on staff: "Now I do the bath and basin, toilets and the floor and washing and […] yeah and do cups and that" (O'Brien et al., 2001, p. 79). Managing finances, which were often restricted in hospitals, was also important for promoting freedom and choice: "I have a bank card, I can go to the bank machine every week if I want to, yeah […] get out my own money" (Sheerin et al., 2015, p. 273). However, some people with LD who moved to independent living appeared to find the reduced support that came with the

freedom of an 'ordinary life' overwhelming: "I don't know how to use the cooker. I can only switch on the cooker, I don't know the other switches. I'd like staff to show me how to use the cooker" (Karban et al., 2015, p. 90). The advancement in technology over the years (sometimes decades) that people with LD had been in places like prison, meant they often felt disconnected and unprepared for everyday life in the community:

> What they should do for the long termers is mainly courses like – they sort of brought a mobile phone in. ''This is a new thing outside. This is how you use it.'' […] I hardly know how to use mine […] I never knew about it. (Ellem, 2012, p. 131)

After the initial excitement over increased freedom within community settings had receded, people still encountered barriers that appeared to impact on their sense of 'genuine' freedom. After being made aware of more independent living, Janet highlighted that she did not want to continue living with others:

> I really hate it here. I hate it. I don't like the other people. I don't like them at all. I want to leave. I want my freedom. I want to live in a flat alone, or a bungalow alone […] where I can have my freedom (Holland & Meddis, 1997, p. 70)

For people with forensic histories, risk-related restrictions placed on them impacted on their sense of freedom: "Hopefully I'll get my freedom – to just to go to the shop myself, or to go down the town myself, but no […] staff have to come with me and make sure they keep me safe" (Davis, Doyle, Quayle, & O'Rourke, 2015, p. 155). In other cases, the lack of complete autonomy and freedom in people's lives was inherent, observed through people's appreciation of any sense of normality: "We had dinner and then we were even allowed to split up and go shopping" (Strnadova & Evans, 2012, p. 76). Overall, people experienced a sense of feeling more able to do the "simple everyday things" (Burns et al., 2002, p. 22); however there remained some barriers to achieving complete freedom and 'ordinariness'.

Sub-theme 2.2: Re-establishing control and independence. This sub-theme highlights people's process of trying to regain an element of control in their lives and relationships, whilst also continuing to develop a sense of belonging and independence in their 'new lives'.

The importance of having ownership and choice over possessions appeared to give people with LD a sense of belonging: "I have my own bedroom, my own kitchen, my own bathroom" (Karban et al., 2013, p. 89). This appeared extremely important for people in the context of moving from somewhere familiar and comfortable, even if past placements were not always remembered fondly. People choosing and buying their own possessions represented the importance of being able to build a new life, one with increased autonomy and decision-making: "It's a home where you comfortable, and you happy […] because you have your own personal stuff in it" (Walker et al., 2018, p. 138).

The process of moving into the community allowed people to reject previously used institutional language: "I'm not a prisoner here. I'm not a patient" (Forrester-Jones et al. 2002, p. 746). This gave people a voice to create their own identity and sense of belonging: "It's residents no patients […] Because I'm big, I'm no a patient […] I'm a grown man now […] I'm no a child anymore" (Jahoda & Markova, 2004, p. 725). For some people, this meant using their new freedom to rediscover their old identity prior to going into inpatient hospitals: "I'm back to the person I used to be. I think I've discovered how to be mischievous again. In a way that I was never mischievous at [hospital]. The opportunity to be mischievous wasn't there" (Head et al., 2018, p. 68). Others saw the move as an opportunity to be seen in a different way, one with unlimited aspirations, rather than remaining restricted by more medical language: "I wouldn't mind […] being called an 'outsider' for a change, instead of a patient. But if you're somebody like outsider, you'd be whatever you'd want to" (Jahoda & Markova, 2004, p. 726).

People with LD spoke about a sense of equality and control in the relationships they formed with staff in community settings, impacting on their sense of acceptance and belonging. People generally appreciated the support they received more than in long-term care. This appeared partly due to the word 'staff' being replaced, as it had negative connotations to previously unequal, overprotective or punitive relationships with staff in hospital: "The staff is better in here. We don't call them staff in here, we just call them helpers, keyworkers" (Cattermole et al., 1990, p. 148); "They're care workers, they're not staff!" (Sheerin et al., 2015, p. 275). The ability to cope with the community allowed some people to regain a sense of power, identity and independence in light of their previous negative experiences with staff: "There was nothing wrong with me. But the staff and the doctor thought I was a bit of a nutcase, that I couldnae look after myself. But I proved them wrong. I am happy the way I am, doing everything" (Jahoda & Markova, 2004, p. 725). Transitions from hospital appeared to allow people to build more reciprocal and collaborative relationships with staff. Several papers reported people with LD describing support as 'peers', 'friends' or even family, reflecting a sense of acceptance and belonging: "I don't call the staff 'staff', I call them family. They're my family" (Head et al., 2018, p. 67); "I really like it here. I like all the staff, they are my friends" (Holland & Meddis, 1997, p. 70). However, others with more forensic needs were at different stages in their relationships with professionals. They remained fearful and felt less supported by services; therefore aimed to prove their ability to belong in the community: "I'm keep on nowadays progressing with my independent living. I'm not giving any of these professional people any excuses or any cases to argue" (Davis et al., 2015, p. 157).

A sense of independence through leaving long-term care appeared to increase people's ability to cope with community life:

I'm not worried about things. What are the things that have changed for me – I've

improved a lot and I go out more on my own and I'm more independent and (I like)

not to be depending on other people. Yes I feel more comfortable in myself, because I

am not relying on anybody. Well, I've had no difficulties at all" (O'Brien et al., 2001,

p. 80).

This sense of independence and therefore belonging increased for the minority who were able

to attain meaningful employment within the community: "I work at Sainsbury's. I stack

shelves. I am completely independent" (Forrester-Jones et al., 2002, p. 750). Overall, having

a sense of belonging and independence allowed people to believe in a positive future: "It's

the first time I feel like I belong" (Forrester-Jones et al., 2002, p. 753).

     Subtheme 2.3: "Will I ever fit in?" Linked to the previous, this sub-theme refers to

the barriers that prevented people with LD from feeling like they truly belonged in the

community and cope with 'normal' life. This reflected a sense of internal stigma of being

'disabled' and in care. In addition, external factors such as societal stigma left people feeling

isolated and segregated from the wider community.

     The majority of papers documented disagreements with other LD residents, to the

point where some people did not want to interact with others, and longed for "more friends"

or "a friend without disabilities" (Holland & Meddis, 1997, p. 70). People struggled to find

friends outside their homes, impacting on the ability of people to feel socially integrated in

their community. Rejecting others they regarded as more 'disabled' appeared to shield from

a sense of internalised stigma. This led to some socially withdrawing: "I just don't want

them pushing, cramping all round me cause I'm no wantin' nothing to do with anybody else

[…] I'm wantin' to be kept a secret" (Davis et al., 2015, p. 158-159). The use of the word

'secret' implied a sense of shame over his identity or ability to fit in. People appeared to be

aware of stigma within the wider community, resulting in trying to maintain a sense of

superiority to their peers: "What happens if you've got visitors or mum and dad's come through. I just wouldnae let hospital boys come down to my house […] I want normal boys. They're no normal in here" (Jahoda & Markova, 2004, p. 725).

Outside of residences, people highlighted limited opportunities for interaction, impacting on their ability to feel accepted and socially integrate themselves into the community: "The neighbours don't talk to me much. I keep to myself. My second-oldest brother said, "You should keep to yourself around there. Mind your own business." And that's what I do" (Strnadova, 2019, p. 61). Experiences of the area not feeling safe or being bullied reinforced a lack of belonging: "The children look through my window and pull faces at me" (Forrester-Jones et al., 2002, p. 749). Living in the community for some people reinforced earlier experienced of stigma:

> I have always been bullied at school, and I'm still being bullied, and I don't like it, but I don't know why I'm a target. When I got punched, I went to the shop for help. He told me to get the eff out of his shop. It's really like I'm being a victim, but I brush it off. I try to keep myself calm, and just ignore it. It's alright, because I'm used to it, all my life […] and it's not going to change. I just have to live with it. (Strnadova, 2019, p. 61)

This led to many people feeling lonely, isolated and pessimistic about their future in the community: "See that's the ironic thing. I said she was gonna die lonely […] and not loved and […] it's gonna be me" (Ellem, 2012, p. 135). Experiences of rejection within society often meant people relied on staff for social contact and support. Some people found moving to independent living without the same level of support difficult, which again brought on feelings of loneliness: "It's just that when I get lonely like when the staff go off […] I kind of felt a bit lonely today because I was sitting […] it can be fairly lonely here" (Sheerin

et al., 2015, p. 275). Consequently, some people suggested they wanted to move out and live by themselves, cutting themselves off from the wider world: "I want to live by myself. I'd like to have a nice bungalow. I'd be happy—I'd rather live by myself, be on my own in my own nice house and get a cat or a dog" (Forrester-Jones et al., 2002, p. 747).

Discussion

This review used meta-ethnography to explore people with LD's experiences of transitioning from long-term care to community-based alternatives. The findings of the synthesis highlighted two over-arching themes: (1) From trauma to the unknown; and (2) Striving to belong. Within the themes, people's transitions into the community highlighted reflections of 'moving on' from negative experiences of historical care, and a chance to begin 'ordinary' life with the freedoms and independence that others have. Methods and barriers to regaining a sense of identity and control after the hierarchical nature of long-term emerged from the data. The synthesis highlights points for discussion that may have clinical and research implications.

'Deinstitutionalisation' and TC provide opportunities to substantially improve the QoL for people with LD. The findings suggest people prefer their lives within the community, with an increase in their sense of freedom, opportunity and independence allowing a more 'normal' life. This supports previous findings that community settings are superior to institutional care for people with LD (Chowdhury & Benson, 2011; Kozma et al., 2009). However, 'normalisation' and 'social role valorisation' (Wolfensberger, 2011) goes beyond the sense of 'normality' focused on in these studies, such as adaptive behaviour or family contact. People initially discussed the enjoyment of being able to complete daily living activities and having control over their possessions and finances; however, these skills have not extended to maintaining valued roles within the wider community for the majority. Similarly, previous research demonstrated QoL plateaus following the initial move, whilst

community integration remains low (Chowdhury & Benson, 2011). Without these roles, people with LD risk becoming further marginalised (Lemay, 2009). Consistent development in QoL for people with LD would require greater use of opportunities available in the community (Chowdhury & Benson, 2011). Individuals represented within this review detailed the barriers to social integration and employment, to the detriment of their sense of identity and belonging. These experiences can be understood partly by the prevalent attitudes regarding seeing people with LD as 'different' (Owen, Hubert, & Hollins, 2008). Through difficulties with language, others can view people with LD as the sum of their impairments and behaviours (Hubert & Hollins, 2006). By merely changing the physical environment, views towards people with LD by staff and wider society does not change (Johnson, 1998).

The desire to regain a sense of control within their environment and their relationships with others was apparent in the findings. The move allowed people with LD time to reflect on their lives and plan for the future. Endings to long-term stays in care acted as a process of fostering independence and 'moving on' from the past, offering potential for new growth (Head, 2017). However, removal of structures and routines without replacing them is linked to increased mental health difficulties (Young-Southward, Philo, & Cooper, 2017). Despite people appreciating freedom, privacy and independence; routine and activities within community settings are vital. People need to feel supported and integrated to foster and maintain feelings of belonging within their new environments. Enhancing people's QoL may help reduce incidents of re-hospitalisation. Readmission shortly after discharge due to community placements breaking down remains a concern (NHS England, 2015).

Loneliness was highlighted across papers, reflecting difficulties people have in feeling integrated within the community. People with LD rarely form significant relationships within their wider communities after transitioning from long-term hospitals (Bigby, 2008). Meaningful community integration for people leaving hospital care remains a significant

obstacle, which has severe implications for people with LD's sense of identity, purpose and mental health. Furthermore, people's rejection of peers they live with due to conflict or stigma, increases the likelihood of people further isolating themselves. This moves people further away from the meaningful life people strive for. Internalised stigma can be a barrier to seeking support and community integration within forensic populations (Gerber, Prince, Duffy, McDougall, Cooper, & Dowler, 2003). Perceptions of being 'different' from others often result in a negative self-image, increased stress and low self-esteem (Johnson, 1998).

Clinical Implications

These findings support the key principles of *Valuing People* (DoH, 2001) that people with LD should enjoy greater rights, choice, inclusion and independence. Clinical practice should continue to support policy in achieving these goals through improving opportunities and support for social integration, raising awareness of people with LD's vulnerabilities rather than their 'disabilities', and maintain an appropriate level of support whilst increasing people's level of choice, autonomy and independence (Bond & Hurst, 2009).

The majority of people detailed experiences of abuse and loss in their relationships, both historically and currently. Reflecting on and making sense of those experiences is more beneficial than trying to merely 'move on' (Fonagy, 2003). Within the review, people reflected on some of these experiences. During the transition process, additional support around people's emotional experiences of loss and change may aid in the overall impact of the experience. However, psychology will need to adapt to people with LD's individual needs. Given experiences of stigma and rejection, people with LD may not have had the opportunity to talk about their stories. Talking therapies may therefore be threatening or distressing for people with LD. Preparation, reasonable adjustments and support around what this may involve is required (Evans & Randle-Phillips, 2018).

The process of transition was often a time of anxiety and uncertainty due to a lack of involvement or control over the situation. All people can find change stressful and difficult. This is increasingly so for people with LD who are leaving 24-hour care and environments that have become familiar, sometimes over decades. People who were allowed to visit their new home first, or met their new support prior to moving appeared to settle more easily (Head et al., 2018). Therefore, continued efforts to join-up communication between inpatient and community services must be encouraged.

People within this review often spoke about the difficulties of living with others who have 'complex' difficulties, reducing satisfaction of their current environment and leading to internalising stigma. Training support staff in approaches such as Positive Behavioural Support (PBS) may not only help increase the individual's own QoL, but also minimise occurrences of 'challenging behaviour' in the environment, thereby creating a more safe space where people would like to remain (LaVigna & Willis, 2012).

Merely closing the remaining specialist hospitals as part of TC is unlikely to give people with LD the chance to fully integrate and belong in the community. Stigma, social exclusion and institutional practice continue to dominate some people's lives (Owen et al., 2008). There is a need to readdress the narratives of people with LD in society, but also raising awareness of the links stigma plays in increasing risk of mental health difficulties (British Psychological Society, 2016). Formulation work around understanding people's difficulties, rather than focusing on their 'disabilities', with those close to people with LD may have a cascading effect on reducing stigma more widely.

Some people with 'complex' needs may not be appropriate for community services at the current time due to the lack of investment in the services (Taylor, 2019). Therefore, clinical psychology may have an important role in working into community settings, using approaches such as PBS, whilst also advocating for more upstream changes to community

provision. PBS allows for more understanding and contextualisation of a person's behaviour, and the language used may help reduce any internalisation of a possible negative identity (Head et al., 2018), as highlighted by some people referring to themselves as "patient", "not normal" or "prisoner".

Limitations

Meta-ethnography relies on quotes and interpretations as reported by others. However, the themes developed do not claim to offer definitive explanations of people's experiences; it is one interpretation of others' interpretations. Each layer of interpretation moves further away from the accounts of the individual themselves. The analytic quality of the review is therefore influenced by the quality of each paper. However, by following the stages of meta-ethnography, themes are developed as transparently and replicably as possible. Furthermore, the results were developed across papers that differ in context, samples, settings and time, increasing the robustness of themes.

Papers were not excluded based on appraisal scores to reduce the risk of excluding valuable data that may be discarded by over-elaborate use of the CASP. The function of the CASP was to review and weigh the data in regards to the credibility of each paper's methodology and analysis rather than assessing any individual's comments about their lived experiences. Higher scoring papers provided more influence on findings, with quotes from low scoring papers only used to illustrate themes that similarly appeared in papers with higher CASP scores (Tong et al., 2012). This allowed for greater systematic quality, transparency and ease of replication, as well as to ensure a minimum standard of research included.

The use of the CASP, along with other qualitative appraisal tools, is still debated in regards to methodology and even the need to critically assess qualitative research. Current tools are often subjective, do not distinguish between different methodological approaches,

often mimic the positivist approach used in quantitative research and therefore offer an incomplete understanding of good 'quality' in qualitative research (Williams, Boylan, & Nunan, 2019). Therefore, further work and debate regarding quality assessment in qualitative research is needed.

The search strategy only allowed papers published in peer-reviewed journals. It is acknowledged that exclusion of alternative sources of qualitative data, which are known to have reported the experiences of many people with LD leaving care, such as books, ethnographic accounts or governmental papers may have influenced the findings. This decision was implemented to ensure a minimum standard of research included and the replicability of the process.

The majority of papers ($n = 14$) were based within the UK. Although some experiences of transitioning into the community may be similar between people, the local context and drivers may also affect the experience. Transitions occurred in a variety of contexts, ranging from prisons to 'congregated' settings in Ireland. The contextual differences would likely influence each individual's experience of transition. Therefore, the generalisability of these findings may be limited. However, it does provide general implications for clinical practice in providing support for easier transitions into the community, and follow-up support. This is particularly timely in the context of TC and its continued commitment to moving people with LD into community-based settings.

Future Research

Research should focus on exploring current experiences of people with LD moving into the community, such as in the context of TC (Head et al., 2018). Qualitative approaches exploring the experiences of people with LD is still emerging in research (Beail & Williams, 2014). Concerns over the implementation of TC (Taylor, 2019), exploring the perspectives of staff who may be working with increased 'complexity' is recommended.

Conclusion

Findings indicate that moving out of long-term care is often a positive move for people with LD. The sense of freedom, independence and choice to live a more 'normal' life is greatly valued and appreciated. Despite this, societal barriers remain in the form of continued stigma and lack of opportunity to integrate into wider community life, which can impact on people's sense of belonging and mental health. Implications for clinical practice in supporting people with LD to cope with transitions and increase community integration are suggested.

References

Banham, K., Garrett, M., McClean, A., Strydom, A., & Hassiotis, A. (2003). About leaving: making sense of moving on. *British Journal of Learning Disabilities*, *31*(2), 70-73. doi:10.1046/j.1468-3156.2003.00200.x

Barbour, R. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal, 322*(7294), 1115-1117. doi:10.1136/bmj.322.7294.1115

Barron, D., Hassiotis, A., & Paschos, D. (2011). Out-of-area provision for adults with intellectual disabilities and challenging behaviour in England: Policy perspectives and clinical reality. *Journal of Intellectual Disability Research*, *55*(9), 832-843. doi:10.1111/j.1365-2788.2011.01405.x

Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *27*(2), 85-96. doi:10.1111/jar.12088

Bigby, C. (2008). Known well by no- one: Trends in the informal social networks of middle- aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual & Developmental Disability*, *33*(2), 148-157. doi:10.1080/13668250802094141

Bigby, C., & Fyffe, C. (2006). Tensions between institutional closure and deinstitutionalisation: what can be learned from Victoria's institutional redevelopment? *Disability & Society*, *21*(6), 567-581. doi:10.1080/09687590600918032

Bond, R., & Hurst, J. (2010). How adults with learning disabilities view living

    independently. *British Journal of Learning Disabilities*, *38*(4), 286-292.

    doi:10.1111/j.1468-3156.2009.00604.x

Boodle, A., Ellem, K., & Chenoweth, L. (2013). Anna's story of life in prison. *British Journal*

    of Learning Disabilities, *42*(2), 117-124. doi:10.1111/bld.12015

Booth, T., Simons, K., & Booth, W. (1989). Perspectives of people with learning difficulties

    on relocation and community care. *International Journal of Rehabilitation*

    Research, *12*(2), 167-174. doi:10.1097/00004356-198906000-00005

Booth, W., Booth, T., & Simons, K. (1990). Return journey: The relocation of adults from

    long-stay hospital into hostel accommodation. *The British Journal of Mental*

    Subnormality, *36*(71), 87-97. doi:10.1179/bjms.1990.010

British Psychological Society. (2016). *Working relationally with adults with an intellectual*

    disability: A discussion [PDF file]. Retrieved from

    https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Divisions/DCoP/

    INF311%20WEB.pdf

Britten, N., Campbell, R., Pope, C., Donovan, J., Morgan, M., & Pill, R. (2002). Using meta-

    ethnography to synthesise qualitative research: A worked example. *Journal of Health*

    Services Research & Policy, *7*(4), 209-215. doi:10.1258/135581902320432732

Brown, J., Dodd, K., & Vetere, A. (2010). 'I am a normal man': A narrative analysis of the

    accounts of older people with Down's syndrome who lived in institutionalised

    settings. *British Journal of Learning Disabilities*, *38*(3), 217-224. doi:10.1111/j.1468-

    3156.2009.00596.x

Burns, M., Silberman, W., & McCann, G. (2010). 'It's what happens when you're ready to leave hospital that's really important' - commissioning secure services for people with learning disabilities. *Journal of Learning Disabilities and Offending Behaviour*, *1*(1), 17-28. doi:10.5042/jldob.2010.0174

Cattermole, M., Jahoda, A., & Markova, I. (1990). Quality of life for people with learning difficulties moving to community homes. *Disability, Handicap & Society*, *5*(2), 137-152. doi:10.1080/02674649066780141

Chowdhury, M., & Benson, B. (2011). Deinstitutionalization and quality of life of individuals with intellectual disability: A review of the international literature. *Journal of Policy and Practice in Intellectual Disabilities*, *8*(4), 256-265. doi:10.1111/j.1741-1130.2011.00325.x

Cooke, A., Smith, D., & Booth, A. (2012). Beyond PICO: The SPIDER tool for qualitative evidence synthesis. *Qualitative Health Research, 22*(10), 1435-1443. doi:10.1177/1049732312452938

Davis, A., Doyle, M., Quayle, E., & O'Rourke, S. (2015). Am I there yet? The views of people with learning disability on forensic community rehabilitation. *Journal of Intellectual Disabilities and Offending Behaviour*, *6*(3/4), 148-164. doi:10.1108/jidob-08-2015-0024

Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century. (CM4683).* London. UK: HMSO. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf

Department of Health. (2010). *Valuing people now: Summary report March 2009 to September 2010* [PDF File]. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

Department of Health. (2012). *Transforming care: A national response to Winterbourne View hospital* [PDF file]. Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213215/final-report.pdf

Department of Health (2015). *Transforming Care for people with learning disabilities – Next Steps* [PDF file]. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

Dias, S., Ware, R., Kinner, S., & Lennox, N. (2013). Co-occurring mental disorder and intellectual disability in a large sample of Australian prisoners. *Australian & New Zealand Journal of Psychiatry*, *47*(10), 938-944. doi:10.1177/0004867413492220

Drake, G. (2013). The transinstitutionalisation of people living in licensed boarding houses in Sydney. *Australian Social Work*, *67*(2), 240-255. doi:10.1080/0312407x.2013.843714

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research, 20*(2), 148-158. doi:10.1177/104973230935832

Ellem, K. (2012). Experiences of leaving prison for people with intellectual disability. *Journal of Learning Disabilities and Offending Behaviour*, *3*(3), 127-138. doi:10.1108/20420921211305873

Ellem, K., Wilson, J., & Chui, W. (2012). Effective responses to offenders with intellectual disabilities: Generalist and specialist services working together. *Australian Social Work*, *65*(3), 398-412. doi:10.1080/0312407x.2011.625433

Emerson, E., & Einfeld, S. L. (2011). *Challenging behaviour: analysis and intervention in people with intellectual disabilities* (3rd ed.). Cambridge: Cambridge University Press.

Emerson, E., & Hatton, C. (1996). Deinstitutionalization in the UK and Ireland: Outcomes for service users. *Journal of Intellectual & Developmental Disability*, *21*(1), 17-37. doi:10.1080/13668259600033021

Evans, L., & Randle-Phillips, C. (2018). People with intellectual disabilities' experiences of psychological therapy: A systematic review and meta-ethnography. *Journal of Intellectual Disabilities*, 174462951878435. doi:10.1177/1744629518784359

Fakhoury, W., & Priebe, S. (2007). Deinstitutionalization and reinstitutionalization: Major changes in the provision of mental healthcare. *Psychiatry*, *6*(8), 313-316. doi:10.1016/j.mppsy.2007.05.008

Fazel, S., Xenitidis, K., & Powell, J. (2008). The prevalence of intellectual disabilities among 12000 prisoners - A systematic review. *International Journal of Law and Psychiatry*, *31*(4), 369-373. doi:10.1016/j.ijlp.2008.06.001

Fish, R., & Lobley, J. (2001). Evaluating a forensic service for people with learning disabilities. *Journal of Learning Disabilities*, *5*(2), 97-109. doi:10.1177/146900470100500201

Fonagy, P. (2003). Genetics, developmental psychopathology, and psychoanalytic theory:

The case for ending our (not so) splendid isolation. *Psychoanalytic Inquiry*, *23*(2),

218-247. doi:10.1080/07351692309349032

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., &

Beecham, J. (2002). The quality of life of people 12 years after resettlement from long

stay hospitals: Users' views on their living environment, daily activities and future

aspirations. *Disability & Society*, *17*(7), 741-758. doi:10.1080/0968759021000068469

Gerber, G., Prince, P., Duffy, S., McDougall, L., Cooper, J., & Dowler, S. (2003).

Adjustment, integration, and quality of life among forensic patients receiving

community outreach services. *International Journal of Forensic Mental Health*, *2*(2),

129-136. doi:10.1080/14999013.2003.10471184

Hamilton, D., Sutherland, G., & Iacono, T. (2005). Further examination of relationships

between life events and psychiatric symptoms in adults with intellectual

disability. *Journal of Intellectual Disability Research*, *49*(11), 839-844.

doi:10.1111/j.1365-2788.2005.00761.x

Head, A. (2017). *How people with intellectual disabilities experience transitions through the*

transforming care programme: A grounded theory study (Unpublished doctoral

dissertation). Retrieved from

https://pdfs.semanticscholar.org/6de4/347990365f68a6af3f76352ea977b2f9870c.pdf

Head, A., Ellis-Caird, H., Rhodes, L., & Parkinson, K. (2018). Transforming identities

through Transforming Care: How people with learning disabilities experience moving

out of hospital. *British Journal of Learning Disabilities*, *46*(1), 64-70.

doi:10.1111/bld.12213

Holland, A., & Meddis, R. (1997). People living in community homes: Their views. *British Journal of Learning Disabilities*, *25*(2), 68-72. doi:10.1111/j.1468-3156.1997.tb00013.x

Holland, S., & Persson, P. (2011). Intellectual disability in the Victorian prison system: characteristics of prisoners with an intellectual disability released from prison in 2003–2006. *Psychology, Crime & Law*, *17*(1), 25-41. doi:10.1080/10683160903392285

Holland, T., Clare, I., & Mukhopadhyay, T. (2002). Prevalence of 'criminal offending' by men and women with intellectual disability and the characteristics of 'offenders': Implications for research and service development. *Journal of Intellectual Disability Research*, *46*(s1), 6-20. doi:10.1046/j.1365-2788.2002.00001.x

Hubert, J., & Hollins, S. (2006). Men with severe learning disabilities and challenging behaviour in long-stay hospital care. *British Journal of Psychiatry*, *188*(1), 70-74. doi:10.1192/bjp.bp.105.010223

Hutchison, M., Hummer, D., & Wooditch, A. (2013). A survey of existing program strategies for offenders with intellectual and developmental disabilities under correctional supervision in Pennsylvania. *Probation Journal*, *60*(1), 56-72. doi:10.1177/0264550512470189

Ideas Collective. (2015). *Keeping out of trouble: Alternatives to prison or hospital for people with learning disabilities who get into trouble with the law* [PDF file]. Retrieved from http://www.learningdisabilityengland.org.uk/wp-content/uploads/2018/04/Keeping-out-of-trouble.pdf

Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual

disabilities moving from institutions and family home. *Journal of Intellectual*

Disability Research, *48*(8), 719-729. doi:10.1111/j.1365-2788.2003.00561.x

Johnson, K. (1998). Deinstitutionalisation: The management of rights. *Disability &*

Society, *13*(3), 375-387. doi:10.1080/09687599826696

Karban, K., Paley, C., & Willcock, K. (2013). Towards support: Evaluating a move to

independent living. *Housing, Care and Support*, *16*(2), 85-94. doi:10.1108/hcs-02-

2013-0001

Kozma, A., Mansell, J., & Beadle-Brown, J. (2009). Outcomes in different residential

settings for people with intellectual disability: A systematic review. *American Journal*

on Intellectual and Developmental Disabilities, *114*(3), 193-222. doi:10.1352/1944-

7558-114.3.193

LaVigna, G., & Willis, T. (2012). The efficacy of positive behavioural support with the most

challenging behaviour: The evidence and its implications. *Journal of Intellectual &*

Developmental Disability, *37*(3), 185-195. doi:10.3109/13668250.2012.696597

Lemay, R. (2009). Deinstitutionalization of people with developmental disabilities: A review

of the literature. *Canadian Journal of Community Mental Health*, *28*(1), 181-194.

doi:10.7870/cjcmh-2009-0014

Loucks, N. (2007). *No one knows: Offenders with learning difficulties and learning*

disabilities – Review of prevalence and associated needs [PDF file]. Retrieved from

http://www.ohrn.nhs.uk/resource/policy/NoOneKnowPrevalence.pdf

Mansell, J. (2006). Deinstitutionalisation and community living: Progress, problems and

    priorities. *Journal of Intellectual & Developmental Disability*, *31*(2), 65-76.

    doi:10.1080/13668250600686726

Mansell, J., & Beadle-Brown, J. (2010). Deinstitutionalisation and community living:

    position statement of the Comparative Policy and Practice Special Interest Research

    Group of the International Association for the Scientific Study of Intellectual

    Disabilities. *Journal of Intellectual Disability Research*, *54*(2), 104-112.

    doi:10.1111/j.1365-2788.2009.01239.x

Martin, L., & Ashworth, M. (2010). Deinstitutionalization in Ontario, Canada: Understanding

    who moved when. *Journal of Policy and Practice in Intellectual Disabilities*, *7*(3),

    167-176. doi:10.1111/j.1741-1130.2010.00261.x

McConkey, R., Abbott, S., Walsh, P., Linehan, C., & Emerson, E. (2007). Variations in the

    social inclusion of people with intellectual disabilities in supported living schemes

    and residential settings. *Journal of Intellectual Disability Research*, *51*(3), 207-217.

    doi:10.1111/j.1365-2788.2006.00858.x

McConkey, R., McConaghie, J., Mezza, F., & Wilson, J. (2003). Moving from long-stay

    hospitals. *Journal of Learning Disabilities*, *7*(1), 78-93.

    doi:10.1177/1469004703007001986

National Development Team for Inclusion. (2010), *Supported living – Making the move.*

    Developing supported living options for people with learning disabilities [PDF File].

    Retrieved from https://www.ndti.org.uk/uploads/files/Supported_Living_-

    _Making_the_Move,_May_2010.pdf

NHS England. (2015). *Building the right support: A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition* [PDF File]. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/10/ld-nat-imp-plan-oct15.pdf

Noblit, G. W., & Hare, R. D. (1988). *Meta-ethnography: Synthesising qualitative studies*. London: Sage Publications.

O'Brien, P., Thesing, A., Tuck, B., & Capie, A. (2001). Perceptions of change, advantage and quality of life for people with intellectual disability who left a long stay institution to live in the community. *Journal of Intellectual & Developmental Disability*, *26*(1), 67-82. doi:10.1080/13668250020032778

Owen, K., Hubert, J., & Hollins, S. (2008). Moving home: the experiences of women with severe intellectual disabilities in transition from a locked ward. *British Journal of Learning Disabilities*, *36*(4), 220-226. doi:10.1111/j.1468-3156.2007.00484.x

Parkes, J., Pyer, M., Ward, A., Doyle, C. and Dickens, G. (2015). 'Going into the unknown': Experiences of male patients in secure settings during environmental transition. *International Journal of Mental Health Nursing*, 24(1), 2-10. doi:10.1111/inm.12088

Public Health Resource Unit. (2006). *The Critical Skills Appraisal Programme: making sense of evidence.* Public Health Resource Unit: England. Retrieved from: http://www.casp-uk.net/

Purandare, K., & Wijeratne, A. (2015). Reflections on the use of a specialist acute assessment

    and treatment unit for adults with intellectual disability. *Advances in Mental Health*

    and Intellectual Disabilities, *9*(3), 132-138. doi:10.1108/amhid-07-2014-0029

Reed, S., Russell, A., Xenitidis, K., & Murphy, D. (2004). People with learning disabilities in

    a low secure in-patient unit: Comparison of offenders and non-offenders. *British*

    Journal of Psychiatry, *185*(6), 499-504. doi:10.1192/bjp.185.6.499

Salmon, N., Garcia Iriarte, E., Donohoe, B., Murray, L., Singleton, G., Barrett, M., & Dillon,

    M. (2018). Our homes: An inclusive study about what moving house is like for people

    with intellectual disabilities in Ireland. *British Journal of Learning Disabilities*, *47*(1),

    19-28. doi:10.1111/bld.12251

Schlossberg, N. (1981). A model for analyzing human adaptation to transition. *The*

    Counseling Psychologist, *9*(2), 2-18. doi:10.1177/001100008100900202

Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A

    systematic review. *Research in Developmental Disabilities*, *32*(6), 2164-2182.

    doi:10.1016/j.ridd.2011.07.005

Sheerin, F., Griffiths, C., de Vries, J., & Keenan, P. (2015). An evaluation of a community

    living initiative in Ireland. *Journal of Intellectual Disabilities*, *19*(3), 266-281.

    doi:10.1177/1744629515573679

Simpson, G., & Price, V. (2010). From inclusion to exclusion: Some unintended

    consequences of Valuing People. *British Journal of Learning Disabilities*, *38*(3), 180-

    186. doi:10.1111/j.1468-3156.2009.00572.x

Slevin, E., McConkey, R., Truesdale-Kennedy, M., & Taggart, L. (2008). People with

    learning disabilities admitted to an assessment and treatment unit: Impact on

challenging behaviours and mental health problems. *Journal of Psychiatric and Mental Health Nursing*, *15*(7), 537-546. doi:10.1111/j.1365-2850.2008.01262.x

Strnadová, I. (2019). Transitions in the lives of older adults with intellectual disabilities: "Having a sense of dignity and independence". *Journal of Policy and Practice in Intellectual Disabilities*, *16*(1), 58-66. doi:10.1111/jppi.12273

Strnadová, I., & Evans, D. (2012). Subjective quality of life of women with intellectual disabilities: The role of perceived control over their own life in self-determined behaviour. *Journal of Applied Research in Intellectual Disabilities*, *25*(1), 71-79. doi:10.1111/j.1468-3148.2011.00646.x

Talbot, J. (2008). *No one knows – Prisoners' voices: Experiences of the criminal justice system by prisoners with learning disabilities and difficulties* [PDF file]. Retrieved from http://www.prisonreformtrust.org.uk/Portals/0/Documents/No%20One%20Knows%20report-2.pdf

Tanner, D., Glasby, J., & McIver, S. (2014). Understanding and improving older people's experiences of service transitions: Implications for social work. *British Journal of Social Work*, 45(7), 2056-2071. doi:10.1093/bjsw/bcu095

Taylor, J. (2019). Delivering the Transforming Care programme: a case of smoke and mirrors? *BJPsych Bulletin*, 1-3. doi:10.1192/bjb.2019.3

Taylor, J., McKinnon, I., Thorpe, I., & Gillmer, B. (2017). The impact of transforming care on the care and safety of patients with intellectual disabilities and forensic needs. *BJPsych Bulletin*, *41*(4), 205-208. doi:10.1192/pb.bp.116.055095

Tong, A., Flemming, K., McInnes, E., Oliver, S., & Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BioMed Central Medical Research Methodology, 12*(1), 181-188. doi:10.1186/1471-2288-12-181

Walker, C., Ryan, T., & Walker, A. (1995). A step in the right direction: people with learning difficulties moving into the community. *Health & Social Care in the Community*, *3*(4), 249-260. doi:10.1111/j.1365-2524.1995.tb00026.x

Warner, M. (2018, November 21). *Out of the shadows: The untold story of people with learning disabilities in prison*. Retrieved from https://www.bjp-online.com/2018/11/out-of-the-shadows-prison/

Williams, E., Thrift, S., & Rose, J. (2018). The subjective experiences of women with intellectual disabilities and offending behaviour: Exploring their experiences of 'home'. *International Journal of Developmental Disabilities*, *64*(3), 132-143. doi:10.1080/20473869.2017.1413153

Williams, W., Boylan, A-M., & Nunan, D. (2019). *Critical appraisal of qualitative research - Necessity, partialities and the issue of bias.* Retrieved from https://ora.ox.ac.uk/objects/uuid:02c2003d-7262-4458-bdd8-de8fe6848917/download_file?file_format=pdf&safe_filename=Williams_etal_2019_Critical_appraisal_of_qualitative_research.pdf&type_of_work=Journal+article

Wolfensberger, W. (2011). Social role valorisation: A proposed new term for the principle of normalisation. *Intellectual and Developmental Disabilities*, *49*(6), 435-440. http://dx.doi.org/10.1352/1934-9556-49.6.435

Woodman, A., Mailick, M., Anderson, K., & Esbensen, A. (2014). Residential transitions among adults with intellectual disability across 20 years. *American Journal on*

Intellectual and Developmental Disabilities, *119*(6), 496-515. doi:10.1352/1944-7558-119.6.496

Young, L., Sigafoos, J., Suttie, J., Ashman, A., & Grevell, P. (1998). Deinstitutionalisation of persons with intellectual disabilities: A review of Australian studies. *Journal of Intellectual & Developmental Disability*, *23*(2), 155-170. doi:10.1080/13668259800033661

Young-Southward, G., Rydzewska, E., Philo, C., & Cooper, S. (2017). Physical and mental health of young people with and without intellectual disabilities: Cross-sectional analysis of a whole country population. *Journal of Intellectual Disability Research*, *61*(10), 984-993. doi:10.1111/jir.12422

Tables

Table 1

Search terms within the SPIDER framework

SPIDER tool	Search Terms
S (AND)	"intellectual disabilit*" OR "intellectual impairment" OR "intellectual difficult*" OR "intellectual handicap" OR "learning disabilit*" OR "learning difficult*" OR "mental handicap" OR "mental impairment" OR "mental deficiency" OR "mental retardation" OR "special needs" OR "learning needs" OR "cognitive deficiency" OR "cognitive impairment" OR "cognitive needs" OR "cognitive disabilit*" OR "developmental disorder" OR "developmental disabilit*"
P of I (AND)	inpatient* OR institution* OR hospital* OR psychiatric OR ward OR unit OR forensic OR secure OR "long stay" OR "long term" OR prison OR resident*
P of I (2) (AND)	transition* OR moving OR move OR deinstitutionalis* OR discharge OR rehabilitat* OR deinstitutionaliz* OR leave OR leaving OR community OR relocat* OR release
D (OR)	interview* OR "focus group*"
E (OR)	experience* OR view* OR opinion* OR story OR stories OR perspective*
R (OR)	qualitative* OR "thematic analysis" OR ethnograph* OR phenomenolog* OR "grounded theory"

Note. Additional subject terms

PsycINFO Thesaurus Terms

- (DE "Learning Disorders" OR DE "Learning Disabilities" OR DE "Developmental Disabilities") OR (DE "Learning Disabilities" OR DE "Learning Disorders") OR (DE "Cognitive Impairment" OR DE "Cognitive Ability" OR DE "Intellectual Development Disorder") OR (DE "Cognitive Ability" OR DE "Cognitive Impairment")

- (DE "Psychiatric Units) OR (DE "Psychiatric Hospitals") OR (DE "Institutional Release" OR DE "Institutionalization") OR (DE "Facility Discharge") OR (DE "Hospital Discharge" OR DE "Facility Discharge" OR DE "Hospitalization" OR DE "Institutional Release" OR DE "Psychiatric Hospital Discharge" OR DE "Discharge Planning") OR (DE "Prisoners" OR DE "Prisons") OR (DE "Prisoners" OR DE "Criminal Offenders" OR DE "Criminal Rehabilitation" OR DE "Reintegration") OR (DE "Residential Care Institutions")

- (DE "Discharge Planning" OR DE "Deinstitutionalization" OR DE "Facility Discharge" OR DE "Hospital Discharge" OR DE "Institutional Release" OR DE "Psychiatric Hospital Discharge") OR (DE "Deinstitutionalization" OR DE "Community Mental Health" OR DE "Community Mental Health Services" OR DE "Discharge Planning" OR DE "Habilitation" OR DE "Institutional Release" OR DE "Rehabilitation")) OR (DE "Reintegration" OR DE "Socialization" OR DE "Prisoners" OR DE "Social Processes" OR DE "Society")

- (DE "Qualitative Measures") OR (DE "Qualitative Methods" OR DE "Focus Group" OR DE "Grounded Theory" OR DE "Interpretative Phenomenological Analysis" OR DE "Narrative Analysis" OR DE "Semi-Structured Interview" OR DE "Thematic Analysis") OR (DE "Experiences (Events)" OR DE "Life Experiences" OR DE "Life Review" OR DE "Interpretative Phenomenological Analysis")) OR (DE "Public Opinion" OR DE "Attitudes" OR DE "Community Attitudes") OR (DE "Attitudes" OR DE "Preferences" OR DE "Adult Attitudes" OR DE "Attitude Change")

CINAHL/Medline MeSH terms

- (MH "Intellectual Disability+") OR (MH "Learning Disorders") OR (MH "Mental Retardation, X-Linked") OR (MH "Developmental Disabilities")

- (MH "Inpatients") OR (MH "Correctional Health Services") OR (MH "Correctional Facilities") OR (MH "Hospitals, Psychiatric") OR (MH "Mentally Ill Offenders") OR (MH "Hospital Units") OR (MH "Residential Care") OR (MH "Residential Facilities") OR (MH "Rehabilitation Centers")

- (MH "Transitional Care") OR (MH "Continuity of Patient Care") OR (MH "Discharge Planning") OR (MH "Transfer, Discharge") OR (MH "Patient Discharge Education") OR (MH "Early Patient Discharge") OR (MH "Patient Discharge") OR (MH "After Care") OR (MH "Community Mental Health Services") OR (MH "Correctional Health Services") OR (MH "Deinstitutionalization") OR (MH "Rehabilitation") OR (MH "Relocation")

- (MH "Qualitative Studies+") OR (MH "Phenomenology") OR (MH "Life Experiences") OR (MH "Social Attitudes") OR (MH "Patient Attitudes") OR (MH "Attitude") OR (MH "Attitude to Aging") OR (MH "Attitude to Change") OR (MH "Attitude to Disability") OR (MH "Attitude to Health") OR (MH "Attitude to Illness") OR (MH "Attitude to Life") OR (MH "Attitude to Risk") OR (MH "Personal Satisfaction") OR (MH "Social Constructionism") OR (MH "Semi-Structured Interview") OR (MH "Interviews")

Table 2

CASP Quality Appraisal

CASP Checklist	Booth et al. (1990)	Brown et al. (2010)	Burns et al. (2010)	Cattermole et al. (1990)	Davis et al. (2015)	Ellem (2012)	Fish & Lobley (2001)	Forrester-Jones et al. (2002)	Head et al. (2018)	Holland & Meddis (1997)
Design Strategy?	1	3	2	2	3	3	3	3	3	3
Recruitment Strategy?	2	2	3	2	3	2	1	2	2	3
Data Collected appropriately?	2	3	3	3	3	2	2	3	3	3
Relationship between researcher and participants considered?	1	3	1	1	3	1	2	2	1	1
Ethical issues considered?	1	3	1	1	3	2	1	2	2	2
Rigorous data analysis?	1	3	3	3	3	3	1	3	3	1
Clear findings?	2	3	2	2	3	2	2	3	2	1
Valuable?	2	3	2	2	3	3	2	2	3	1
Total Score (out of 24)	**12**	**23**	**16**	**16**	**24**	**18**	**14**	**20**	**19**	**15**

Table 2

(Continued)

CASP Checklist	Jahoda & Markova (2004)	Karban et al. (2013)	McConkey et al. (2003)	O'Brien et al. (2001)	Sheerin et al. (2015)	Strnadova (2019)	Strnadova & Evans (2012)	Walker et al. (1995)	Williams et al. (2018)
Design Strategy?	3	3	3	3	3	3	3	3	3
Recruitment Strategy?	2	2	2	2	2	3	3	3	3
Data Collected appropriately?	3	3	3	3	3	3	2	3	3
Relationship between researcher and participants considered?	1	1	1	2	2	2	2	1	2
Ethical issues considered?	2	3	2	2	3	2	3	3	3
Rigorous data analysis?	2	2	1	2	2	3	3	1	3
Clear findings?	2	3	2	2	3	3	3	3	3
Valuable?	3	2	2	2	3	3	3	2	3
Total Score (out of 24)	**18**	**19**	**16**	**18**	**21**	**22**	**22**	**19**	**23**

1-47

Table 3

The seven stages of Noblit & Hare's meta-ethnographic approach

Stage of Meta-Ethnography (Noblit & Hare, 1988)	Description of process
Stage 1: Getting started	The research topic was identified: "the experiences of people of learning disabilities going through a residential transition from long-term care". An initial literature search and overview of key studies indicated that qualitative research has been limited over the years, in particular studies highlighting service-user experiences of transitions, therefore a focus on exploring this from a service-user perspective was chosen. The majority of research had focused on staff or carer perspectives, or included ethnographic, case-study or vignette type information rather than qualitative analysis. Papers also reflected a variety of different contexts, therefore a focus was placed on investigating the experiences of leaving long-term, more restrictive care such as older institutions, mental health/forensic hospitals and prison.
Stage 2: Deciding what is relevant to the initial interest	A specific aim was determined to include and synthesise studies that included participant quotes to conceptualise themes. Papers had to have used a qualitative analysis on the information resulting in first-order and/or second-order results. From this, inclusion and exclusion criteria were identified, and a systematic search strategy created based on the SPIDER qualitative framework.
Stage 3: Reading the studies	Nineteen papers were identified. The synthesised papers were read repeatedly to extract information relevant to transitional experiences from long-term care of people with learning disabilities. Notes regarding key concepts and ideas were made for each paper. A Microsoft Excel spreadsheet with columns pertaining to each synthesised paper and rows listing first-order interpretations (i.e. participant quotes), followed by second-order interpretations (i.e. author interpretations), along with any initial ideas regarding third order interpretations and contextual information (i.e. how second order interpretations related to one another). This stage was quality-checked by the academic research supervisor.
Stage 4: Determining how the studies are related	The list of key ideas, concepts, themes and interpretations identified in the previous stage were further reviewed, juxtaposed and colour-coded in Microsoft Excel. This resulted in the identification of five key aspects of the relationship under investigation: clients' experiences of past care, uncertainty over transitions, feelings of freedom, feelings of independence and belonging, and continued stigma or difficulties. Key concepts were grouped within each of these domains, and to investigate the relationships between them. From

Table 3

(Continued)

	this, two over-arching themes were identified relating to the trauma, chaos and uncertainty in past care, and the continued search for 'normality' in the community. Reciprocal translation was chosen as the method for this stage's translation process due to the strong similarities identified between the second order interpretations of the synthesised papers. Although there were some differences and juxtapositions, a refutational synthesis was not deemed appropriate due to the similarity of phenomena described across the studies. Most phenomena were interpreted to have arisen from similar situations, for example, relational perceptions within relationships with family, peers, staff and the wider public. This stage was quality-checked by the academic research supervisor.
Stage 5: Translating the studies into one another	The main concepts and a description for each paper were integrated using the reciprocal translation process. This was conducted chronologically, i.e. by date of publication. Once paper 1 and paper 2 were thematically compared and integrated, the resulting synthesis was then compared with paper 3 to identify similar concepts and differences. This was completed until all 19 papers had been integrated. The starting point was the concepts and categories created above, but keeping an open mind for emerging, different concepts. This was quality-checked by further re-reading of the studies and the information recorded in Stages 3 and 4. Conceptualisation and third order interpretations were avoided to ensure that the original interpretations were preserved. This stage was further quality-checked by the academic research supervisor.
Stage 6: Synthesising translations	The combination of the above stages resulted in third order interpretations derived from the synthesis of the first and second order constructs reported in the primary studies. This created a 'line of argument' whereby second-order juxtapositions and similarities were described using psychological concepts and language. This resulted in new, interpretative conceptualisations and understandings of the same phenomena in each synthesised study. Before the final stage, these conceptualisations were discussed with the research team.
Stage 7: Expressing the synthesis	The intended audience was identified as mental health/learning disability professionals and service-users. The conceptualisations and themes identified in the previous stages were expressed in prose, with participant quotes used to highlight all themes and concepts. There was a focus on how the results fit into existing and new research, clinical practice and current policy.

Table 4

Characteristics of the studies included in the review

Authors	Location	Research Question	Participants	Data Collection	Analysis	CASP Score (out of 24)
Booth, Booth, & Simons (1990)	Yorkshire, UK	What are the most and least successful aspects of new placements for people who have left hospital	16 people (8 men, 8 women) who left hospital 1 year ago – 12 interviewed, median age of 34	One-to-one interviews with participants, staff and family	No clear method – 'themes' and some narrative stories	12
Brown, Dodd, & Vetere (2009)	Surrey, UK	Documenting the life-stories of older people with Down's Syndrome who lived in institutions	6 older people with Down's Syndrome – age range 50-56	Semi-structured, 1:1 interviews in each person's home	Narrative Analysis	23
Burns, Silberman, & McCann (2010)	England, UK	Scoping exercise to gather information from service users in order to develop commissioning of secure LD services	Established service user group with experience of providing expert advice in policy development (sample size not given)	Semi-structured, steering group	Thematic Analysis	16
Cattermole, Jahoda, & Markova (1990)	Scotland, UK	Perceptions of people with LD moving from hospital and parental homes to community-based residencies, with a focus on quality of life	15 people with learning difficulties – 8 men from hospital group between ages of 20-55	Mixed methods. Semi-structured interviews both pre- and post-hospital move	Summaries and themes on three dimensions of (1) resource, (2) regulation, and (3) closeness	16
Davis, Doyle, Quayle, & O'Rourke (2015)	Scotland, UK	What are the views of people with LD subject to community rehabilitation orders?	10 male on community-based order, age range 23-49, previously in hospital	Semi-structured interviews	Interpretative Phenomenological Analysis	24
Ellem (2012)	Queensland, Australia	What are the community re-entry experiences people with LD leaving prison?	10 people with LD – 7 men and 3 women. Age range from 26 to 68 years old	Semi-structured life stories method over 1 year	Themes derived from Narrative and Thematic Analysis	18
Fish & Lobley (2001)	Lancashire, UK	What are the differences in QoL between a medium secure unit for people with LD and community-based service?	All residents who moved to a community-based home. No participant information or demographics given	Mixed methods – interviews after move and quality of life measure	Themes based on participant quotes, staff and research observations	14

Table 4

(Continued)

Authors	Location	Research Question	Participants	Data Collection	Analysis	CASP Score (out of 24)
Forrester-Jones et al. (2002)	England, UK	Service user views on their quality of life after living in the community for 12 years after resettlement from hospital	196 people with LD in addition to 128 people with 'mental health problems'	Structured interview with open questions	Thematic content analysis	20
Head, Ellis-Caird, Rhodes, & Parkinson (2018)	Hertfordshire, UK	How do people with LD experience the process of moving as part of Transforming Care?	11 people with mild/moderate LD and mental health or behaviour that challenged. All moved between 4 months and 2 years prior	1:1 semi-structured interviews – adapted for each participant	Grounded Theory	19
Holland & Meddis (1997)	England, UK	What are the views of people with LD living in a residential service and what factors influence this?	6 people with LD – 4 men, 2 women. 3 moved from hospitals or units. Age range between 21 and 42.	Interviews with open-ended questions. Questionnaire also used	Vignettes and themes derived from interview tape recordings	15
Jahoda & Markova (2004)	Scotland, UK	How do people with LD cope with social stigma after moving from institutions and family homes?	18 people with LD moving from long-stay hospitals. 15 men, 3 women in hospital group. Age range 20-55, mean 37. 11	Semi-structured interviews. At least 2 interviews per person	Both groups analysed separately to allow comparison. Content analysis. Summaries of each person then merged into 'themes'	18
Karban, Paley, & Willcock (2013)	United Kingdom	An evaluation of the experiences of people with LD or mental health needs moving to independent living	40 service users. 10 co-researchers with experiences of using services or caring for others	1:1 interviews with residents, family carers and staff	Data coded and themes identified, then cross-checked with research team	19
McConkey, McConaghie, Mezza, & Wilson (2003)	Northern Ireland, UK	What are the views of people with LD and their relatives regarding moving from long-stay hospitals in Northern Ireland?	39 people with LD interviewed. Median age of 37 from overall sample of 68 (37 male, 31 female).	Interviews and questionnaires	Not clear – patterns of responses summarised with highlighted quotes	16

1-51

Table 4

(Continued)

Authors	Location	Research Question	Participants	Data Collection	Analysis	CASP Score (out of 24)
O'Brien, Thesing, Tuck & Capie (2001)	New Zealand	To investigate the outcomes of the move into community homes in 1988, with a focus on the effects of moving and amount of community involvement	9 people with LD who fell into low and medium support needs. Age range from 37-65 (mean = 53). Length of stay in hospital ranged from 9-31 years (mean = 17 years)	Semi-structured interviews	Coding and content analysis. Reliability checking by wider research team	18
Sheerin, Griffiths, de Vries, & Keenan (2015)	Dublin, Ireland	To understand the significance of moving in terms of integration into the community	5 people with LD – 3 women, 2 men. Mild to moderate levels of LD	Semi-structured interviews within own homes	Thematic Analysis	21
Strnadova (2019)	New South Wales, Australia	What types of transitions are experienced by older people with LD? What are the barriers to planning for the future?	17 people with LD (9 women, 8 men) aged 40 years and above. Age range 40-69 (mean 50.8 years)	Semi-structured interviews	Inductive content analysis	22
Strnadova & Evans (2012)	Sydney, Australia & Prague, Czech Republic	The subjective perception of quality of life in adult women with LD, with a focus on self-determinism and barriers to this	55 women (40 years old and above) with LD from Sydney (mean age = 49) and Prague (mean age = 51).	Semi-structured interviews with 1 year follow-up	Grounded Theory	22
Walker, Ryan, & Walker (1995)	North-West England, UK	To evaluate the quality of life offered to people with LD following a move into the community	102 people with LD - 58 men, 44 women. 22 people were interviewed. Average age was 48.7 years	Unstructured interviews with participants, staff and family	Unknown –analysis with quotes to represent themes	19
Williams, Thrift, & Rose (2018)	Midlands, UK	To explore how women with LD and offending behaviour experience the places they have lived, and what they would value in future	7 women with LD all living on a low-secure LD unit. All White British	Semi-structured interviews	Interpretative Phenomenological Analysis	23

Table 5

Summary of papers contributing to each theme

| Included Papers	Over-arching themes / Subthemes	From Trauma to the Unknown			Striving to Belong	
		Leaving the trauma behind	Thrust into the unpredictable unknown	'Ordinary' is extraordinary	Re-establishing control and independence	"Will I ever belong?"
Booth et al. (1990)		X	X	X	X	X
Brown et al. (2009)		X		X	X	
Burns et al. (2010)		X		X	X	
Cattermole et al. (1990)				X	X	X
Davis et al. (2015)				X	X	X
Ellem (2012)		X	X			X
Fish & Lobley (2001)		X	X	X	X	X
Forrester-Jones et al. (2002)				X	X	X
Head et al. (2018)		X	X	X	X	X
Holland & Meddis (1997)		X	X	X	X	X
Jahoda & Markova (2004)		X			X	X
Karban et al. (2013)		X		X		X
McConkey et al. (2003)		X	X		X	X
O'Brien et al. (2001)		X		X	X	
Sheerin et al. (2015)		X		X	X	X
Strnadova (2019)			X		X	X
Strnadova & Evans (2012)		X	X	X		X
Walker et al. (1995)		X	X	X	X	X
Williams et al. (2018)		X		X	X	X

1-53
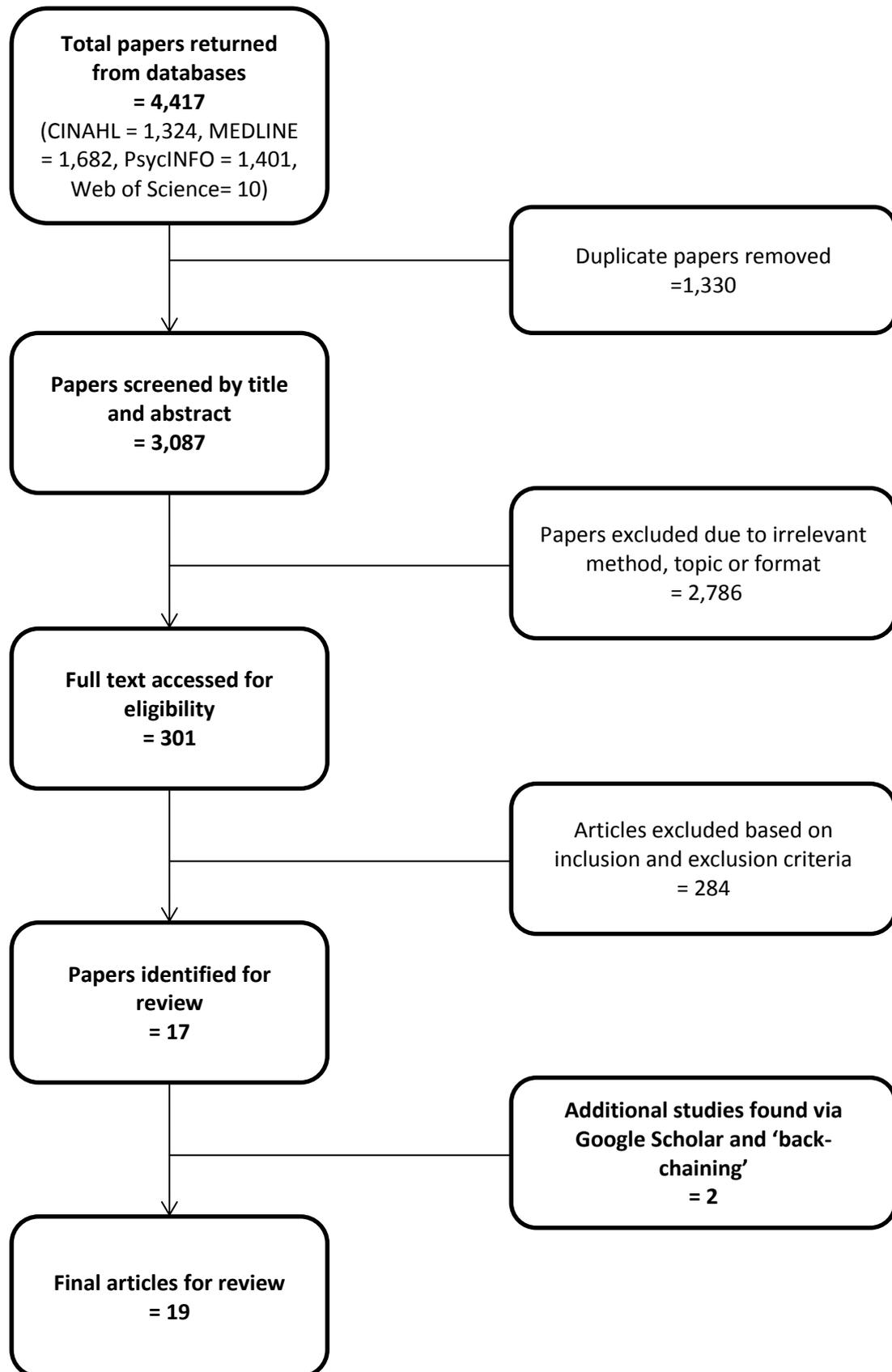
Figures

Figure 1. Search process flowchart

Appendix 1-A

British Journal of Learning Disabilities Author Guidelines

INSTRUCTIONS FOR AUTHORS

The journal to which you are submitting your manuscript employs a plagiarism detection system. By submitting your manuscript to this journal you accept that your manuscript may be screened for plagiarism against previously published works.

1. GENERAL

Aims and Scope

British Journal of Learning Disabilities is an interdisciplinary international peer-reviewed journal which aims to be the leading journal in the learning disability field. It is the official Journal of the British Institute of Learning Disabilities. It encompasses contemporary debate/s and developments in research, policy and practice that are relevant to the field of learning disabilities. It publishes original refereed papers, regular special issues giving comprehensive coverage to specific subject areas, and especially commissioned keynote reviews on major topics. In addition there are reviews of books and training materials, and a letters section. The focus of the journal is on practical issues, with current debates and research reports. Topics covered could include, but not be limited to:

- Current trends in residential and day-care services
- Inclusion, rehabilitation and quality of life
- Education and training
- Historical and inclusive pieces [particularly welcomed are those co - written with people with learning disabilities]
- Therapies
- Mental health issues
- Employment and occupation
- Recreation and leisure
- Ethical issues, advocacy and rights
- Family and carers
- Health issues
- Adoption and fostering
- Causation and management of specific syndrome
- Staff training
- New technology
- Policy critique and impact

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Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. Brain, 126(4), 841–865. doi: 10.1093/brain/awg076

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Chapter Two: Empirical Paper

The subjective experiences of people with a diagnosis of learning disability and

'borderline personality disorder'

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Word Count: 7968 (Max 8000 excluding references, appendices, tables and figures)

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Abstract

2-2

Existing research has not explored the lived experiences of people with learning disabilities (LD) and a concurrent 'personality disorder' (PD) diagnosis. This research aimed to explore people's understanding of their diagnosis of 'PD' and its subsequent impact on their well-being and relationships. The study adopted Interpretative Phenomenological Analysis to investigate the experiences of eight adults with LD (6 females and 2 males), all who were diagnosed and aware of their 'PD' diagnosis. One-to-one interviews were conducted with all participants. Four super-ordinate themes emerged from the data: Knowledge is power – Diagnosis as the domain of professionals; Understanding difficulties through a trauma lens; The stigma of diagnosis – Feeling different, seeking acceptance; and Taming the 'beast' inside – The journey towards regaining control. Clinical implications, limitations and opportunities for future research are discussed.

Key Words: Learning disabilities, personality disorder, borderline personality disorder, emotionally unstable personality disorder, experiences, interpretative phenomenological analysis

The diagnosis of 'personality disorder' (PD) remains highly controversial for many who use and work in mental health services. In this paper, it represents a shorthand term for the difficulties that people can experience, without ascribing to the 'medicalisation' of those difficulties implied by the term 'disorder'. The author acknowledges movements across both mental health professionals and service users to replace the terminology with a less stigmatising and more helpful name to describe the often understandable psychological and behavioural difficulties developed in response to extreme interpersonal distress and trauma. Within current clinical and research practice, the diagnosis 'PD' is the only widely understood term for the collection of these difficulties; therefore, it will be used throughout this paper.

There is a reluctance to diagnose people with LD with 'PD' (Moreland, Hendy, & Brown, 2008) which has resulted in limited attention being paid to people with LD and 'complex' difficulties (Flynn, Matthews, & Hollins, 2002). People with LD are widely acknowledged to be equally at risk, if not more likely than the general population to experience mental health difficulties, due to persistent trauma and social exclusion faced by this population (British Psychological Society, 2016). Therefore people with LD often experience difficulties that are associated with a diagnosis of 'PD'.

Prevalence rates of 'PD' diagnoses in LD populations vary significantly from 1-91% within community settings to 22-92% within inpatient settings (Alexander & Cooray, 2003). Alternatively, 'PD' was diagnosed in 7% of people with LD within a community sample, and 58% within an inpatient sample via clinical records (Naik, Gangadharan, & Alexander, 2002). Anderson et al. (2015) indicated the prevalence of 'PD' within community LD populations as between 0.7-35%. Undifferentiated diagnoses of 'PD' are often unhelpful, as it results in the large prevalence rates and discrepancies previously described, whilst over-simplifying and generalising the idiosyncratic experiences and subsequent coping

mechanisms of individuals. This may limit the reflexivity and individuality of service provision or support.

Conceptual issues with 'PD' diagnoses

Different conceptual issues with 'PD' diagnoses may account for the variability in prevalence rates. The DSM and ICD indirectly define what is considered to be 'normal', by considering deviation away from socially accepted norms as 'disordered' (Crowe, 2000). Therefore, clinicians make judgements about whether an individual's presentation falls outside this range and therefore may warrant a diagnosis. This view can often be skewed according to the professional and clinical culture in their practice, with some questioning the scientific nature of diagnostic processes due to the subjectivity of clinicians' moral and cultural experiences (Crowe, 2000).

Furthermore, doubt remains whether diagnosis encapsulates other factors linked to development of difficulties, including trauma and adverse childhood experiences. Criticism of the underlying premise that human distress can be understood within a 'disease' framework remains, with 'PD' hypotheses having little empirical evidence to support them (Tyrer, 2009). Significant overlap exists between different 'PD' types and other mental health conditions (Pridding & Proctor, 2008).

There are further conceptual issues regarding diagnosis of 'PD' in LD populations. Theories of personality development in people with LD and those underpinning 'PD' are not integrated; therefore, defining 'PD' in LD populations remains unclear (Morrissey & Hollin, 2011). Characteristics common in people with LD overlap with various 'PD' criteria, including sudden emotional changes, self-harm, impulsivity, and aggressive behaviour; therefore 'challenging behaviours' can often be misinterpreted as mental health difficulties (Morrissey & Hollin, 2011; Pridding & Proctor, 2008).

Recommendations have been suggested to improve the reliability of 'PD' diagnoses in people with LD; including diagnosis should not be given before 21 years-old, be restricted to those with mild/moderate levels of LD, and extended assessments involving key informers (Alexander, Chester, Gray, & Snowden, 2012; Lindsay, Steptoe, McVicker, Haut, & Robertson, 2018). A prevalence rate of 33.3% was found within a community LD forensic sample using these recommendations (Lindsay et al., 2006).

Despite concerns over the diagnosis of 'PD' in people with LD, many recognise a clinical utility and potential benefits of a diagnosis (Lidher, Martin, Jayaprakash, & Roy, 2005). Diagnosis can highlight the complexity of a person's needs, thus enabling access to specialist services and improved outcomes (Alexander et al. 2006; Lindsay et al. 2006). For some people with LD, receiving a diagnosis may help individuals experience relief by attributing their difficulties to a label (Williams & Healy, 2001). For others, diagnosis may provoke extreme distress or hopelessness (Moreland et al., 2008).

The impact of 'PD'

There is a wealth of research regarding the impact of a 'PD' diagnosis on service users. People with LD diagnosed with 'PD' are more likely to receive psychotropic drugs, demonstrate increased offending behaviour, and require more hospital admissions due to difficulties arising from transitions to the community (Lidher et al., 2005). People with a diagnosis of 'PD' are more likely to experience restrictive support (Reiss, 1994), be viewed as 'untreatable' (Pridding & Proctor, 2008) or divide opinion within teams (Mavromatis, 2000). Therefore, diagnosis may have a negative impact on the individual and their experiences of services (Chester, 2010). Recent research has focused on the perspectives of people receiving the diagnosis. People hold pejorative views of the label, experience stigma, and have negative relationships with services (Horn, Johnstone, & Brooke, 2007; Rogers & Dunne, 2011; Stalker, Ferguson, & Barclay, 2005). Within LD populations, there is concern

a diagnosis of 'PD' may add a further stigmatising label, resulting in further societal exclusion and devaluation (Moreland et al., 2008). The impact of 'PD' may be more 'disabling' than the cognitive impairment in people with LD and 'PD', with these individuals requiring the most intensive care and intervention (Torr, 2003).

Current Service Provision in the UK

Specialist UK services for people with LD and mental health difficulties are going through a period of transition. Following the exposure of systematic abuse and mistreatment within the long-term LD hospital, Winterbourne View, Transforming Care (TC; Department of Health, 2012) aimed to make significant changes to service provision. A commitment was made to close specialist inpatient beds and support people with LD in the community. However, reductions in beds may not be justified for people with 'complex' needs, such as those with 'PD' diagnoses (Taylor, 2019). To reduce the reliance on hospital beds, Intensive Support Teams aim to provide greater levels of support for people with LD and 'complex' needs. More people with LD and diagnoses of 'PD' will therefore be supported within community settings.

Research Aims

Existing research has not explored the experiences of people with LD given a diagnosis of 'PD'. Research has explored the experiences of those with LD and 'psychosis' within a community service (Robinson, Escopri, Stenfert Kroese, & Rose, 2016) and those diagnosed with 'schizophrenia' in a secure LD setting (Cookson & Dickson, 2010). A recent systematic review exploring 'PD', offending behaviour and LD called for more qualitative research into the experiences of people accessing community services (Rayner, Wood, Beail & Nagra, 2015). Therefore, this research aims to explore the experiences of those given a diagnosis of 'PD'. The results will add a service user perspective to on-going debates

regarding clinical usefulness of diagnosis. It will also provide greater understanding of the

needs of this population, in order to inform clinical practice and person-centred support.

Method

Design

A qualitative methodology was adopted to enable an exploratory, interpretative

approach. One-to-one interviews were determined to best meet the research aims and allow

individuals to explore how they made sense of their experiences. The author adopted an

interpretivist stance, whereby multiple realities exist and are constructed in the individual's

mind (Hansen, 2004).

Interpretative Phenomenological Analysis (IPA; Smith, Flowers, & Larkin, 2009) was

used to explore the experiences of participants. IPA is based upon the theoretical principles

of phenomenology, idiography and hermeneutics (Smith, Flowers, & Larkin, 2009). It

explores individuals' perceptions and sense-making of events, rather than any objective

'truths' around the event itself (Arroll & Senior, 2008). IPA was chosen because of its focus

on idiography, looking into the particularity of people's experiences rather than the universal

(Smith, Flowers, & Larkin, 2009). IPA recognises the connection between what people say

and their thoughts or emotions can be difficult to describe (Smith & Osborn, 2003).

Therefore, the researcher plays an active role in becoming as close to the participants' world

as possible by interpreting what people are thinking and feeling, described as the 'double-

hermeneutic' (Smith, Flowers, & Larkin, 2009).

Participants

The research aimed to recruit between six and 10 participants. Smaller samples allow

each individual's story to be explored in depth, without being integrated into a collective

'whole' (Robinson, 2013). A purposive sampling method was adopted, inviting individuals

with both LD and 'PD' diagnoses currently using LD services to participate. The sample

design allowed homogeneity in the core aspects of the research, whilst also allowing for some variation in participant demographics, such as age and gender. A homogenous sample is important within IPA to increase confidence in the theoretical generalisability of findings (Smith & Osborn, 2004). Furthermore, homogeneity allows detailed exploration of the phenomenon in question by identifying similarities and differences (Smith, Flowers, & Larkin, 2009).

Nine individuals were approached, with all determined to have capacity to consent to participate. However, the ninth individual responded after the research cut-off date, therefore was not interviewed. Overall, eight people participated in the interviews (see Table 1 for demographics). Participants were recruited through two local community LD teams. Inclusion criteria for participants included: aged 18 and over; had a documented diagnosis of LD and 'PD'; currently using services; and were able to give verbal and written consent. Participants were excluded if a formal diagnosis of PD was not documented or they were unaware of the diagnosis. Despite recruitment being open to people with any diagnostic sub-type of 'PD', all participants were diagnosed with either 'Borderline PD' (BPD), the ICD-11 equivalent 'Emotionally Unstable PD' (EUPD) or unspecified 'PD' with borderline traits. Six females and two males participated, all of White British ethnicity, with an age range of 21 to 57 (mean = 35.9). Seven participants had experience of inpatient stays, within acute psychiatric inpatient services, specialist LD or forensic units. Participants either lived in independent supported living or small-scale residential homes.

Ethics

Prior to the research commencing, ethical approval for the research was sought and granted by an NHS Research Ethics Committee and the Research and Development Department of the participating NHS Trust. The research was sponsored by Lancaster University. Approval letters can be seen in Appendix 4-A-4-D.

Procedure

Materials were initially developed by the author and reviewed by the research team. A service-user group and an individual with diagnoses of both LD and 'PD' acted as consultants on the research, inputting into the research materials (Appendix 4-E-4-G). Research materials were in 'easy-read' format.

Potential participants were approached by their care co-ordinator, who provided them with copies of the participant information sheet and consent form. Individuals were contacted again one week later to ask whether they consented to participate. Consenting participants were then contacted by the author to arrange an appropriate day, time and setting for interviewing. Interviews were conducted face-to-face with the author, lasting between 38-64 minutes. Participants were offered the opportunity to have someone present for support. Immediately before interviewing, written consent was gained. Participants could choose a pseudonym for use within the paper.

Data Analysis

All interviews were audio-recorded and transcribed verbatim by the author. Identifying information was removed or replaced to preserve participants' identities. The research followed the IPA process highlighted by Smith, Flowers, and Larkin (2009). Each transcript was analysed individually. Immediately after interviews, the author made notes of any initial reflections, in order to minimise bias on the analysis. The first stage involved reading and re-reading each transcript to become more familiar with the data. Initial notes were made alongside the text, relating to the content of the text, use of language or tone, and potential interpretations. This process was completed line-by-line, with the author commenting on any area of significant interest or concern to the participant. Next, attempts were made to identify potential emerging themes, at a more interpretative level than the initial notes (see Appendix 2-B for excerpt of transcript). Connections between emerging

themes enabled the development of main themes for each transcript (see Table 2). Once this was complete for all transcripts, main themes and sub-themes were analysed across the transcripts in order to identify similarities or points of divergence. This process produced a final set of 'super-ordinate themes' (see Table 3).

Validity and Credibility

To maximise credibility of the analysis, a transcript was coded across the researcher team. Supervision was used to discuss interpretations and emerging themes, ensuring any interpretations were grounded within the data. This triangulation approach aimed to minimise researcher bias and therefore increase the plausibility, coherency and integrity of interpretations (Biggerstaff & Thompson, 2008). However, themes reflect the author's interpretations of participants' own sense-making. Therefore, other researchers may construct alternative interpretations which is an inevitable bias inherent within IPA (Smith, Flowers, & Larkin, 2009). The Tables and Appendices sections present examples of each stage of the analysis. A reflective diary was maintained throughout the research, where I reflected on my own cognitive and emotional reactions during the process. Within qualitative methodologies, self-reflection is an important process which allows the researcher to 'bracket off' their own beliefs, experiences and assumptions, thereby reducing the potential impact of researcher bias (Tufford & Newman, 2012).

Results

Four super-ordinate themes were developed: (1) Knowledge is Power – Diagnosis as the domain of professionals; (2) Understanding difficulties through a trauma lens; (3) The stigma of diagnosis – Feeling different, seeking acceptance; (4) Taming the 'beast' inside – The journey towards regaining control.

Theme 1: Knowledge is Power – Diagnosis as the domain of professionals

This super-ordinate theme relates to participants' experiences of having limited knowledge and understanding of the diagnosis of 'PD'. It encompasses the way information about diagnosis is received by people, and how information is given by professionals, reflecting an inherent power imbalance.

When asked about their 'PD' diagnosis, only two participants were able to talk in detail. The majority had little to no understanding of the diagnosis and did not feel it helped them make sense of their difficulties. Five participants commented on cognitive difficulties affecting their understanding and a need to increase accessibility of information: "Like break it down a bit. Like long words I don't know, how to pronounce them or understand […] and the meaning behind it as well" (Andrew). Ben felt services had not provided the information or support needed to understand his difficulties:

> I need to understand it a bit better. So say, how can I just switch like that, one minute I could be happy and then I could be doing something. But I don't know what tips or switches it. The light bulb moment. I don't know what turns the light bulb on. And what turns it off. I just need some information about it. (Ben)

Similarly, Amy gave up trying to understand her diagnosis due to difficulties related to her LD: "They did give me paperwork, like what the hell is it, but because I've got learning disabilities, I can't read it so I just left it and went "oh, I've got a personality disorder leaflet", just left it" (Amy). Most participants were unsure why they were given a diagnosis and what it meant for them regarding services and support moving forward.

For others, their lack of understanding demonstrated an implicit reliance on professionals to make decisions for them, reflecting a lack of power they hold within services: "Yeah someone must have said something, there was a letter or something, I'm not sure I've had, my doctor wrote a letter about something" (Kylie). Inability to retain information reinforced this reliance, resulting in a passive stance towards diagnosis: "It's

alright really, I don't mind really […] I've been diagnosed with it for a while now" (Kylie). For others, a process of getting "used to it" revealed an adverse impact of being given the diagnosis originally: "Doesn't bother me. It's not a word for me anymore. I'm not happy with it but it don't bother me" (Vera). Again, Amy highlights the impact of professionals withholding knowledge about diagnosis:

> I just wish when they gave me the illness and told me what it is, they would have told me why I got it in the first place, because they never, they just said "you've got a personality disorder". So for a couple of years, I didn't know why they diagnosed me with that because they never give me why I've got it […] no one told me the reason. (Amy)

This example illustrates Amy's trust in services to meet her everyday needs. The use of the word 'they' represented all professionals as an amorphous, powerful 'other', highlighting the power difference between participants and professionals in diagnostic processes.

Receiving their diagnosis was not viewed positively by most participants, reflecting frustration at being unaware or uninvolved in the process. Andrew described shock at finding out his 'EUPD' diagnosis within a busy meeting: "It was in a meeting believe it or not. And me mum and dad were there. They didn't even know I had this until then" (Andrew). For Beth, her mother rather than her team informed her of the diagnosis, invoking confusion and uncertainty: "I just said "what does it mean?" […] I just wanted to know about it" (Beth). Beth spoke of others infantilising her, which was reinforced by others holding back knowledge about diagnosis: "Like and I think she's probably waiting for me to get older to know about it […] I don't know when she's going to read it to me" (Beth). This placed Beth in a continued position of dependence on others.

For Fiona and Vera, receiving the diagnosis resulted in outright rejection of the label. Fiona felt "angry" and "ashamed" receiving her diagnosis from social services and not her

care team: "Because no-one else had mentioned it to me. Everyone else knew about it, except me. And me social worker told me. And he said the people in [previous team] should have told me" (Fiona). Again, this highlights the power that comes with 'hidden' knowledge and also possible worries professionals may have in disclosing diagnoses, with potentially adverse consequences:

> I burst out crying, and I said "no, I haven't got it". And the social worker said "Fiona you have". […] I turned round said "fuck off now, and get out that door now". "I haven't got it so there!" And he said "Fiona love, you have got it" and we were arguing and fighting. In the end I got told that I did have it. (Fiona)

Theme 2: Understanding difficulties through a trauma lens

The majority of participants struggled to use their diagnoses to help make sense of their difficulties. However, all reflected on their past experiences and linked them to their current difficulties. This allowed participants to normalise and contextualise their often traumatic, relational experiences.

Amy held more detailed knowledge of 'PD', which she attributed to receiving further "training" from psychology to help her understand the context of the diagnosis, by linking her past trauma to current difficulties with self-harm, emotion regulation and relationships:

> They erm, I didn't know what personality disorder was or what it was caused by until they did the training with the staff, and they said what it is. [Psychologist] said it's through trauma through my life and that's why, that's what it is. (Amy)

The process of normalising her current difficulties in context of what had happened to her helped Amy link together specific experiences: "You know certain things but then I started clicking everything in my head" (Amy).

Vera made sense of her current interpersonal difficulties through her relational patterns and traumatic experiences from early childhood:

I have a bad relationship with my mother and I have a bad relationship with anybody at the moment. I don't let anybody get close to me, because I let people get close, they leave me and things happen. […] I do have a lot of flashbacks as well. You know, my past history, I have a lot of flashbacks, because I got sex assaulted when I was very young. […] That's what the personality disorder is for. I've been put through too much trauma and everything. (Vera)

Christine linked periods of separation from her father to her difficulties with mood: "I just wasn't happy, I wasn't happy, I was unhappy. Because me dad was working abroad [...] When my dad came home, he was only home for a couple of weeks and then he'd have to go back again" (Christine). Andrew linked current difficulties to experiences of being separated from his parents due to witnessing violence in the home. Andrew also linked more recent behavioural problems to a sexual assault:

And that day I was having a bad day, so I took it out on him. I only pinned him up against the wall […] I'm not proud, because I've been kicked out […] And also I got sexual abused. (Andrew)

For Fiona and Kylie, talking about historical sexual abuse enabled them to link these experiences to current emotional difficulties or inability to trust others easily: "I've been raped quite a few times in my life and been abused […] so it's been difficult" (Kylie). Fiona explicitly linked her use of self-harm as a coping mechanism for emotions brought on by traumatic memories: "About my dad, about me brother beating me mum up, about me getting me head split open by my brother, about me brother putting the house on fire, about me taking overdoses, why do I cut up for" (Fiona). However, she felt her 'PD' diagnosis was a

"different thing altogether" and not linked to the sense-making she achieved through discussing her "problems". Sense-making allowed Fiona develop a sense of self-compassion: "I know it wasn't my fault what me dad did to me" (Fiona).

Theme 3: The stigma of diagnosis – Feeling different, seeking acceptance

Participants reflected on how their experiences, relationships and diagnoses impacted on identity. Participants often felt different from others around them, reflecting a vicious cycle of both internal beliefs and difficult interpersonal or stigmatising experiences. Participants continued to battle for acceptance and understanding.

Several participants often spoke about themselves using institutional language, which impacted on how they viewed themselves and their difficulties. Vera, despite rejecting the medical narrative of diagnosis, appeared to have unconsciously internalised risk-related, forensic terminology in the way she described herself as having "deteriorated" or "a bad attitude": "I'm a danger to public and a danger to myself really bad. Self-harmed all me life, ligatured all me life, took overdoses over me life as well" (Vera). This appears to have reinforced her sense of 'difference', by separating herself from the 'public'.

Some participants appeared to be aware of the stigma associated with a 'PD' diagnosis, with four participants specifically not naming their 'PD' diagnosis during the interview: "I know I've got learning disability and the other one, but I'm not happy about it" (Fiona). Similarly for Andrew, experiences of rejection by others when disclosing his diagnosis resulted in him not naming it at times during the interview: "I tell them all me, you know I've got ADHD and this diagnosis and everything and they walk away. And call me names and that" (Andrew). Ben wanted "only the people that need to know" to be aware of his diagnosis, whilst Vera explicitly stated she does not tell anyone about her diagnosis due to experiencing stigma from wider family:

> We kept it to ourselves. I kept it between our family at the time because none of them outside our family would know. And then someone heard it and it's all over Facebook about me and me mum's side of the family set rumours about me. "I'm a psychopath", "look at her", "she's a psycho" and all that. (Vera)

Several participants described how receiving a diagnosis negatively impacted on their identity or confirmed beliefs that there was "something wrong" with them or they were 'different' or 'not normal'. Fiona's self-esteem was significantly affected after receiving her 'PD' and LD diagnoses: "What a dirty cow. What a mong. What a slut. What a cunt. What a bastard. All those" (Fiona). In turn, this appears to have reinforced beliefs about not deserving relationships or acceptance from others: "I can't trust her. It's been since I've been told all this, I ended me relationships" (Fiona). Diagnoses have confirmed her 'difference' and therefore her worthiness for intimacy with others:

> We went out together. We went out for a meal, we went for a drink. We went to Mencap together. And then when I got to know I got that, I thought "no I'm not going out with a sensible lad who can read and write, and someone like me who can't". I'm not having it. So I just phoned him up and went "Mike, it's not you, I'm sorry but I've got these things and it's over with, the relationship". (Fiona)

For Andrew, receiving a 'PD' diagnosis contributed to a negative self-identity and longing to be "normal": "Like, I don't know. Like I'm not normal. But every time I tell me mum – 'I wish I was normal' – she says 'you are'" (Andrew). In response to this, Andrew felt new people needed to know his diagnosis, hoping they would accept him and "stick by me". Due to experiences of abuse over social media and being targeted in the community, Andrew felt special and incredibly close to people who he had maintained relationships with, including his social worker who "throws himself out the way to help me" and a friend who he described as "me brother who's not me brother". Andrew had a strong sense of purpose by helping

others with needs, which appeared to represent a way of showing and hopefully receiving acceptance:

> They tell me what's wrong with them. Like me mate has got epilepsy. And I say "I'm like you". I haven't got epilepsy like, but "I'm like you, I'm not normal so I'll be there for ya and help you through it". (Andrew)

Positive relationships with others helped to build a sense of self-acceptance: "No I started looking at it the way me mum is now. Because I am who I am, you know what I mean?" (Andrew).

Both Fiona and Vera rejected their diagnosis due to experiences of people referring to the diagnosis rather than themselves as people. Fiona wished people spoke about her "problems", with Vera commenting: "I wish people stop using the personality disorder. Just go 'how's your day?'" (Vera). Vera often spoke about viewing herself as 'normal', which appeared to reflect day-to-day experiences of stigmatisation:

> It's not a normal person who goes "oh yeah, she's got personality disorder, he's got personality disorder, they've got personality disorder". It's not tattooed on you. You look normal. That's what I always say. Labels, I wish never ever people used labels on people. (Vera)

Christine felt her diagnosis had impacted on her mental health, as it reinforced her 'difference' and restrictions in living a 'normal life': "It just drags me down if I think about it" (Christine). Being discharged after 13 years in forensic settings, alongside developing positive current relationships with staff, gave Christine a sense of acceptance from others, helping her integrate into the community:

> You see when I go outside, in the community, I think to myself "I'm in the community, I want the comfort of the community". It makes me feel good that no-one

else thinks, I don't look any different from other people, know what I mean. No one

can tell I've got anything wrong with me. […] No I just thought it's my normal life.

You know like you'd do at home. So I just lived a normal life. (Christine)

In her current placement, Vera now felt accepted by others: "In here, no-one treats me

as different" (Vera). For Amy and Fiona, it was important for staff to emotionally connect to

their distress to help them feel accepted and able to build relationships with people: "And

when she got to know what happened to me, it was awful for her, yeah awfully upset. I got

on brilliant with her, and now she works here, I go out with her, have a laugh with her"

(Fiona). Amy felt staff understood her more after receiving "training" regarding her

diagnosis and difficulties:

> I did the training with them because they needed to know why, what personality
>
> disorder emotionally is. They needed to know why I got it. The staff were a bit upset
>
> because of what I've gone through to get that […] so they were shocked I think.
>
> (Amy)

Theme 4: Taming the 'beast' inside – The journey towards regaining control

This super-ordinate theme relates to the ever-changing sense of control participants

had over their difficulties. Due to a limited understanding of 'PD', most appeared to attribute

their diagnosis to having an "illness". This became a part of them of which they had no

control. 'PD' as an 'illness' sometimes allowed others to externalise a person's difficulties.

Finally, participants spoke about having a sense of hope for the future despite continued

difficulties, which appeared to reflect a greater sense of feeling in control.

The majority of participants related to their diagnosis of PD with a medical

understanding, which confirmed that there was something "sick" or "ill" about them. For

Andrew, diagnosis confirmed he had been living with a hidden illness: "Apparently I've had

it all my life" (Andrew). This provided him with a sense of hope for the future: "I know, like

that I've got it, and know what to do now" (Andrew). Similarly, Amy felt diagnosis provided

a sense of relief:

> Because all them years, they didn't know what was wrong with me. And they found
>
> out, it was good to know what's wrong with me […] It was just a relief that I knew
>
> what was wrong with me. (Amy)

Likewise, despite her vocal rejection of the medical model, Vera spoke about her sense of

relief regarding diagnosis, which appeared to minimise responsibility for engendering her

own change: "But I've finally found what's really wrong with me. And get the treatment

what's needed" (Vera).

Several participants linked their diagnosis to an immediate response from services in

prescribing medication such as "diazepam", "lithium" and "clozapine". There was an

assumption that long-term medication would be required in order to manage the 'illness',

with Vera insisting that medication should never be withdrawn. Kylie linked her medication

to her stability in mood and therefore lack of need for hospital: "I've not been back in now

for over a year. Because I'm on new medication now" (Kylie). Despite this, Kylie and Amy

demonstrated a sense of conflict over medication, with concerns over side-effects of

medication and ambivalence over its effectiveness at more challenging times, which again

left them feeling out-of-control over their difficulties: "But sometimes when I'm really low, it

doesn't help me the medication" (Amy).

For some participants, the diagnosis suggested they were under the influence of a

separate entity. Andrew described his 'PD' diagnosis as a "beast" which appeared to reside

within him that he had no control over. Similarly, for Ben: "I think there's two people inside

of me. There's a nice side to me and a horrible side of me" (Ben). For Beth, diagnosis "might

be part of me" and her difficulties represented "two different personalities". Across

participants' accounts, this narrative appeared to influence the amount of control they felt

over their mood and behaviours, with Beth describing the other side to her as a "switch" that left her feeling "calm and fine one minute, then I can be like this explosion". Likewise Ben explained that "when I'm on one, the horrible part of me comes out" and he does not know what "tips or switches it".

For Amy, this sense of helplessness and lack of control over her experiences relating to her 'PD' diagnosis was linked to her fears and belief that others were "the cause of me getting ill" and "they make me sick". Receiving the diagnosis appeared to have changed her beliefs around her ability to cope with difficulties, again demonstrating an illness narrative which decreased her sense of control over her difficulties: "I'm used to being ill with the personality disorder. […] But before I was ill, I didn't know what was wrong with me, it doesn't bother me as much" (Amy).

There was a narrative across several of the interviews regarding diagnosis being used by others to minimise a person's difficulties. Vera felt frustrated by staff members using her diagnosis to explain her behaviours: "Some of the staff think when I kick off 'it's your personality disorder, it's you're mental health, you'll be alright'. I wish they didn't use that" (Vera). Similarly for Andrew, diagnosis appeared to be a way for his father to attribute previous traumatic experiences to an external 'illness' and excuse his own previous behaviour towards him: "He regrets what he's done. Even he says I should have got it [PD diagnosis] earlier, and he might have treated me differently" (Andrew). Kylie experienced her parents attributing her distress to merely "being paranoid": "Me dad says "it's in your head" or me mum says "it's in your mind" or something" (Kylie). Therefore, family members and staff also appeared to develop sense-making through viewing diagnosis as an 'illness', minimising not only the participant's but also their own role in managing the participants' difficulties.

All participants spoke about personal journeys of change, and how they now felt more in control of difficulties. Beth referred to her difficulties now feeling like "a blip" whereas

previously it was due to her "aggressive" personality. For several participants, an increase to their sense of control and coping reflected awareness of possible negative consequences:

> Don't get me wrong, me and me mum argue still. I still turn into like […] I let the beast out but not letting it. Because I know if I batter me mum again, I'd be nicked again. And then I'd lose the flat. (Andrew)

Beth described the ability to now stop herself in situations where she may have previously become aggressive: "But that's what I feel like saying to them, but I can't because I'll get into trouble" (Beth).

Kylie describes life as a "battle", but she recognises she is now more in control of her thoughts and can manage "ups and downs":

> I have to keep telling my head and I get these thoughts in my head and I try to battle me thinking and it's hard. Sometimes, like I can reassure myself sometimes but it just, it's really difficult sometimes you know […] Sometimes it does work actually, but it's like a battle to keep it up all the time. (Kylie)

For Vera, feeling more in control was reflected in her ability to not allow difficult weeks hold her back: "Don't look back on your past, look forwards. And keep your head down and if you self-harm, try and do a do-over, and say 'I'm not self-harming this week'" (Vera).

Discussion

The main aim of this research was to explore the experiences of people with LD who had received a diagnosis of 'PD'. All eight participants were able to reflect on their experiences of living with a diagnosis of 'PD', their experiences of LD services, their difficulties and their relationships with others and the wider world. Participants' narratives were constructed based on their experiences of early relationships with caregivers, wider

society and within services. Four superordinate themes were generated from participants'

narratives: (1) Knowledge is power – Diagnosis as the domain of professionals; (2)

Understanding difficulties through a trauma lens; (3) The stigma of diagnosis – Feeling

different, seeking acceptance; (4) Taming the 'beast' inside – The journey towards regaining

control.

The findings contribute to the on-going debate over the clinical utility of a 'PD'

diagnosis and the meaning it can hold for people diagnosed, reinforcing calls for caution over

its use (Hayne, 2003). The impact of receiving a diagnosis was experienced differently by

participants and its meaning or acceptance changed over time, similar to findings by Horn et

al. (2007). Receiving a 'PD' diagnosis may provide benefit to some individuals in terms of

the personal relief of attributing a label to their difficulties (Williams & Healy, 2001).

However, for other individuals, labelling may also provoke confusion, rejection or distress

(Moreland et al., 2008).

Participants who accepted or were indifferent to their diagnosis linked this stance to

receiving access to appropriate services and support, discharge from inpatient services and a

relief that others will know how to manage their "illness". Whilst some recognised hope for

change related to receiving their diagnosis, others struggled to recognise any benefits. Hope

appeared in part to refer to others managing their 'illness' or distress by offering support,

reinforcing possible acquiescent or reliant on others roles. People with LD have often had

contact with services from an early age, identify those caring for them as authority figures,

and are often reliant on staff for social connection and general wellbeing (Goble, 1999).

A few participants appeared to hold conflicting views of diagnosis. For example, for

Vera, diagnosis provided a sense of relief in knowing what was "wrong" and, by implication,

how to move forward, but she also vocally rejected the use of "labels" as they represented a

form of oppression and marginalisation by being labelled 'not normal'. This reflects long-

standing research within LD populations that categorisation by conditions and labelling is stigmatising and leads to exclusion from mainstream society; instead people want to be seen as 'people first' (Sutcliffe & Simons, 1995). Conflict in this case may therefore be linked to people's awareness of requiring support from services, whilst being aware of the double impact of stigma around 'PD' and LD diagnoses.

However, alongside participant narratives about being "ill" or "different" ran the alternative conceptualisation of making sense through exploring the links between current difficulties and past traumatic and interpersonal experiences. Again, there was ambivalence and conflict in participants' accounts of the reasons behind their difficulties, possibly reflecting acquiescence to professional practice and the support that it enables, rather than indicating belief in a 'medical' understanding as 'truth'. Several participants spoke about ambivalence over the effectiveness of medication. Participants appeared to be aware that one viewpoint was not elaborate enough to explain all their experiences or needs. The theme of sense-making reflects participants being able to develop a more psychosocial understanding of themselves, others and their relationships. All participants described no longer being the same person they used to be, with more hope for their future and periods of feeling more in control of their difficulties. Moving away from previous positions of certainty towards more complexity, allows participants to hold multiple and transformative narratives about their lives and difficulties. Personality is not a fixed or "true" concept of the self, but rather something that exists between people (Burr, 1995).

Several participants spoke about some level of increased control over their experiences and subsequent emotions and behaviour, which appeared linked to both external support and personal resources such as resilience, interests/activities, and changes to coping strategies. Older participants appeared to undergo a period of adapting to diagnosis, in addition to years of inpatient and/or community support. This appeared linked to their

increased ability to tolerate their own distress. The younger participants were less able to articulate links between their past experiences and current difficulties, and felt less of a sense of control over possible triggers for emotions or behaviours. Research into 'PD' has shifted from the viewpoint that it is a lifetime condition to a more adaptive stance which suggests behavioural traits associated with diagnoses of 'PD' change over time and age, such as reduced impulsiveness, feeling less overwhelmed by emotional sensitivity, and increased responsibility taking (Biskin, 2015). This was reflected in some of the participants' narratives.

Clinical Implications

Three participants discussed receiving or hearing about the diagnosis for the first time at the age of 18, which is the earliest recommended age of diagnosis (National Institute for Health and Care Excellence, 2015). However, difficulties with the 'PD' diagnosis within LD populations are related to indications that the developmental phase of lasting personality traits should be extended beyond adolescence (Alexander & Cooray, 2003). If services are to continue to be based upon a diagnostic framework in the near future, assessment of 'PD' may need to be delayed, especially in those who demonstrate behaviours linked to a diagnosis of 'BPD/EUPD' which can reduce with age (Biskin, 2015).

It was unclear in all participants' accounts what process of assessment was undertaken to identify a 'PD' diagnosis. However, it appeared most 'PD' diagnoses were established on interview only, which opens diagnosis up to professional bias and possible inaccuracy due to limited time for the clinician to gather information from multiple sources (Lindsay et al., 2018). Future practice should look to be collaborative between differing professions, family or carers, and the individual themselves and be structured around appropriate assessments such as the International Personality Disorder Examination (IPDE; Loranger, Janca, & Sartorius, 1997). For diagnoses to be clinically useful, it is important to be explicit about

possible implications for individuals. At present there is little research and few recommended interventions, therefore diagnosis could be viewed as not being in the benefit of the individual (Moreland et al., 2008). However, as mental health services still utilise diagnostic frameworks to inform management and treatment, not 'labelling' individuals could restrict people from accessing vital support (Williams & Rose, 2018).

Findings suggested the majority of participants did not hold a clear understanding of 'PD' or how their diagnosis was made, reflecting previous research that found participants were often not informed or were uncertain over the meaning (Horn et al., 2007). Participants in this research had no awareness of being involved in a diagnostic process, which may indicate several reasons such as lack of collaboration or cognitive limitations relating to their LD. Some participants spoke about finding out their diagnosis from others outside their care team, such as family or social care. There appears to be reluctance from professionals regarding informing people about their diagnosis. Both professionals and parents struggle to talk to people with LD about diagnosis, fearing the impact it may have on identity or assuming it will be too difficult to understand (Craig, Craig, Withers, Hatton, & Limb, 2002). Regardless, a more collaborative and open approach should be aspired to if diagnosis is deemed necessary, with adaptations made for people with LD to become more involved. The majority of participants within this study appeared unaware of agreeing to or undergoing any diagnostic process. Therefore, seeking consent to diagnosis and increasing awareness of its potential impact is vital, especially as many people with LD have capacity to make decisions around their own healthcare and desire greater involvement in services. To increase equity of access to healthcare, informed consent (where possible) to assessments and interventions from people with LD is required (Goldsmith, Skirton, & Webb, 2008). This is vital to building trusting relationships between services and service users, as reflected in resulting

themes surrounding power, disengagement and deference to others in participants' own treatment.

Taking into consideration the theme around 'PD' diagnoses confirming 'difference' or 'illness', space should be created to explore the reasons for diagnosis as well as alternative narratives that can help to overcome negative beliefs associated with diagnosis and lack of agency over their difficulties. Alternatives to the medical model should be explored, such as the Power Threat Meaning Framework (PTMF; Johnstone & Boyle, 2018) which aims to reposition current symptoms of mental disorder back into the range of universal human experience, and focus on developing more hopeful narratives around the concepts of survival and resilience.

From several participants' accounts, a theme emerged around experiences of having "different personalities" or "two sides" to themselves that were distinct and not emotionally integrated. Difficulties with identity and experiences of dissociative states, lack of control or agency and emotion dysregulation are representative of people who attract a 'PD' diagnosis (Gold & Kyratsous, 2017). Participants' recognition of having different 'states' that can quickly change implies people with LD may benefit from specific psychological therapies aimed at recognising, understanding and managing these often intense and sudden emotional shifts. Approaches such as Schema Therapy (ST: Young, Klosko, & Weishaar, 2007) may therefore be indicated, as this aims to help those with entrenched interpersonal and self-identity difficulties, focusing on different 'modes' people rapidly shift between. In addition, Cognitive Analytic Therapy (CAT) and the Multiple Self-States Model may be helpful to be adapted for people with LD, with research growing in this area (Lloyd & Clayton, 2013).

Limitations

The findings are primarily based upon the experiences of females, all diagnosed with 'EUPD/BPD'. This may reflect individuals with 'BPD' being more likely to access services

(Tyrer, Mitchard, Methuen, & Ranger, 2003). Whilst women are more likely to receive a 'PD' diagnosis, males with LD and 'PD' are more likely to commit offences (Rayner et al., 2015). Males potentially suitable for the research were unfortunately re-established in the criminal justice system by time of recruitment, which highlights a barrier to increasing heterogeneity of research samples for future research. All participants were of a White British background therefore diversity was limited. Variation in the prevalence of 'PD' diagnoses across different ethnicities is currently unclear due to limited samples and potential methodological issues with diagnostic assessment, cross-cultural bias and under-representation in services (McGilloway, Hall, Lee, & Bhui, 2010). Therefore, the generalisability of these findings is unclear.

A criticism made of IPA is the difficulty to balance representing an individual's 'voice' idiographically whilst contextualising this as part of a wider group sample to posit a psychological understanding and experience of a phenomenon. By reflecting on the use of Heideggerian phenomenology in IPA, data in this research aimed to balance the first-order key concerns of how each participant has understood their diagnosis, with a more interpretative contextualisation of the meaning they have assumed from this in regards to their relationship with the wider world, and ultimately commonalities across all participants (Larkin, Watts, & Clifton, 2006). However, it is acknowledged that by moving away from participants' descriptive quotes, idiography may be reduced in the pursuit of making sense of a phenomenon across several individuals. IPA complements the 'personal' with a responsibility in psychological research to explore how a phenomenon is experienced (Larkin et al., 2006).

Future Research

Further research should be conducted with people with the diagnoses of LD and 'PD'. Establishing experiences from people diagnosed with other types of 'PD' than 'BPD/EUPD'

would be beneficial, as this was not possible during the course of this research. As participants' narratives exposed negative self-beliefs, poorly integrated 'self states' of which participants can quickly shift, difficulties in relationships and other experiences or phenomena linked to a diagnosis of 'PD', research into the adaption, use, effectiveness and client experiences of psychotherapies aimed at helping with these difficulties would be beneficial. At the current time, there is limited research into the use of approaches such as Mentalisation-Based Therapy, CAT and ST within LD populations. A recent systematic review by Williams and Rose (2018) into non-pharmacological approaches to people with LD and 'PD' were only able to draw conclusions from 11 research papers, demonstrating the dearth of knowledge in this area to date. Hollins and Sinason (2018) also call for professionals to extend their therapeutic repertoire and report outcomes for people with LD.

Conclusion

This research identified four overarching themes that incorporated people's experiences of having LD and a diagnosis of 'PD'. Themes relating to power, knowledge and a sense of being "ill", "different" and not in control of their difficulties contribute to the discussion around clinical utility of 'PD' diagnoses. Participants also gained more understanding through linking past experiences to their current difficulties. However, participants are still searching for acceptance and understanding from others. Participants acknowledged change to their ability to cope despite continued difficulties.

References

Alexander, R., Chester, V., Gray, N., & Snowden, R. (2012). Patients with personality disorders and intellectual disability – closer to personality disorders or intellectual disability? A three-way comparison. *Journal of Forensic Psychiatry & Psychology*, *23*(4), 435-451. doi:10.1080/14789949.2012.694462

Alexander, R., & Cooray, S. (2003). Diagnosis of personality disorders in learning disability. *British Journal of Psychiatry*, *182*(S44), s28-s31. doi:10.1192/bjp.182.44.s28

Anderson, J., Sellbom, M., Pymont, C., Smid, W., De Saeger, H., & Kamphuis, J. (2015). Measurement of DSM-5 section II personality disorder constructs using the MMPI-2-RF in clinical and forensic samples. *Psychological Assessment*, *27*(3), 786-800. doi:10.1037/pas0000103

Arroll, M., & Senior, V. (2008). Individuals' experience of chronic fatigue syndrome/myalgic encephalomyelitis: An interpretative phenomenological analysis. *Psychology & Health*, *23*(4), 443-458. doi:10.1080/14768320701246469

Biggerstaff, D., & Thompson, A. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, *5*(3), 214-224. doi:10.1080/14780880802314304

Biskin, R. (2015). The Lifetime Course of Borderline Personality Disorder. *The Canadian Journal of Psychiatry*, *60*(7), 303-308. doi:10.1177/070674371506000702

British Psychological Society. (2016). *Working relationally with adults with an intellectual disability: A discussion* [PDF file]. Retrieved from

https://www.bps.org.uk/sites/bps.org.uk/files/Member%20Networks/Divisions/DCoP/
INF311%20WEB.pdf

Burr, V. (1995). An introduction to social constructionism. *Choice Reviews Online*, *33*(05),
33-3018-33-3018. doi:10.5860/choice.33-3018

Chester, R. (2010). Diagnosing personality disorder in people with learning
disabilities. *Learning Disability Practice*, *13*(8), 14-19.
doi:10.7748/ldp2010.10.13.8.14.c8017

Cookson, A., & Dickson, J. (2010). The subjective experiences of people with an intellectual
disability and diagnosis of schizophrenia who are detained in a medium secure
unit. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 379-389.
doi:10.1111/j.1468-3148.2010.00554.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*(1), 61-72.
doi:10.1046/j.1360-2322.2002.00101.x

Crowe, M. (2000). Constructing normality: a discourse analysis of the DSM-IV. *Journal of
Psychiatric and Mental Health Nursing*, *7*(1), 69-77. doi:10.1046/j.1365-
2850.2000.00261.x

Department of Health. (2012). *Transforming care: A national response to Winterbourne View
hospital* [PDF file]. Retrieved from
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachme
nt_data/file/213215/final-report.pdf

Flynn, A., Matthews, H., & Hollins, S. (2002). Validity of the diagnosis of personality disorder in adults with learning disability and severe behavioural problems. *British Journal of Psychiatry*, *180*(06), 543-546. doi:10.1192/bjp.180.6.543

Goble, C. (1999). "Like the Secret Service Isn't It". People with Learning Difficulties,' Perceptions of Staff and Services: Mystification and disempowerment. *Disability & Society*, *14*(4), 449-461. doi:10.1080/09687599926064

Gold, N., & Kyratsous, M. (2017). Self and identity in borderline personality disorder: Agency and mental time travel. *Journal of Evaluation in Clinical Practice*, *23*(5), 1020-1028. doi:10.1111/jep.12769

Goldsmith, L., Skirton, H., & Webb, C. (2008). Informed consent to healthcare interventions in people with learning disabilities - An integrative review. *Journal of Advanced Nursing*, *64*(6), 549-563. doi:10.1111/j.1365-2648.2008.04829.x

Hansen, J.T. (2004). Thoughts on knowing: Epistemic implications of counseling practice. *Journal of Counseling & Development, 82*(2), 131-138. doi:10.1002/j.1556-6678.2004.tb00294.x

Hollins, S., & Sinason, V. (2018). Psychotherapy, learning disabilities and trauma: New perspectives. *British Journal of Psychiatry*, *176*(1), 32-36. doi:10.1192/bjp.176.1.32

Horn, N., Johnstone, L., & Brooke, S. (2007). Some service user perspectives on the diagnosis of Borderline Personality Disorder. *Journal of Mental Health*, *16*(2), 255-269. doi:10.1080/09638230601056371

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An alternative nondiagnostic conceptual System. *Journal of Humanistic Psychology*, *0*(0), 1-18. doi:10.1177/0022167818793289

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*(2), 102-120. doi:10.1191/1478088706qp062oa

Lidher, J., Martin, D., Jayaprakash, M., & Roy, A. (2005). Personality disorders in people with learning disabilities: follow-up of a community survey. *Journal of Intellectual Disability Research*, *49*(11), 845-851. doi:10.1111/j.1365-2788.2005.00762.x

Lindsay, W., Hogue, T., Taylor, J., Mooney, P., Steptoe, L., Johnston, S., … Smith, A. (2006). Two studies on the prevalence and validity of personality disorder in three forensic intellectual disability samples. *Journal of Forensic Psychiatry & Psychology*, *17*(3), 485-506. doi:10.1080/14789940600821719

Lindsay, W., Steptoe, L., McVicker, R., Haut, F., & Robertson, C. (2018). DSM IV, DSM-5, and the five-factor model: The diagnosis of personality disorder with intellectual and developmental disabilities. *Journal of Mental Health Research in Intellectual Disabilities*, *11*(1), 1-15. doi:10.1080/19315864.2017.1350226

Lloyd, J., & Clayton, P. (2013). *Cognitive analytic therapy for people with intellectual disabilities and their carers*. London, UK: Jessica Kingsley Publishers.

Loranger, A., Janča, A., & Sartorius, N. (2007). *Assessment and diagnosis of personality disorders*. Cambridge: Cambridge University Press.

Mavromatis, M. (2000). The diagnosis and treatment of borderline personality disorder in persons with developmental disability: Three case reports. *Mental Health Aspects of Developmental Disabilities, 3*(3), 89-97. Retrieved from http://www.worldcat.org/title/mental-health-aspects-of-developmental-disabilities/oclc/926214983/editions?editionsView=true&referer=br

McGilloway, A., Hall, R., Lee, T., & Bhui, K. (2010). A systematic review of personality disorder, race and ethnicity: prevalence, aetiology and treatment. *BMC Psychiatry, 10*(33), 1-14. doi:10.1186/1471-244X-10-33

Moreland, J., Hendy, S., & Brown, F. (2008). The validity of a personality disorder diagnosis for people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *21*(3), 219-226. doi:10.1111/j.1468-3148.2007.00399.x

Morrissey, C., & Hollin, C. (2011). Antisocial and psychopathic personality disorders in forensic intellectual disability populations: what do we know so far?. *Psychology, Crime & Law*, *17*(2), 133-149. doi:10.1080/10683160903392442

Naik, B., Gangadharan, S., & Alexander, R. (2002). Personality disorders in learning disability – The clinical experience. *The British Journal of Development Disabilities*, *48*(95), 95-100. doi:10.1179/096979502799104210

National Institute for Health and Care Excellence. (2015). *Personality disorders: borderline and antisocial* [PDF file]. Retrieved from https://www.nice.org.uk/guidance/qs88

Pridding, A., & Procter, N. (2008). A systematic review of personality disorder amongst people with intellectual disability with implications for the mental health nurse practitioner. *Journal of Clinical Nursing*, *17*(21), 2811-2819. doi:10.1111/j.1365-2702.2007.02269.x

Rayner, K., Wood, H., Beail, N., & Nagra, M. (2015). Intellectual disability, personality disorder and offending: a systematic review. *Advances in Mental Health and Intellectual Disabilities*, *9*(2), 50-61. doi:10.1108/amhid-04-2014-0007

Reiss, S. (1994). *Handbook of challenging behaviour*. Worthington, Ohio: IDS Publishing.

Robinson, L., Escopri, N., Stenfert Kroese, B., & Rose, J. (2016). The subjective experience of adults with intellectual disabilities who have mental health problems within community settings. *Advances in Mental Health and Intellectual Disabilities*, *10*(2), 106-115. doi:10.1108/amhid-04-2015-0017

Robinson, O. (2013). Sampling in Interview-Based Qualitative Research: A Theoretical and Practical Guide. *Qualitative Research in Psychology*, *11*(1), 25-41. doi:10.1080/14780887.2013.801543

Rogers, B., & Dunne, E. (2011). 'They told me I had this personality disorder … All of a sudden I was wasting their time': Personality disorder and the inpatient experience. *Journal of Mental Health*, *20*(3), 226-233. doi:10.3109/09638237.2011.556165

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, England: Sage.

Smith, J.A., & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A Smith (Ed.), *Qualitative Psychology: A practical Guide to Methods* (pp. 53-80). London: Sage.

Stalker, K., Ferguson, I., & Barclay, A. (2005). 'It is a horrible term for someone': service user and provider perspectives on 'personality disorder'. *Disability & Society*, *20*(4), 359-373. doi:10.1080/09687590500086443

Sutcliffe, J., & Simons, K. (1995). *Self advocacy and adults with learning difficulties*. Leicester: National Institute of Adult Continuing Education.

Taylor, J. (2019). Delivering the Transforming Care programme: a case of smoke and mirrors? BJPsych Bulletin, 1-3. doi:10.1192/bjb.2019.3

Torr, J. (2003). Personality disorder in intellectual disability. *Current Opinion in Psychiatry*, *16*(5), 517-521. doi:10.1097/00001504-200309000-00005

Tufford, L., & Newman, P. (2012). Bracketing in qualitative research. *Qualitative Social Work, 11*(1), 80-96. doi:10.1177/1473325010368316

Tyrer, P. (2009). Why borderline personality disorder is neither borderline nor a personality disorder. *Personality and Mental Health*, *3*(2), 86-95. doi:10.1002/pmh.78

Tyrer, P., Mitchard, S., Methuen, C., & Ranger, M. (2003). Treatment rejecting and treatment seeking personality disorders: Type R and Type S. *Journal of Personality Disorders*, *17*(3), 263-268. doi:10.1521/pedi.17.3.263.22152

Williams, B., & Healy, D. (2001). Perceptions of illness causation among new referrals to a community mental health team: "explanatory model" or "exploratory map"? *Social Science & Medicine*, *53*(4), 465-476. doi:10.1016/s0277-9536(00)00349-x

Williams, E., & Rose, J. (2018). Nonpharmacological treatment for individuals with intellectual disability and "personality disorder". *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12527

Young, J., Klosko, J., & Weishaar, M. (2007). *Schema therapy*. New York: Guilford.

Tables

Table 1

Demographics of participants

Name	Age	Gender	Ethnicity	Diagnosis	Current accommodation
'Andrew'	24	Male	White British	Mild LD, ADHD, EUPD	Supported living
'Ben'	35	Male	White British	Mild LD, EUPD	Supported living
'Kylie'	33	Female	White British	Mild LD, BPD, Psychotic Episodes, Anxiety Disorder	Supported living
Vera	30	Female	White British	Mild LD with 'Challenging Behaviour', EUPD	Supported living in group home – independent flats
'Christine'	57	Female	White British	Mild LD, Unspecified PD – antisocial, EUPD traits	Residential group care home
'Fiona'	52	Female	White British	Mild to moderate LD with challenging behaviour, EUPD	Supported living in group home – independent flats
'Beth'	21	Female	White British	Mild LD, unspecified PD	Supported living
'Amy'	35	Female	White British	Mild LD, EUPD – borderline type, recurrent depressive disorder	Supported living in group home – independent flats

Table 2

Individual participants' themes and sub-themes

Participant	Main theme	Sub-themes
'Andrew'	Need for acceptance and understanding	The impact of disclosing my diagnosis to others
		Reliance on others for support
		Achievement and connection through caring for others
	Trying to understand what my diagnosis means	PD is a "beast" inside me
		"I'm not normal" vs. acceptance of who I am
		Knowledge and power of professionals
	Mechanisms for change	Low expectations of self
		Maintaining hope for the future
		Externalisation of change
		Change in behaviour linked to consequences
'Ben'	Not feeling in control of my mood	Reliance on others to meet needs
		PD as two different sides of me
	How diagnosis impacts my identity	Lack of understanding of PD
		Shame and embarrassment over LD
	Who I was and who I am	Maintaining connections to family and friends
		Life feeling more stable
		Supported to be independent

Table 2

(Continued)

Participant	Main theme	Sub-themes
'Kylie'	Navigating relationships with others	Striving for connection to others
		Feeling 'different' to others
		Others are abusive or shaming
		Reliance on trusted others
	Diagnosis as an illness	My relationship with medication
		I'm not in control of my difficulties
	Life as a battle	Ups and downs
		"I'm no good"
		Overcoming past admissions
		Holding hope for future
'Christine'	Journey to freedom	Longing for freedom
		Hospital as bad and abusive
		Valuing independence
		Beginning to fit in
	What I've learnt about my difficulties	The environment impacts on my mood
		Needing to feel connected
		Changes to coping strategies over the years
	My relationship with diagnosis	'PD' as an "illness"
		Use of institutional/medical language
		Diagnosis has got me right support
		Not letting diagnosis drag me down

Table 2

(Continued)

Participant	Main theme	Sub-themes
	"I'm normal, not ill"	Diagnosis as disempowering
		Understand me, don't label me
		Not ill, but something wrong – ambivalence over diagnosis/medical model
Vera	Importance of relationships	Supported to be independent
		Learning to trust others again
	Life as ups and downs	Living with difficulties for long time
		Sense-making through difficult experiences
		Changes to coping strategies
		Good weeks/bad weeks
	My relationship with myself	Shame
		Feeling different and longing to be normal
		Striving for achievement but not feeling capable
		Better than I was before
'Beth'	Navigating relationships with others	Others see me as childlike
		Reliance on others to meet needs – lack of self-efficacy
		Others as protective – wanting answers
	'PD' as 'other person'	Illness
		Two different sides to me
		Out of my control
		Relationship to medication

Table 2

(Continued)

Participant	Main theme	Sub-themes
	Searching for meaning of diagnosis	Diagnosis as 'depressing' – talk about 'problems'
		Feeling powerless and humiliated
		Lack of understanding
		Shame over LD
		'PD' as illness vs. talking about my experiences
'Fiona'	Longing for connection and understanding	Wanting to meet others with similar experiences
		Trust in relationships
		Differences between services
		Diagnosis means I don't deserve relationships
	Living with ups and downs	Changes to coping strategies
		Ambivalence over future
	Need to be understood and accepted	Stigma in the community over mental health
		Changed dynamics within family
		Need for others to understand her experiences, not the diagnosis
	Illness vs. Trauma	Power of professionals
		'PD' as different person
'Amy'		'PD' as sick
		It's because of my trauma
	Uncertainty over the future	Hospital vs. 'the real world'
		Hoping to stay well
		Living in fear
		Striving for normality

Table 3

Participant's emerging themes and contribution to super-ordinate themes

Super-ordinate theme	Participant 1 ('Andrew')	Participant 2 ('Ben')	Participant 3 ('Kylie')	Participant 4 (Vera)	Participant 5 ('Christine')	Participant 6 ('Fiona')	Participant 7 ('Beth')	Participant 8 ('Amy')
1. **Knowledge is power – Diagnosis as the domain of professionals**	*LD impacts on ability to understanding* *Lack of understanding of 'PD' diagnosis* *Poor memory associated with LD* *Need for clearer information* *Not satisfied with diagnosis process* *Professionals holding power through diagnosis* *Wanting answers earlier*	*Lack of understanding of 'PD'* *Uncertainty of community of 'PD'* *Shame over lack of understanding* *LD impacts on understanding* *Indifference due to lack of understanding* *Wanting more information* *Staff know more about 'PD' – lack of power* *Acquiescence and indifference to diagnosis*	*Lack of own voice – others as powerful* *Lack of understanding of diagnosis* *Passivity within services* *Indifference over diagnosis due to lack of understanding* *Trust in professionals* *Did not read or understand letter from doctor* *Diagnosis as domain of professionals* *Professionals as all knowing* *Lack of communication re: diagnosis/ medication*	*Power of professionals* *Feeling embarrassed* *Feeling accused by professionals* *Getting used to diagnosis – disengaging with label* *Trying to readdress power dynamics* *Labels not given to those in power* *Professionals label rather than understand*	*Diagnosis as professional domain* *Lack of understanding due to indifference* *Not wanting more information – rejection of diagnosis*	*Diagnosis as overwhelming and confusing* *Lack of understanding* *Difficulties with LD* *Anger over diagnosis – lack of understanding* *Diagnosis all professional domain – all-knowing* *Diagnosis held back by professionals* *Diagnosis kept secret – feeling powerless* *Diagnosis impacted on trust in professionals* *Need for respectful approach to diagnosis* *Diagnosis as 'thrown in face'*	*Lack of understanding of diagnosis* *Wanting more information about 'PD' from others* *LD impacts on ability to retain information* *Diagnosis kept secret – being protected by others*	*Diagnosis upsetting due to lack of knowledge and understanding* *Impact of LD on understanding* *Professionals as all-knowing-giving diagnosis but no explanation* *Professionals as powerful* *Powerless and dependent on others – 'waiting' for information* *Frustration at professionals*

Table 3

(Continued)

Super-ordinate theme	Participant 1 ('Andrew')	Participant 2 ('Ben')	Participant 3 ('Kylie')	Participant 4 (Vera)	Participant 5 ('Christine')	Participant 6 ('Fiona')	Participant 7 ('Beth')	Participant 8 ('Amy')
2. **Understanding difficulties through a trauma lens**	*Using diagnosis to search for meaning Diagnosis not means for making sense Sense-making through describing childhood experiences Use of cannabis to cope and fit in Linking sexual abuse to current behaviour*	*Lack of investment in diagnosis No meaning to diagnosis Lack of sense-making through diagnosis Transitions impact on mental health Instability in placements and mood Need for settled staff team* *Certain events or triggers give meaning to experiences Difficulties in relationships Isolation and self-harm to cope with feelings/events*	*'PD' diagnosis not contributed to sense-making Sense-making over previous difficulties and past events Searching for sense-making Instability affects mood and thoughts Experiences of bullying Past abuse/rape linked to current difficulties Lack of trust in others due to past Separation from family*	*No sense-making through diagnosis* *Sense-making through difficulties in relationships and trust Acknowledging impact of trauma/ flashbacks Time needed to build trust and relationships Loss/ bereavement Experiences of abuse Linking 'PD' to trauma Life as series of transitions and inconsistent care*	*Father as uncaring and absent Linking emotions and difficulties to self-harm Self-harm to communicate distress Not feeling safe since school Environment and others impact on mood and behaviour Self-esteem, abuse and issues around body linked to difficulties*	*Violence as way of managing flashbacks Trauma and abuse Talking about past – rejection of diagnosis Diagnosis as not helpful for sense-making Others as rejecting or abusive*	*Others put her in vulnerable positions Being separated and put into care Difficulties within family Difficulties with emotions and behaviour at school Not being able to trust others Aggression due to fear of being judged Feeling inferior Sense-making through telling her story*	*Sense-making through further training with psychology 'PD' linked to trauma Difficulties with family Self-harm to cope with feelings Difficulty in building relationships*
3. **The stigma of diagnosis – Feeling different, seeking acceptance**	*Feeling like an outsider Stigma of diagnosis Abuse within community due to diagnosis*	*Shame over behaviour Diagnosis kept secret - confirms difference Being "trouble" impacts on identity*	*Others shaming over LD "I'm weird" Feeling detached from others Others treat me as different*	*Diagnosis being used to single out people as different or abnormal People act differently around me*	*Shame and 'hate' over identity Being 'different' to other kids Feeling different Bullied due to being 'slow' - LD*	*Diagnosis as shaming and 'depressing' Parents highlighting abnormality Aggressiveness towards self – low self-esteem*	*World treats me as "stupid" Ashamed of behaviour Being treated like a child People not approaching her due to difference*	*Fearing diagnosis will lead to rejection Still feeling 'different' Not feeling able to fit in Hospital removes me from real life*

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Table 3

(Continued)

Super-ordinate theme	Participant 1 ('Andrew')	Participant 2 ('Ben')	Participant 3 ('Kylie')	Participant 4 (Vera)	Participant 5 ('Christine')	Participant 6 ('Fiona')	Participant 7 ('Beth')	Participant 8 ('Amy')
3. The stigma of diagnosis – Feeling different, seeking acceptance (*continued*)	*Online/social media abuse* *Me vs. them – being different* *"Not normal"* *Fearing rejection due to diagnosis* *Diagnosis used to test others' reactions* *Looking for connection to others* *Wanting others to accept his identity and sexuality* *Achievement through caring for others* *Identity through helping others* *Feeling connected to others helps manage emotions* *Seeking to fit in* *New job led to more acceptance*	*Wanting others to take interest and understanding position* *Need to feel cared for* *Connection to others helps with distress* *Importance of maintaining relationships* *Staff go 'beyond' – feeling cared for*	*Me vs. them – being ganged up on* *People noticing 'difference'* *Bullying confirms 'difference'* *Shame over self and ability* *Seeking connection to others* *Importance of family support* *Others need to be caring and understanding* *Support important in recovery* *Wanting acceptance and support from others*	*Difficulties within family* *Abuse through social media* *Diagnosis as secret – shame and rejection* *Diagnosis as stigmatising for rest of life* *Diagnosis as 'labels'* *Use of institutional language to describe self* *Rejection of medical model or being seen as 'ill'* *Rejection of diagnosis as 'not normal'* *Striving for acceptance* *Everyone has mental health – being normal* *Volunteering brings sense of acceptance and belonging* *Diagnosis brings 'right care'*	*Being 'trouble' and 'wrong'* *Hospital admission confirming difference* *Abuse and rejection within hospital care* *Rules and routines in hospital impacting on 'normality'* *Learning to accept and like self* *Good relationships with current staff* *Maintaining relationships* *Striving for social connections* *Own space and activities* *Some independence* *Community as comforting* *Rejection of label due to feeling accepted in community*	*Shame over identity* *Shame of LD* *Shame of 'PD' – 'the other one'* *Being different* *Blaming self* *Not feeling wanted by staff* *Me vs. them/staff* *Stigma/bullying by others in community/staff* *Trying to fit in leads to being taken advantage of* *Caring for others to build connections and acceptance* *Desire for alternative language to diagnosis – 'problems'* *Building trust in relationships*	*Self-criticism* *Difficulty in recognising strengths* *Looking 'different'* *Others tell her she's not 'normal'* *Lack of achievement reinforces feeling of 'difference'* *Feeling incapable and low confidence* *Longing to be 'normal'* *Wanting to prove to others she is 'better'*	*Something being 'wrong with me'* *Diagnosis impacts on building relationships* *Diagnosis impacts on employment/ volunteering* *Striving to be back in 'normality'* *Not feeling connected to 'real world'* *Connection to others who have experienced trauma* *Time needed to build relationships* *Need for staff to understand her through 'PD' training* *Diagnosis does not provide understanding for staff* *Staff showing care and understanding – acceptance*

Table 3

(Continued)

Super-ordinate theme	Participant 1 ('Andrew')	Participant 2 ('Ben')	Participant 3 ('Kylie')	Participant 4 (Vera)	Participant 5 ('Christine')	Participant 6 ('Fiona')	Participant 7 ('Beth')	Participant 8 ('Amy')
3. The stigma of diagnosis – Feeling different, seeking acceptance (*continued*)	*Those that stick by me are family* *People go out their way for me – feeling special* *Trust and confiding in others* *Ambivalence of identity – acceptance vs. not normal*			*New accommodation treats her as 'normal'* *Support working together and caring* *Humour with staff*	*Diagnosis as invisible – can be 'normal'* *There's nothing wrong with me* *Connection to others impacts positively on identity*			*Hope for acceptance of mental health within community* *Noticing changing perceptions of the public*
4. Taming the 'beast' inside – The journey towards regaining control	*"Beast" – 'PD' as a separate entity* *Dangerous and out of control* *"Something wrong with me" – being ill and different* *Lack of agency –out of his control* *'PD' as a 'thing'* *Medical /illness model understanding* *Medication linked to diagnosis management*	*'PD' as two separate identities* *"Nice" and "horrible"* *Out of control of 'horrible' side* *Lack of agency – out of control of mood and behaviour* *"It's my personality" – lack of agency* *Reliance on staff to manage mood or behaviour* *'Advance statement'- safety when out of control*	*Illness narrative 'PD'* *Out of control – coming out the blue* *'PD' lingers within* *Medication as first response* *Importance of support in developing new coping strategies* *Externalisation of coping – reliance on others* *Not internalised own skills*	*Difficulties as separate entity – 'not myself'* *Medication and medical/illness understanding* *Diagnosis used by others to externalise and minimise difficulties* *Staff externalise behaviour to 'PD' – being out of control* *Need others at times to manage self-harm* *Isolation vs. support*	*Medical understanding of 'PD'* *'PD' as tangible 'thing'* *Illness narrative of 'something wrong with me'* *Diagnosis as 'dragging me down' – feeling more out of control* *Control comes from not thinking of difficulties as much* *Just living a 'normal life'*	*'PD' as lifetime illness* *Different person when stressed or unwell* *Reliance on others whilst building self-efficacy* *Still living through difficulties* *Progress "step by step"* *Changes to coping strategies* *Talking helps to manage feelings – more in control*	*Having two different states and personalities* *Out of control of 'explosive' self* *Having 'it' – disease* *Two different personalities* *Reliance on others when feeling out of control* *Knowledge of consequences stops behaviour* *Still building insight and control over difficulties*	*PD' as lifetime illness* *'PD' is a 'different person' – lack of agency/ control* *'PD' as two people* *Medical/illness understanding – "sick"* *Medication as first response* *Self-harm as 'illness'* *Diagnosis as disabling – out of control* *Others make me ill – lack of agency*

Table 3

Super-ordinate theme	Participant 1 ('Andrew')	Participant 2 ('Ben')	Participant 3 ('Kylie')	Participant 4 (Vera)	Participant 5 ('Christine')	Participant 6 ('Fiona')	Participant 7 ('Beth')	Participant 8 ('Amy')
4. Taming the 'beast' inside – The journey towards regaining control (*continued*)	*'PD' and LD diagnosis as externalising responsibility* *Family use diagnosis to externalise* *Change in behaviour linked to consequences* *Shame over behaviour* *Changes to coping over time* *Hope for diagnosis providing answers and change* *Hope for future* *Reliant on others/support* *Changes due to others, not self* *Dependence on staff/family* *Low expectations of achievement*	*Need high levels of support to feel safe* *Others need to manage mood* *Changes to coping over time* *Learning to open up rather than isolate self* *Progress* *Past v present – experiences of hospital* *Life feeling more stable* *Mix of support and independence*	*Medication as facilitator for change* *Diagnosis used by others to minimise difficulties* *Achievement in staying out of hospital* *Life as "ups and downs"* *Life as a battle* *Living and coping with uncertainty* *Feeling more in control and able to cope* *Being more able to cope leads to reduction in medication*	*Supported to be independent – control over future and mood* *Life as ups and downs* *More able to cope now* *"Bad weeks and good weeks"* *Progress – feeling in control of future* *Living with difficulties easier* *New ways to manage distress* *Learning new coping strategies*	*Coping with difficulties* *Wanting to socialise more* *Freedom and supported independence* *Not dwelling on difficulties – ability to cope* *Isolation vs. socialising*	*Isolation leads to feeling out of control/ overwhelmed*	*More positive over future* *Need sense of achievement* *Change to self and coping strategies* *More able to control emotions at times* *Progress – having 'blips' rather than 'my personality'*	*Fearing uncertainty and change – lack of agency/control* *Reliance on others during times of distress* *Low expectations of ability to cope at times* *Inevitability of becoming 'ill' again* *Diagnosis not important when "well"* *Supported to be independent* *Hopes for future* *"Day by day" – progress in coping with difficulties* *Independence and activities foster self-efficacy*

Appendix 2-A: Author Guidelines

Please see Appendix 1-A

Appendix 2-B: Sample of IPA coding

Emerging Themes	Line	Text	Initial codes/ideas
Violence as last resort	127 128 129 130 131 132 133 134 135 136	P: I basically, if they get in the door and I was having one of my moments where I wanted to go walk round the block or something, they'd stop me. And then I just lashed out at them instead. What I used to do is go round the block, and calm down. And when that didn't work, I used to punch walls or whatever. T: Hmm. And what kind of things brought on those feelings of "I just need to get out" or…? P: Don't know. T: Not too sure. It's just a feeling?	'used to do' = anger/aggression in past? No need to do this now? coping strategy – occurs 'accidentally' when other mechanisms thwarted
Internalised stigma – being a beast, out of control	137 138 139 140 141 142 143 144 145 146 147 148 149	P: Yeah. I think I got me dad's temper. And he says he's got a beast in him. If that makes any sense? T: And what does that mean for you? P: Don't know. It's scary like. But he's never hit me. Even though he's argued with me and then punched a wall, but like it's scary though because if I moved slightly to a different way that could have been me, you know what I mean? But me dad would never hit me. T: I was interested when you said your dad said he had a beast inside him, and you said you are a lot like your dad. So does that me you see yourself in the same way? P: Yeah T: So have other people reacted you know when you say you've had to go through people?	Sees self as similar to dad. Internalised self as a 'beast'? Asks question to avoid directly stating – externalising behaviour linked to shame? Seeking reassurance/meaning from me? Sense-making through dad Dad also punches walls – links to his previous coping strategy. Feelings of fear. Out of control
Being dangerous	150 151 152 153	P: Scared, they phone the police and everything. T: Who would phone the police? Was that in supported living or elsewhere? P: No, this was before I got there. When I was living at home when I	Himself as scary/dangerous enough for police involvement – people severely worry
Experience of consequences bringing change to identity/coping strategies	154 155 156 157 158	was a child. Me mum used to ring them on me. But I'm made up she has, because it's made me the person I am today. T: Ok, in what way? P: Like I know how to control me temper now, you know what I mean? Don't get me wrong, me and me mum argue still. I still turn	Mum reporting his behaviour (caring?) linked to identity building Developed coping strategies to regulate emotions. 'Things are still

Chapter Three: Critical Appraisal

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CRITICAL APPRAISAL

The aim of this critical appraisal is to provide an overview of the research process, including reflections on completing research with a learning disability (LD) population. Given the controversy 'personality disorder' (PD) diagnoses, I will discuss my interest in conducting research in this area, and reflect on my stance on diagnosis in light of this research. Finally, I will reflect on my experience of working within services and clients affected by Transforming Care (TC; Department of Health, 2012).

Summary of findings

This thesis used qualitative methodology to explore people with LD's experiences across two main contexts; firstly, Chapter 1 reports the findings of a systematic review investigating experience of transitions from long-term care, whilst Chapter 2 consists of an empirical paper focused on people's experiences of a 'PD' diagnosis. What is notable across both papers is the sense of people's struggle for acceptance by others and the world around them, and desire for 'normality' in their lives. The impact of difficult experiences in hospital, limitations to their independence and often continued experiences of bullying or stigma within the community often meant people were ashamed of their identity as an individual. The empirical paper suggests further negative impacts for participants with a 'PD' diagnosis. The importance of other people and relational experiences often underpinned people's understanding of their identities, well-being and their place within communities.

Both papers contribute understanding of the difficulties some people with 'LD' may experience during their use of mental health services. Participants had different levels of understanding around the diagnosis of 'PD' and therefore their relationship with it. However, all participants described difficult early life experiences, and recognised balancing a need for support with maintaining a sense of independence. People often spoke negatively about past experiences of services, but were more hopeful in their current placements. This hope appeared linked to factors including valued placements, relationships with staff, feeling

supported and independent, and resilience from continuing to manage traumatic difficulties. The process of being interviewed may have allowed participants a space to reflect on their lives and significant changes.

This research reinforces the need for support for people with LD and complex needs; and suggestions for the way in which support is provided. For example, communication and contextualisation of 'PD' is often lacking, or is at least not understood well by clients, leading to avoidable negative consequences for people. It also highlights how psychological interventions, alongside a systemic support network and wider acceptance within communities are required to best meet the needs of this vulnerable group.

Epistemological position

I adopted a critical realist perspective in relation to people's experiences of leaving long-term care as explored in Chapter 1. It is my belief that the physical experience of transition and the subsequent interpersonal dynamics reflect real phenomena, with language contributing to various interpretations of experiences, and the subsequent impact on themselves and their relationships.

For the empirical research in Chapter 2, I adopted a critical realist stance of trying to uncover a reality, which could only ever be partial, contextual and transitory. A 'PD' diagnosis aims to categorise a variety of co-occurring difficulties; however we should aim to understand its underlying reality. Despite disagreeing with the diagnosis, I do not dispute the very real impact or difficulties that are faced by people living with a 'disability' and/or 'PD' (Sinason, 2010; Webb, 2014). The purpose of the research was to investigate meaning by taking an interpretive stance and co-constructing this within the researcher-participant relationship. These processes enabled sense-making to surface and understand what life is like for people living with LD and 'PD'.

CRITICAL APPRAISAL

My relationship to the topic

The thesis was partly inspired by my previous clinical experiences. My pre-training experiences included working as a healthcare worker within a low-secure hospital for males diagnosed with 'LD', 'complex' difficulties and offending histories. It was around this time that I became aware of TC and the scandal that preceded it at Winterbourne View. I felt dismayed seeing the videos of the abuse, especially whilst working with people who were experiencing significant levels of distress and were often dependent on support for their physical, emotional and social needs. Despite empathy with people working on the frontline in incredibly stressful environments, working long shifts with multiple demands, often without the adequate support and supervision psychologists receive, I could not understand how staff could treat their clients in the way those at Winterbourne View did, or how services could fail to monitor and safeguard this. I welcomed the changes and renewed focus on improving community services that TC advocated. During writing this thesis, systematic abuse at Whorlton Hall uncovered by the BBC's Panorama series aired on television. I remember feeling horror that the apparent learning from Winterbourne View had not been sufficiently implemented, and that all the positive work and continued passion to provide the best care possible to some of the most vulnerable people in the country could potentially be overshadowed by this incident. As I was writing a theme around people's past experiences of abuse within long-term care, it felt like it was a historical issue. It was shocking to see this level of abuse occurring in the present day. I hope participants' experiences of traumatic events and abuse as documented within this research will be a reminder of the needs and vulnerabilities of people with LD.

Prior to clinical training, my experience of psychology was within forensic contexts, often specialist wards or services for people who have attracted a diagnosis of 'PD'. I have previously been conflicted over the diagnosis, reflecting the similar ambivalence clients had.

CRITICAL APPRAISAL

This conflict comes in part from the risk the label pathologises difficulties that are often the result of interpersonal trauma (Shaw & Proctor, 2005). On the other hand, I recognise diagnosis has benefit in categorising people in terms of need, and thereby enabling the provision of appropriate levels of support. However, I have always considered the connotations of describing someone's personality, essentially their core identity, 'disordered' troublesome and disheartening. The diagnosis of 'PD' has often been used to mask the difficulties it aims to address, and adds to the problems people with the label experience (Willmot & Evershed, 2018). Use of the label has often led to inexcusable treatment of people within services (Lamb, Sibbald, & Stirzaker, 2018). I have witnessed mental health clinicians diagnosing and labelling service users with multiple personality disorders, which I believe provides no clinical utility when the interventions offered are limited and not tailored towards individual need, e.g. offering everyone 'evidence-based' Dialectical Behaviour Therapy despite debatable long-term outcomes (Reddy & Vijay, 2017). The range of interventions for people experiencing difficulties related to the diagnosis of 'PD' has significantly increased (Duggan, Huband, Smailagic, Ferriter, & Adams, 2007), yet access still appears limited in some services (Lamb et al., 2018). This makes me uneasy at some of the current practice within services, despite welcoming a renewed focus and positivity towards developing interventions for a group that have often been ostracised or ignored. As the diagnosis of 'PD' in particular appears to divide professional opinion, I was curious to explore if these differences are experienced by those diagnosed with 'PD' in order to add more voices to the debate, challenge my own thinking about diagnosis and inform my future clinical practice. It has previously been assumed that diagnosis must be a traumatic time for people with LD (Todd, 2000), therefore the research aimed to explore people's own experiences.

My role in the research

Choosing an area of passion and interest enabled me to sustain my motivation during times of frustration and challenge over a hectic few years. I have regularly thought about my stance towards diagnosis and in particularly 'PD', and the possible impact it may have on the interpretative nature of the research I was conducting. I wondered whether even investigating 'PD' could be viewed as giving legitimacy to a term I have debated over my career to date. However, due to the prevalence of the label within services, I felt it important to adopt the terminology and maintain a critical stance, whilst reflecting the experiences of the people themselves, rather than avoiding the term altogether. I took the position that a diagnosis has been made and 'given' by professionals, but it may not necessarily be accepted by the person (Willmot & Evershed, 2018). Like many others, I have found diagnosis a helpful 'short-cut' way of communicating to other professionals about someone's general pattern of difficulties. In addition, I recognise the benefits the label has brought to many clients I have worked with in bringing a sense of relief, hope and belonging to others with the label. The sense of solidarity that develops between clients sharing similar experiences is something a diagnosis can foster for some people. This is something I believe all professionals should hold in mind when critiquing a medical model of mental health. Therefore, it has been important to me not to misrepresent the views of the people who have graciously and bravely taken the time to share their experiences. I wrote the introduction of the empirical paper from a more critical stance, whilst adopting a more 'neutral' style in the results section by sticking closely to participants' words during interpretation. This process, in addition to cross-checking themes with research supervisors, hoped to minimise any biases on the research.

I chose to use the language of mental health 'difficulties' or 'distress' often throughout this research. This was done deliberately to avoid using language that is associated with a bio-medical model of mental health. I feel uncomfortable using words such

as 'disability' or 'disorder', and the use of quotation marks around these terms is my way of conveying what the research is about using currently accepted terminology, whilst maintaining a critical stance.

Transforming Care

When I became aware of the possible impact TC may have on clients I was working with, who all naturally expressed a desire to have more independence and freedom despite positive experiences of care, I felt happy that people may be moved to less restrictive settings. Conducting this research has given me more understanding regarding the socio-political drives surrounding TC, in addition to the different lived experiences of people with LD. My views regarding TC and its intended benefits have altered. I do not question the positive intentions behind the directive, as I believe it is very natural and admirable to want everybody to have the best possible quality of life. Many people with LD would be better served in homes rather than hospitals (Taylor, 2019a). However, it is an assumption that discharging people with LD back to the community they are from is always helpful. The participants in this research all maintained relationships with family in the area, however not all people with LD and 'PD' will feel the same, especially in the context of interpersonal trauma, abuse, and stigma from families or the community. Wolfensberger (2011) suggests the same social forces that demean, restrict and devalue people with LD in hospital are also part of our culture and society. Therefore, TC needs to consider how to help people manage in new settings without reverting to previously unsuccessful ways of coping, and to provide new experiences that address issues of early rejection, abuse, bullying and service failures throughout their life (Sinclair, 2018).

Whether isolated incidents should result in the reduction of beds or closure of all specialist inpatient LD services is debatable. Policy change because of socio-political pressure rather than credible evidence can pose significant risks and cost (Cumella, 2010), as

demonstrated in the introduction and subsequent expensive decommissioning of the

Dangerous and Severe Personality Disorder strategy (Taylor, 2019a). There are a group of

people with LD who are currently placed in hospital settings who pose a significant risk to

others or themselves (Sinclair, 2018). The enthusiasm to reduce numbers of beds and move

service users into the community quickly raises questions regarding the motivations, and the

evidence-based reasons for this approach (Taylor, 2019a). Questions remain over whether

community-based services have been adequately developed, implemented and resourced to

manage the needs of people with LD and complex needs, such as 'PD'. Closing specialist

NHS LD beds before adequate community services are implemented runs the risk of sending

people with LD and complex needs to independent sector beds (Taylor, 2019b). One

participant interviewed as part of the empirical paper really brought this viewpoint to light.

She was currently placed within independent sector supported living which on arrival had the

appearance and management of a secure unit, due to the needs of the clients it is expected to

care for. Restrictions were still placed on her ability to visit the community independently

due to her forensic risk; therefore, her needs may have been met within the specialist NHS

service she relocated from, for less financial cost. However, it is important to note she

experienced more positive relationships with staff currently. Negative experiences of

inpatient care, fear of returning to hospital and difficult transitions themselves were apparent

in the narratives. Therefore until appropriate community services are in place that can

manage the need of people with LD and 'PD', there is potential for increased negative

experiences due to instability and increased changes to a person's environment.

Methodological Considerations

During clinical training, we received a lecture regarding co-production of research,

with a specific focus on a LD population. This made me passionate about the meaningful

involvement of service users in all stages of research. Much has been written about people

with LD not having a voice, or being treated as no more than research subjects or respondents (Walmsley, 2001). Thought was given as to how people with LD could become more active in the research, beyond the role of participant. Four experts-by-experience were involved in the beginning stages of the research, providing contributions regarding the accessibility and structure of the study materials and interview schedule. For example, preference for the word 'label' over 'diagnosis' was identified, therefore a question was introduced exploring participants' preference for language at the beginning of interviews.

I recognise the drive behind this research was determined by the research team in regards the research questions, data collection and analysis. Therefore, even qualitative research which aims to 'ground' studies in the experiences of others encounters ethical issues around power of the researcher compared to those who are being 'researched' (Nind, 2008). I have aimed to acknowledge the power that comes with being the researcher, particularly one who is 'non-disabled'. Therefore, even though I aimed to enable the voices of participants to be heard, this research could not claim to be 'inclusive' or 'emancipatory' as the research ideas have not been directed by people with LD themselves (Strnadova & Walmsley, 2017).

Interpretative Phenomenological Analysis (IPA) recognises the role of the researcher is subject to potential bias, assumption or experience (Smith, Flowers, & Larkin, 2009). The reflective diary was useful to note any prior expectations, reactions during the interview and potential 'leading' questions. I noted feeling some dismay when participants were unaware of what the diagnosis of 'PD' meant or why it had been attributed to them, in addition to feeling pleased when some spoke about their dislike of the label. I did not notice during the transcribing any suggestion of my perspective 'leaking' out, as the majority of questions remained open and curious, without hinting at my own viewpoint. I did change the way I asked one question in particular, so as not to emphasise any particular viewpoint. One

question began by stating "some people like the term 'personality disorder', others do not". I felt stating this may potentially make participants wonder if there was a 'right' response of what I want to hear, so I would acknowledge any viewpoints as valid in later interviews, and reinforce at the beginning that there were no right or wrong responses. I felt in my position of researcher that many participants placed me in the 'they' category of professionals. I felt acknowledging difference of opinions regarding diagnosis would allow participants a greater sense of freedom in discussing their true opinions, rather than potentially acquiesce to a perspective participants may have expected me to hold.

The process of member-checking was not undertaken due to the number of interviews, the availability of the participants and the length of time between interviews all making this process potentially counter-productive (Larkin & Thompson, 2012). It is acknowledged that 'respondent validation' may have further increased the validity of the themes (Pope & Mays, 2009). However, the interpretative nature of IPA could have made this process feel tokenistic (Bird, Scott, Cavers, Campbell, & Walter, 2016), as the role of an IPA researcher is to interpret across all participants' interpretations. Therefore, even if each participant checked their own themes, the final themes would still be based on the researcher's interpretations. In order to maximise the quality of the research, I followed LD specific quality appraisal as suggested by Rose et al. 2019. The richness of some of the findings should add to the argument that IPA is an appropriate methodology for exploring the experiences of people with LD, although it is recognised that participants within this study (along with the majority with a 'PD' diagnosis) are on the mild end of the LD spectrum.

To enable participants to talk in detail about their lived experiences, I needed to deviate from the IPA guidelines. For example, rather than let the interview be more of a 'one-sided conversation' (Smith, Flowers, & Larkin, 2009), content was regularly summarised back to participants to ascertain if I had understood what they were

communicating. Letting others lead the conversation would not have elicited much detail with many of the participants, therefore I felt sharing responsibility for the conversation whilst being careful not to test out interpretations too much was appropriate (Smith, Flowers, & Larkin, 2009). IPA allowed me to follow my natural instincts and values as a clinician, as I could feel the rapport building as we focused on exploring topics participants felt were important to discuss. The interview schedule often became a 'back-up' for when conversation had naturally ended, or to bring focus back to the research aims. Due to the nature of difficulties in relationships and communication, as well as the initial relationship building that was required before some participants agreed to speak to me, I tried to maintain a balance between guiding the interview towards the research aims and allowing a space for conversation about their interests, hobbies or other experiences. This appeared to help build trust toward myself and enabled others to discuss often difficult experiences, thoughts or beliefs. I reminded myself that IPA allowed space to explore whatever is important to participants, which resulted in other valuable contributions from a population that are often unheard, dismissed or minimised.

The majority of participants commented on the benefits of taking part and sharing their experiences, even if this initially brought on some hesitation or anxiety. They spoke about the positives of taking part and the potential meaning it could have for people with similar difficulties. After going through the consent form and information regarding participant 'pseudonyms', it is interesting to note that one participant, Vera, insisted on her real name being used in the final paper. This acknowledgment and pride in her identity felt empowering and appropriate as it linked back to the research aim of having people's lived experience highlighted and having their voice heard (Swain, Heyman, & Gillman, 1998). This especially made sense in Vera's case as diagnosis was interpreted as a way of categorising and externalising her experiences as part of her 'PD' or 'mental health', rather

than seeing her for the 'normal' person she is. In regards to future research, I would endeavour to make this option clear for people to choose, as I was naturally inclined to assume 'pseudonyms' would be used based on my reading of previous IPA studies. Much thought would go into this decision, including thinking about the consequences of removing someone's anonymity and the potential reactions of others around the person (Nind, 2008).

Impact on clinical practice

My reflective journal noted the initial wariness I felt about asking people about difficult experiences and the possible impact afterwards, especially as I have not had the opportunity to build a therapeutic relationship with participants that I would normally do in clinical practice. This linked back to a question I received in the Research Ethics Committee meeting I attended, where one panel member was concerned about the impact of asking people with 'PD' about their experiences. In reality, I was surprised by the openness of participants, who all spoke about their life experiences and how it still impacts on them. This contributed to the theme of sense-making around their difficulties. I wondered whether in clinical practice, many people may be wary of asking people with 'PD' diagnoses uncomfortable questions due to fear of consequences, making things worse or hurting others. Many professionals do not ask about childhood experiences (Read, Harper, Tucker, & Kennedy, 2018) which could potentially allow unresolved or unacknowledged trauma to remain hidden and continue to negative impact their physical and psychological wellbeing, or as in Amy's case, miss opportunities to make "links" between experiences and their difficulties.

Seeing some participants describe their 'PD' diagnosis as a lifetime 'sickness' that they cannot control and therefore being afraid it will come back was difficult to hear, and I felt an emotional pull to challenge their belief. These made me reflect on professionals' responsibility to contextualise and explain diagnoses that are given to people, who may not

acknowledge that they do not understand or cannot retain what was said. I reflected on a time when I was asked by a client what 'borderline personality disorder' was and did I agree with her GP that she "has it". I remember experiencing a 'rabbit in the headlights' moment. To impose my own position on diagnosis would potentially disregard her distress and also go against my values as both a person and a clinician. I therefore said I was unable to diagnose, gave her information about psychiatric diagnoses (Johnstone, 2014) and allowed her to explore her concerns, feelings and difficulties. I have wondered whether my approach would be different in future, due to the some of the negative impacts and the consequences of people not having an awareness or understanding of the diagnosis. I wondered whether I should be more open in challenging biogenetic or 'illness' narratives of clients, especially if the client is expressing fear over it returning. Pragmatically I would need to reflect on the function and impact of diagnosis for each individual, as even though I personally feel uncomfortable with pathologising human distress, I recognise there is some clinical utility and positives of diagnosis for some service users. In my role as a clinical psychologist, I would continue to provide psychosocial ways of understanding distress through use of collaborative psychological formulation, or possibly the Power Threat Meaning Framework (Johnstone & Boyle, 2018).

Final reflections

This paper aimed to present my reflections on carrying out qualitative research in the area of LD and 'PD'. Ethical and methodological challenges have been explored. The process of continual reflection has allowed me to acknowledge my own experiences, values and assumptions relevant to the research. However, bringing myself and my values to the research has contributed to the collaborative meaning-making nature of IPA research. The process of conducting this research has been both a challenging and immensely rewarding experience. My clinical interest, passion and personal investment in the area sustained my

determination to make this thesis a meaningful piece of work, not just for myself but for the

clients who graciously gave their time and shared their personal experiences for the research.

The findings have significant implications for service provision and my own clinical practice.

References

Birt, L., Scott, S., Cavers, D., Campbell, C., & Walter, F. (2016). Member

checking. *Qualitative Health Research*, *26*(13), 1802-1811.

doi:10.1177/1049732316654870

Cumella, S. (2010). Public policy in intellectual and developmental disability. *Current*

Opinion in Psychiatry, *23*(5), 417-420. doi:10.1097/yco.0b013e32833be998

Department of Health. (2012). *Transforming care: A national response to Winterbourne View*

hospital [PDF file]. Retrieved from

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachme

nt_data/file/213215/final-report.pdf

Duggan, C., Huband, N., Smailagic, N., Ferriter, M., & Adams, C. (2007). The use of

psychological treatments for people with personality disorder: A systematic review of

randomized controlled trials. *Personality and Mental Health*, *1*(2), 95-125.

doi:10.1002/pmh.22

Johnstone, L. (2014). *A straight talking introduction to psychiatric diagnosis*. London, UK:

PCCS Books.

Johnstone, L., & Boyle, M. (2018). The Power Threat Meaning Framework: An alternative

nondiagnostic conceptual System. *Journal of Humanistic Psychology*, *0*(0), 1-18.

doi:10.1177/0022167818793289

Lamb, N., Sibbald, S., & Stirzaker, A. (2018). Shining lights in dark corners of people's lives:

Reaching consensus for people with complex mental health difficulties who are given

a diagnosis of personality disorder. *Criminal Behaviour and Mental Health*, *28*(1), 1-

4. doi:10.1002/cbm.2068

Larkin, M., & Thompson, A. (2012). Interpretative phenomenological analysis. In A. Thompson, & D. Harper (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners*. (pp. 99-116). Oxford: John Wiley.

Nind, M. (2008). *Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges* [PDF file]. Retrieved from http://eprints.ncrm.ac.uk/491/

Pope, C., & Mays, N. (2009). Critical reflections on the rise of qualitative research. *British Medical Journal*, *339*(2), 3425-3425. doi:10.1136/bmj.b3425

Read, J., Harper, D., Tucker, I., & Kennedy, A. (2017). Do adult mental health services identify child abuse and neglect? A systematic review. *International Journal of Mental Health Nursing*, *27*(1), 7-19. doi:10.1111/inm.12369

Reddy, M., & Vijay, M. (2017). Empirical reality of dialectical behavioral therapy in borderline personality. *Indian Journal of Psychological Medicine*, *39*(2), 105. doi:10.4103/ijpsym.ijpsym_132_17

Rose, J., Malik, K., Hirata, E., Roughan, H., Aston, K., & Larkin, M. (2019). Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities? *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.12605

Shaw, C., & Proctor, G. (2005). Women at the margins: A critique of the diagnosis of borderline personality disorder. *Feminism & Psychology*, *15*(4), 483-490. doi:10.1177/0959-353505057620

Sinason, V. (2010). *Mental handicap and the human condition: An analytical approach to intellectual disability* (2nd Eds.). UK: Free Association Books.

Sinclair, N. (2018). Transforming care: problems and possible solutions. *Tizard Learning Disability Review*, *23*(1), 51-55. doi:10.1108/tldr-10-2017-0040

Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London, England: Sage.

Strnadová, I., & Walmsley, J. (2017). Peer-reviewed articles on inclusive research: Do co-researchers with intellectual disabilities have a voice? *Journal of Applied Research in Intellectual Disabilities*, *31*(1), 132-141. doi:10.1111/jar.12378

Swain, J., Heyman, B., & Gillman, M. (1998). Public research, private concerns: Ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability & Society*, *13*(1), 21-36. doi:10.1080/09687599826894

Taylor, A. (2019a). *Into the unknown – A discussion of Transforming Care* [PDF file]. Retrieved from https://www.rcpsych.ac.uk/docs/default-source/members/faculties/forensic-psychiatry/andrew-taylor.pdf?sfvrsn=632a6d2a_2

Taylor, J. (2019b). Delivering the Transforming Care programme: a case of smoke and mirrors? BJPsych Bulletin, 1-3. doi:10.1192/bjb.2019.3

Todd, S. (2000). Working in the public and private domains: Staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research*, *44*(5), 600-620. doi:10.1046/j.1365-2788.2000.00281.x

Walmsley, J. (2001). Normalisation, emancipatory research and inclusive research in learning disability. *Disability & Society*, *16*(2), 187-205. doi:10.1080/09687590120035807

Webb, J. (2014). *A guide to the psychological understanding of people with learning disabilities*. UK: Routledge.

Willmot, P., & Evershed, S. (2018). Interviewing people given a diagnosis of personality disorder in forensic settings. *International Journal of Forensic Mental Health*, *17*(4), 338-350. doi:10.1080/14999013.2018.1508097

Wolfensberger, W. (2011). Social role valorisation: A proposed new term for the principle of normalisation. *Intellectual and Developmental Disabilities*, *49*(6), 435-440. http://dx.doi.org/10.1352/1934-9556-49.6.435

Chapter Four: Ethics Documents

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Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
What do people using CLDT think about their diagnosis of PD? Version 1

1. Is your project research?

◉ Yes ○ No

2. Select one category from the list below:

○ Clinical trial of an investigational medicinal product

○ Clinical investigation or other study of a medical device

○ Combined trial of an investigational medicinal product and an investigational medical device

○ Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice

○ Basic science study involving procedures with human participants

○ Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology

◉ Study involving qualitative methods only

○ Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)

○ Study limited to working with data (specific project only)

○ Research tissue bank

○ Research database

If your work does not fit any of these categories, select the option below:

○ Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation? ○ Yes ◉ No

b) Will you be taking new human tissue samples (or other human biological samples)? ○ Yes ◉ No

c) Will you be using existing human tissue samples (or other human biological samples)? ○ Yes ◉ No

3. In which countries of the UK will the research sites be located?*(Tick all that apply)*

☑ England
☐ Scotland

18/LO1931

☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

◉ England

○ Scotland

○ Wales

○ Northern Ireland

○ This study does not involve the NHS

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4. Which applications do you require?

IMPORTANT: If your project is taking place in the NHS and is led from England select 'IRAS Form'. If your project is led from Northern Ireland, Scotland or Wales select 'NHS/HSC Research and Development Offices' and/or relevant Research Ethics Committee applications, as appropriate.

☑ IRAS Form
☐ Confidentiality Advisory Group (CAG)
☐ Her Majesty's Prison and Probation Service (HMPPS)

For NHS/HSC R&D Offices in Northern Ireland, Scotland and Wales the CI must create NHS/HSC Site Specific Information forms, for each site, in addition to the study wide forms, and transfer them to the PIs or local collaborators.

For participating NHS organisations in England different arrangements apply for the provision of site specific information. Refer to IRAS Help for more information.

Most research projects require review by a REC within the UK Health Departments' Research Ethics Service. Is your study exempt from REC review?

○ Yes   ◉ No

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5. Will any research sites in this study be NHS organisations?

◉ Yes   ○ No

5a. Are all the research costs and infrastructure costs (funding for the support and facilities needed to carry out research e.g. NHS Support costs) for this study provided by a NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC), NIHR Patient Safety Translational Research Centre or a Diagnostic Evidence Co-operative in all study sites?

Please see information button for further details.

○ Yes   ◉ No

Please see information button for further details.

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) Support and inclusion in the NIHR Clinical Research Network Portfolio?

Please see information button for further details.

○ Yes   ◉ No

The NIHR Clinical Research Network provides researchers with the practical support they need to make clinical studies happen in the NHS e.g. by providing access to the people and facilities needed to carry out research "on the ground".

If you select yes to this question, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form (PAF) immediately after completing this project filter question and before submitting other applications. Failing to complete the PAF ahead of other applications e.g. HRA Approval, may mean that you will be unable to access NIHR CRN Support for your study.

6. Do you plan to include any participants who are children?

○ Yes   ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes   ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes   ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes   ○ No

Please describe briefly the involvement of the student(s):
Thesis as part of Doctorate in Clinical Psychology

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ Yes   ○ No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ Yes   ◉ No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ Yes   ◉ No

Integrated Research Application System
Application Form for Research involving qualitative methods only

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IRAS Form (project information)

Please refer to the E-Submission and Checklist tabs for instructions on submitting this application.

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
What do people using CLDT think about their diagnosis of PD? Version 1

Please complete these details after you have booked the REC application for review.

REC Name:
London - Chelsea Research Ethics Committee

REC Reference Number: **Submission date:**
18/LO1931   11/10/2018

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

A2-1. Educational projects

Name and contact details of student(s):

Name and contact details of academic supervisor(s):

Academic supervisor 1

Address

Post Code
E-mail
Telephone
Fax

Academic supervisor 2

	Title Forename/Initials Surname	
	Dr Suzanne Hodge	
Address	Faculty of Health and Medicine	
	Furness College	
	Lancaster University	
Post Code	LA1 4YG	
E-mail	s.hodge@lancaster.ac.uk	
Telephone	01524 592712	
Fax		

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

◉ Student

◯ Academic supervisor

◯ Other

A3-1. Chief Investigator:

	Title Forename/Initials Surname	
	Mr James Taylor	
Post	Trainee Clinical Psychologist	
	BSc (Hons) Psychology	
Qualifications	MSc Applied Forensic Psychology	
	Working towards Doctorate in Clinical Psychology	
ORCID ID		
Employer	Lancashire Care NHS Foundation Trust	
Work Address	Sceptre Point	
	Sceptre Way	
	Walton Summit, Preston	
Post Code	PR5 6AW	
Work E-mail	j.taylor23@lancaster.ac.uk	
* Personal E-mail		
Work Telephone		
* Personal Telephone/Mobile		
Fax		
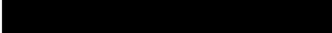
* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title Forename/Initials Surname
	Becky Gordon
Address	Research Support and Systems Manager
	Research Services
	Lancaster University
Post Code	LA1 4YG
E-mail	ethics@lancaster.ac.uk
Telephone	01524 592981
Fax	

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	N/A
Sponsor's/protocol number:	N/A
Protocol Version:	0.3
Protocol Date:	14/09/2018
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	N/A

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes   ◉ No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. *Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.*

This research aims to find out what people who are using Community Learning Disability Teams think about their diagnosis of personality disorder. Personality disorder is a contentious diagnosis, with debates over the validity of its construction, clinical usefulness and potential stigmatising effects on both individuals and the services who work with

18/LO1931

diagnosed clients. Historically, people living with a learning disability have been marginalised and continue to face societal challenges. Despite calls for greater service user inclusion, along with the acknowledgement that people with a learning disability are at increased risk of developing mental health difficulties, there is little research conducted with service users themselves. With the Transforming Care agenda highlighting a need for service users to be supported more effectively within the community, there will be an increase in people with both a learning disability and diagnosis of personality disorder living with community settings and accessing services. The research will explore with service users what their experience is of having this diagnosis in relation to their needs, thoughts, feelings, relationships and support/services. Those who are eligible to participate are current service users of community learning disability teams, who have received and are aware of a diagnosis of 'personality disorder'. They will need capacity to understand and retain the purpose of the study, and be able to consent to engage.

The research aims to conduct between four and ten 1:1 interviews, lasting approximately one hour each with current service users with a diagnosis of both learning disability and personality disorder. Participant may be invited to a follow up session in order to discuss emerging results. Participants will be recruited from four different teams across two separate NHS Trusts.

A6-2. Summary of main issues. *Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.*

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, HRA, or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Purpose and design

This research builds upon previous research in which service users with a learning disability have been asked about diagnoses and how it helps aid their understanding of their experiences. At the current time, no other research available has looked into the impact that the diagnosis of 'personality disorder' has on individuals with a learning disability. With the prevalence rates of 'personality disorder' within learning disability populations varying widely, with some research finding 7% within community services to approximately 50% in inpatient or secure services, there is an available client group to sample from. The variation in prevalence and other research over the past decade has raised debates over the clinical usefulness, validity and construction of personality disorder as a diagnosis. A negative impact of the diagnosis has also been found in staff and service perceptions of clients. Therefore it is imperative that service users who have received diagnoses of learning disability and personality disorder are consulted about their experiences and understanding of having a personality disorder diagnosis and the impact it has had.

This will be researched via 1:1 interviews with service users within community learning disability teams and analysed using Interpretative Phenomenological Analysis due to its focus on a detailed, subjective lived experience of a small sample.

In preparing the research proposal and other materials, the Chief Investigator has received critique from both an academic research supervisor and expert in the field supervisor. Information regarding the consent process, potential location and set up of interview rooms, and feedback regarding the interview topic guide, consent form and participant information sheet has been given by an NHS service user group and an expert-by-experience from a local social enterprise.

Recruitment & Consent

Recruitment will begin by approaching staff within community learning disability teams across two NHS Trusts. Staff will be made aware of the purpose of the research via an email and access to both the participant information sheet and consent form. The lead researcher will also aim to attend a team meeting in order to introduce the project. After this, care co-ordinators will aim to identify potential individuals who may be interested in participating in the research and have capacity to consent. They will highlight the research to these individuals during their next meeting/session, whilst going through the information sheet and leaving copies of the participant information sheet and consent form for potential participants to reflect on. The information sheet highlights individuals' rights to decline to participate or withdraw their information by a specific date. The care co-ordinator will then give these individuals a week to decide whether they would like to participate. If they agree, care co-ordinators will gain consent to disclose an individual's personal contact information (i.e. name and phone number) to the lead researcher. The lead researcher will then contact the potential participant to further explain the research and arrange a date for interview. Immediately prior to the interview, the lead researcher will answer any questions, assess capacity to participate and then ask participants to complete the consent form.

Inclusion/Exclusion Criteria

Inclusion criteria include individuals need to have a documented diagnosis of both 'learning disability' and a type of 'personality disorder' within their clinical records. Participants will also need to be both capacitous and competent in spoken English in order to participate in the interviews.

Risks, burdens and benefits

The benefits of the research include giving service users a platform to describe their perspectives and experiences of the usefulness of diagnostic frameworks and community learning disability services in general. It is acknowledged that the risks include discussing potentially distressing topics with participants. To minimise the potential of this and to offer further support afterwards, the topic guide has been developed in conjunction with an expert-by-experience. The participant information sheet offers contact details in case of distress after the interview, including emergency options. Care co-ordinators or other staff working with an individual will also be made aware of the interview date so they will be available to check-in with if needed. If distress or safeguarding concerns are apparent within the interview, the interview will be immediately stopped and Trust policies followed at all times.

Confidentiality

Confidentiality cannot be guaranteed in this research as quotes of participants may be used in the final paper. Anonymity will be ensured by giving participants a numerical identifier as part of the written interview transcripts, and an alias as part of the write-up of the analysis. This is clearly detailed within both the participant information sheet and consent form.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. *Please tick all that apply*:

- ☐ Case series/ case note review
- ☐ Case control
- ☐ Cohort observation
- ☐ Controlled trial without randomisation
- ☐ Cross-sectional study
- ☐ Database analysis
- ☐ Epidemiology
- ☐ Feasibility/ pilot study
- ☐ Laboratory study
- ☐ Metanalysis
- ☑ Qualitative research
- ☑ Questionnaire, interview or observation study
- ☐ Randomised controlled trial
- ☐ Other (please specify)

A10. What is the principal research question/objective? *Please put this in language comprehensible to a lay person.*

The principal research question is aimed at discovering how individuals with both a learning disability and diagnosis of personality disorder understanding their experiences and relationships in the context of their diagnosis.

A11. What are the secondary research questions/objectives if applicable? *Please put this in language comprehensible to a lay person.*

N/A

A12. What is the scientific justification for the research? *Please put this in language comprehensible to a lay person.*

The Department of Health has called for greater service user inclusion and the within learning disability populations. Despite this, there is still little research being conducted with service users themselves. Although more recognition and awareness has been raised over the past decade, people diagnosed with a learning disability remain at risk of being marginalised within society. Additionally, the diagnosis of personality disorder has previously been found to raise negative perceptions in staff working with those individuals. Therefore, it is important to highlight service users' experiences of living with this diagnosis and their perceptions of both their needs and experiences of support and services.

Diagnosing 'personality disorder' within learning disability populations remains problematic and widely disputed. Its construct and clinical usefulness has been questioned by the wide variation in its prevalence in learning disability settings. More recent estimations suggest 50% of secure learning disability services meet the criteria for a 'personality disorder' and approximately 7% of one community team within an NHS Trust. Prevalence of service users with a diagnosis of personality disorder is likely to increase due to Transforming Care prioritising moving service users back to their home area more efficiently and increasing community support.

No other known research at the time of this application has investigated what this research aims to discover. Therefore it is hoped that new information from service users in this area will help inform future clinical practice in regards to service users' needs, services and support. It will also add a service user perspective to the current debates regarding the clinical usefulness of the diagnosis of personality disorder.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The proposed research will use a qualitative design, and be analysed using Interpretative Phenomenological Analysis [IPA]. IPA was chosen over other qualitative methodologies due to its focus on going beyond descriptive information and exploring an individual's perspective and their understanding from an insider position. One-to-one interviews were identified as the best method of collating useful information, over focus groups, due to the potential for participants to disclose personal or potentially distressing information. The information will be collected via a series of one-to-one semi-structured interviews, following the design contain within the interview topic guide. The length of the interviews will dependent on the needs of each participant, with an aim of approximately one hour per interview. The topic guide for the interview has been co-developed and reviewed by individuals with a learning disability diagnosis, and an expert-by-experience who has been diagnosed with both a learning disability and personality disorder. The topic guide contains a series of introductory 'ice breaker' type questions before leading into a series of open questions as a way of exploring participants' experiences in the context of their diagnosis. Interview location was flexible according to participants' needs and location, however it is hoped a non-clinical Trust location will be primarily used to help create a more relaxed, informal setting to help with engagement. As themes are emerging during the analysis stage, participants will be given the opportunity to meet again with the lead researcher in order to review and offer feedback on the identified themes.

Once ethics have been approved, it is hoped interviews will take place during October - December 2018. Analysis and further meeting to discuss themes with participants will then take place during January - March 2019. The final paper will be submitted for evaluation (as part of the Doctorate in Clinical Psychology) in May 2019. Dependent on the marking of the paper, it will then be considered for publication in late 2019.

Information gained from service user consultation resulted in wording changes to both the consent form and participant information sheet in order to make them more accessible to service users with a learning disability diagnosis. An expert-by-experience also helped in creating the topic guide including specific questions and topics to include. They also helped to review and approve areas and questions already identified by the research team. In addition, methods to make the interview as informal and comfortable for service users were highlighted.

It is acknowledged that by the lead researcher taking an 'insider perspective' as part of the IPA analysis, there is a risk of researcher bias. This is aimed to be minimised by the rest of the research team reviewing recordings, transcripts and initial analysis of themes. Themes will then be taken back to participants (at their discretion) to confirm the understanding is accurate and useful. In addition, the lead researcher will keep a 'reflective journal' in order to continually reflect on their active role in both the interviews and subsequent analysis. This will be commented on in the final paper.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- ☑ Design of the research
- ☐ Management of the research
- ☐ Undertaking the research
- ☐ Analysis of results
- ☐ Dissemination of findings
- ☐ None of the above

Give details of involvement, or if none please justify the absence of involvement.
Service users of a community learning disability team and an expert-by-experience have reviewed and inputting into the research materials - interview topic guide, information sheet, consent form. In addition, the expert-by-experience was consulted regarding practicalities of the research including possible ways of gaining consent without coercion and the structure and location of interviews.

Approximately 5 service users with a learning disability reviewed the participant information sheet and consent form for content and ease of accessibility during August 2018. In addition, one carer and one member of staff from a community learning disability team inputted on the information included. An expert-by-experience who has been diagnosed with both a learning disability and personality disorder inputted on both the above as well as helping to design the topic guide for the interviews. This included discussing relevant topics and ideas around what they would want to be asked when discussing their experiences of having a diagnosis of 'personality disorder'. It was deemed highly relevant and ethical to have a current service user involved considering the collaborative nature and ethos to the research question.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

Select all that apply:

- ☐ Blood
- ☐ Cancer
- ☐ Cardiovascular
- ☐ Congenital Disorders
- ☐ Dementias and Neurodegenerative Diseases
- ☐ Diabetes
- ☐ Ear
- ☐ Eye
- ☐ Generic Health Relevance
- ☐ Infection
- ☐ Inflammatory and Immune System
- ☐ Injuries and Accidents
- ☑ Mental Health
- ☐ Metabolic and Endocrine
- ☐ Musculoskeletal
- ☐ Neurological
- ☐ Oral and Gastrointestinal
- ☐ Paediatrics
- ☐ Renal and Urogenital

☐ Reproductive Health and Childbirth

☐ Respiratory

☐ Skin

☐ Stroke

Gender:	Male and female participants
Lower age limit: 18	Years
Upper age limit: 75	Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

1) Service users who have received a diagnosis of both learning disability and personality disorder which is documented within clinical records
2) Service users who are capacitous and able to consent to engage
3) Service users who are confidently able to communicate verbally in English as part of the interview process

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A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

N/A

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

    1. Total number of interventions/procedures to be received by each participant as part of the research protocol.

    2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?

    3. Average time taken per intervention/procedure (minutes, hours or days)

    4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Seeking consent	3	2	1 hour	First time will be care co-ordinator or other involved staff member. They will follow this up after a week at next meeting or by phone call. Third contact will be by lead researcher regarding organising interview via phone call.
Interviews	1	1	1 hour	Conducted by lead researcher in Trust non-clinical premises where available and appropriate. Will remain flexible dependent on participant needs
Follow up meeting/results discussion	1	1	1 hour	If participants agree, the lead researcher will meet during the analysis stage to feedback and cross-check initial emerging themes for accurate understanding of their information. This may take place on an NHS Trust premises or over the phone dependent on need and availability.

A21. How long do you expect each participant to be in the study in total?

The average expected time from gaining consent to final contact with the research team will be approximately five months. This last contact will be dependent on participants consenting to meet regarding emerging themes and the results.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Risks of the research include possible upset or distress during the interview. This has been considered by involving a service user within the construct of the interview schedule. The participant information sheet also details contact details for the research team if a participant would like to discuss the interviews further or emergency contact details if participants are in significant distress afterwards. Participants will be made aware via the participant information sheet and through contact with the research team how the interview will be conducted and time allowed for breaks or stopping the interview completely if needed for the participant's well-being. Care co-ordinators or other members of staff involved in participants' care will be informed of the interview date and time in order to be contactable for more support after the interview if required. The procedure for breaking confidentiality in regards to safeguarding concerns (if a participant highlights risk towards themselves or others) will be explained to participants prior to the interview. This will involve ending the interview immediately, and collaboratively discussing with the participant how the safeguarding concerns will be raised with the care co-ordinator and appropriate social services. Providing this information prior to gaining consent and the interview will allow participants to decide whether they would like to proceed. If a participant would like to withdraw their information, the consent form details they are able to until 1st April 2019 at which point the paper will be finalised for submission and evaluation by Lancaster University. Participants will be given contact details for the research team and Lancaster University as part of the information sheet in order to withdraw their information. The participant information sheet and consent form also details how confidentiality cannot be guaranteed due to the use of quotes in the final paper. Anonymity will be ensured via numerical identifiers and alias in the transcripts and final paper. Signed consent forms will be held securely on University premises under the care of the Research Co-ordinator.

The potential benefits include bringing new information to the forefront regarding an under-researched client group and potentially impacting on future interventions, clinical practice and service development. All participants will be given information and time to decide whether the benefits for them outweigh the risks highlighted above.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

◉ Yes　　○ No

If Yes, please give details of procedures in place to deal with these issues:

With regards to interview questions raising sensitive or upsetting topics, participants will be offered comfort breaks or option to end the interview by the lead researcher (interviewer). Care co-ordinators will be aware of the interview time and date, in order to be contactable in the period after interviews. Participants will also have contact details for the research team, and information about contacting more immediate services including GP, A&E and Samaritans in case of significant distress. Prior to participants leaving, there will be a debrief that acts as a risk assessment in terms of participant's wellbeing post-interview. As a trainee clinical psychologist, the interviewer is experienced at managing and containing sessions in which upsetting or distressing information is being discussed, explored and disclosed, including working with clients who have been diagnosed with both 'learning disabilities' and 'personality disorder'. The interviews will also be conducted using the Lancaster University policy regarding lone working, fieldwork and personal safety, including thinking about where the interviewer sits, nearest exits etc. The site support and field researcher supervisor will be informed of the interview schedule and location of the lead researcher, and they will be contacted after completion of interviews or in case of emergency.

Under circumstances where a participant disclosing information that raising concerns over their own or others wellbeing (including potential criminal disclosures), the interview will be stopped and interviewee informed of the safeguarding process. This will be done as collaboratively as possible, for example, asking how best to inform their care co-ordinator or team involved in their care. Information regarding safeguarding and the need to break confidentiality will be explained to participants during the consent process.

A24. What is the potential for benefit to research participants?

The research aims to benefit participants by highlighting service user perspectives on diagnosis, support and service experiences. There may be no direct or immediate benefit for participants, however information obtained may be useful for future clinical practice, support and interventions offered to service users diagnosed with both 'learning disabilities' and 'personality disorder'. Some participants may experience a positive effect of participating in the interview and discussing personal experiences.

Participants will be invited to enter into a prize draw to win a £50 Amazon voucher. This incentive will be paid for by the Lead Researcher. To enter, participants will be asked to provide an email address on the consent form, and consent

that they wish to enter. The voucher will be sent randomly picked winner via email (or via the post if they do not have access to e-mail). This will occur after all interviews have taken place.

A26. What are the potential risks for the researchers themselves? *(if any)*

Potential risk include potential to raise distress in participants. This will be managed as best as possible by holding interviews on NHS Trust properties which will be staffed. The interviewer will also use Lancaster University policy regarding personal safety off campus when setting the room for interviews (i.e. knowing nearest exits and sitting closest to exit). This will be conducted in conjunction with Lancaster University's policies on 'lone working' and 'fieldwork'.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? *For example, identification may involve a disease register, computerised search of GP records, or review of medical records. Indicate whether this will be done by the direct healthcare team or by researchers acting under arrangements with the responsible care organisation(s).*

Prior to participants being identified, the lead researcher will aim to visit each team that is highlighted as part of the recruitment sample in order to explain the purpose of the research and familiarise staff with the researcher. In addition, an email will be sent to all staff members regarding the purpose of the research and instructions on recruiting participants. The email will also contain attachments of two versions of both the participant information sheet and consent form. One will be in an 'easy-read' format for potential participants who may benefit from pictures to aid understanding. Care co-ordinators can decide which version their clients would be most appropriate. Staff will identify potential participants from their caseloads who may be interested in the interviews. They will discuss the research with their clients and go through the participant information sheet and consent form, and assess ability to consent. Copies of these will be left with the participants in order for them to make an informed choice on whether to take part. This meeting and ability to consent will be detailed on the relevant Trust's clinical note system. Contact details for the research team will also be included in case potential participants want further information. Care co-ordinators will then re-contact their clients after a week to elicit interest and consent to give the lead researcher their contact details, i.e. name and contact number. The lead researcher will then contact the client in order to answer any further questions and organise an interview date and location. Participants will then complete the consent form immediately prior to the interview if not already completed. This will be scanned into a participant's electronic clinical note records.

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

◉ Yes   ○ No

Please give details below:
Care co-ordinators or other members of staff involved in a potential participant's current care may need to review their electronic clinical records to determine eligibility of client for the research.

A27-3. Describe what measures will be taken to ensure there is no breach of any duty of confidentiality owed to patients, service users or any other person in the process of identifying potential participants. *Indicate what steps have been or will be taken to inform patients and service users of the potential use of their records for this purpose. Describe the arrangements to ensure that the wishes of patients and service users regarding access to their records are respected. Please consult the guidance notes on this topic.*

Only the current clinical care team will be accessing a patient's records to assess for eligibility. Potential participants will only be highlighted to the lead researcher and contacted once consent to participate has been determined.

A27-4. Will researchers or individuals other than the direct care team have access to identifiable personal information of any potential participants?

○ Yes   ◉ No

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

◉ Yes   ○ No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Care co-ordinators, the chief investigator or another member of the patient's clinical care team will provide the patient with copies of both the participant information sheet and consent form in order to aid recruitment. These will detail contact details for the research team in case of queries or interest in participating.

A29. How and by whom will potential participants first be approached?

By care co-ordinator or other member of patient's current clinical care team. They will arrange to meet with the potential participant to deliver the participant information sheet and consent form, and be on hand to discuss the purpose of the research and answer any questions. The Chief Investigator will also attend this meeting to introduce themselves, be on hand for any questions and assess ability to consent. Care co-ordinators will decide which version of the participant information sheet and consent form would be most appropriate. They will then be left with the information for a week to reflect on whether they want to engage. Contact details will be included on the participant information sheet if a client would like to contact the research team with queries or expressions of interest. This meeting and ability to consent will be detailed on the relevant Trust's clinical note system.

A30-1. Will you obtain informed consent from or on behalf of research participants?

◉ Yes   ○ No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

Participant information sheets will detail potential participant's rights not to participate and how to withdraw their information from the research until the paper is too close to submission (1st April 2019). In order to reduce coercion, the purpose of the research will be introduced by an identified participant via their care co-ordinator or other clinical team member involved via phone or in a session. They will leave copies of the participant information sheet and consent form with them for 1 week, in which they can decide to participate. They will also have contact details for the research term in case of queries or expressing interest in participating. Care co-ordinators or the Chief Investigator will then contact the potential participant to explore whether they have retained information regarding the research and their ability to consent to engage. If they express interest in participating, consent for their contact information will be gained so that lead researcher can arrange an interview date and time. Capacity and consent processes will then be further established by the lead researcher immediately prior to the interview. The participants' rights to withdraw information or decline participation will be reinforced throughout the recruitment process.

If you are not obtaining consent, please explain why not.
N/A

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

◉ Yes   ○ No

A31. How long will you allow potential participants to decide whether or not to take part?

Minimum of one week. It is likely this will be one week in most participants' cases due to this being the regular length

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of time between sessions/meetings with care co-ordinators or clinical care team members. If no further sessions are currently planned, care co-ordinators or the chief investigator will contact potential participants after 1 week. Participants will also able to express their interest earlier by contacting the lead researcher as per the contact information on the participant information sheet.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs? *(e.g. translation, use of interpreters)*

Due to limited resources, an inclusion criteria is participants will need to be competent and comfortable in spoken English. The participant information sheet and consent form have been created and reviewed by service users within a community learning disability team to ensure their accessibility for those with learning disabilities. Care co-ordinators and the lead researcher will also explain the purpose of the research and ascertain capacity to consent prior to their engagement.

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? *Tick one option only.*

◉ The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.

○ The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.

○ The participant would continue to be included in the study.

○ Not applicable – informed consent will not be sought from any participants in this research.

○ Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

Care co-ordinators will be responsible for contacting the research team or lead researcher if a participant loses capacity to consent after completing of the interviews. Each this stage, the lead researcher will then delete the audio recording and/or transcript dependant on the progress of the analysis. If a participant appears to lose consent during the interview or recruitment stage, the participant will be excluded from progressing further in the research, or the interview will be terminated and all collected information deleted.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? *(Tick as appropriate)*

☐ Access to medical records by those outside the direct healthcare team

☐ Access to social care records by those outside the direct social care team

☑ Electronic transfer by magnetic or optical media, email or computer networks

☐ Sharing of personal data with other organisations

☐ Export of personal data outside the EEA

☑ Use of personal addresses, postcodes, faxes, emails or telephone numbers

☑ Publication of direct quotations from respondents

☐ Publication of data that might allow identification of individuals

☑ Use of audio/visual recording devices
☐ Storage of personal data on any of the following:

☐ Manual files (includes paper or film)
☐ NHS computers
☐ Social Care Service computers
☐ Home or other personal computers
☑ University computers
☐ Private company computers
☐ Laptop computers

Further details:
Transcripts and audio interview recordings will be held securely until transferred to as a password protected file to the lead researcher's personal secure drive used by Lancaster University. Some of this information will be uploaded to a cloud-based storage system used by Lancaster University so that the other two members of research team can have access to the files for analysis purposes. Once the research is complete, the data will be transferred to the Research Co-Ordinator for the Faculty of Health and Medicine at Lancaster University. This will then be held securely for 10 years.

Any contact information used to recruit participants will be shredded immediately after use.

Anonymity of participants will be ensured by using a numerical identifier within interview transcripts and an alias within the final paper for any quotations included.

The audio recording device will be stored in a locked cabinet at the lead researcher's home before transferring back to Lancaster University. This will only be accessible by the lead researcher. Data on the audio recorder will be deleted as soon as possible after transfer to the secure personal drive as designated by Lancaster University.

All information will be transferred to the designated Lancaster University Research Co-ordinator following completion of the research, and held securely for 10 years before deletion.

A37. Please describe the physical security arrangements for storage of personal data during the study?

Written consent forms will be kept in a key locked cabinet at the lead researcher's home. Access to this cabinet will be limited to the lead researcher. At the earliest possible opportunity, these consent forms will then be transferred to be held securely at Lancaster University with the academic research supervisor. It is anticipated that consent forms will not be held at the lead researcher's home for any longer than one working week. Once the research is complete, these consent forms will be transferred from the academic supervisor to the Research Co-ordinator at Lancaster University for secure storage for 10 years.

The audio recorder containing the interviews will be stored securely until the files can be transferred to a secure personal drive designated to the lead researcher by Lancaster University. This will occur as soon as possible after the interview has taken place. Once the files have been secured, they will be deleted from the audio recorder. Some of these files will be transferred to a cloud-based storage system for analysis purposes. They will be password protected. Access to the files on the Box will be limited to the lead researcher and two supervisors (Research Team).

A38. How will you ensure the confidentiality of personal data? *Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.*

All participants identifiable information will be replaced by a numerical identifier at the transcript stage to maintain anonymity. A pseudonym will be used to highlight participants quotes within the final paper. Confidentiality cannot be guaranteed due to the use of quotes within the final paper.

Consent forms will be held securely in a locked cabinet to ensure personal data remains confidential. They will then be transferred at the earliest possible opportunity to the academic supervisor who will store them securely at Lancaster University. Following completion of the research, they will be transferred to the Research Co-ordinator at Lancaster University for secure storage until their deletion after 10 years.

A40. Who will have access to participants' personal data during the study? *Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.*

Access to personal data will be limited to the Research Team for analysis purposes (lead researcher, academic research supervisor, field/site research supervisor). This will include transcripts and audio recordings. This is detailed on both the participant information sheet and consent form for all participants.

Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

Data will be analysed by the lead researcher either at the researcher's home or at Lancaster University. The secure drive can be accessed via VPN and no personal information will be held on a personal computer. The field supervisor and academic research supervisor will be able to access files and review the analysis process via a cloud-based storage system held by the lead researcher.

A42. Who will have control of and act as the custodian for the data generated by the study?

	Title	Forename/Initials	Surname
	Dr	Suzanne	Hodge
Post	Researcher/Lecturer		
Qualifications	PhD, various publications		
Work Address	Faculty of Health and Medicine		
	Furness College		
	Lancaster University		
Post Code	LA1 4YG		
Work Email	s.hodge@lancaster.ac.uk		
Work Telephone	01524 592712		
Fax			

A43. How long will personal data be stored or accessed after the study has ended?

○ Less than 3 months

○ 3 – 6 months

○ 6 – 12 months

○ 12 months – 3 years

◉ Over 3 years

If longer than 12 months, please justify:
Consent forms, audio recordings and anonymised transcripts containing personal information will be held for 10 years as per Lancaster University's Research Data Management Policy.

A44. For how long will you store research data generated by the study?

Years: 10
Months: 0

A45. Please give details of the long term arrangements for storage of research data after the study has ended. *Say where data will be stored, who will have access and the arrangements to ensure security.*

After completion of the research, the data management responsibilities will be taken over by the designated Lancaster

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University Research Co-ordinator who will be responsible for holding the information securely for 10 years. They will save the password protected files on a secure computer university drive.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

◉ Yes   ○ No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.
Any additional expenses accrued for travel will be reimbursed. This will be up to a maximum of £20 as per stated in the Lancaster University Doctorate in Clinical Psychology guidelines on research expenses.

Participants will be invited to enter into a prize draw to win a £50 Amazon voucher. This incentive will be paid for by the Lead Researcher. To enter, participants will be asked to provide an email address on the consent form, and consent that they wish to enter. The voucher will be sent randomly picked winner via email (or via the post if they do not have access to e-mail). This will occur after all interviews have taken place.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

○ Yes   ◉ No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

○ Yes   ◉ No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

○ Yes   ◉ No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50. Will the research be registered on a public database?

◉ Yes   ○ No

Please give details, or justify if not registering the research.
The two NHS Trusts being used for recruitment purposes will document and register the research as per their R&D departments.

Registration of research studies is encouraged wherever possible.
You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

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A51. How do you intend to report and disseminate the results of the study? *Tick as appropriate:*

- ☑ Peer reviewed scientific journals
- ☑ Internal report
- ☑ Conference presentation
- ☑ Publication on website
- ☐ Other publication
- ☐ Submission to regulatory authorities
- ☐ Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- ☐ No plans to report or disseminate the results
- ☐ Other (please specify)

As per expectations of the Doctorate in Clinical Psychology, the research is likely to be submitted for publication in a peer-reviewed journal and corresponding online version. Any conferences in which the results of the research may contribute towards will be considered by the Research Team. An internal report for the NHS Trusts and teams involved will be produced as per guidelines. In addition, the results will be fed back by the lead researcher to the services involved and any participants who agree as part of a presentation.

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

All identifiable information will be replaced at the transcript stage, i.e. names of participants, family members or staff mentioned, locations, services etc.

A53. Will you inform participants of the results?

◉ Yes   ○ No

Please give details of how you will inform participants or justify if not doing so.
Participants will be contacted by the lead researcher in the first instance in order the feedback results, dependant on the participant's wishes. Feedback will also be given to the services involved so that care co-ordinators or other clinical care team members could feedback the results or short, written report to participants after the research has concluded. Publication information is documented within the participant information sheet and consent form.

5. Scientific and Statistical Review

A54. How has the scientific quality of the research been assessed? *Tick as appropriate:*

- ☐ Independent external review
- ☐ Review within a company
- ☐ Review within a multi–centre research group
- ☑ Review within the Chief Investigator's institution or host organisation
- ☑ Review within the research team
- ☑ Review by educational supervisor
- ☐ Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:
A proposal of the research was independently reviewed and approved by the Lancaster University Doctorate in Clinical Psychology Research Team and the Chair of the Board. The lead researcher's academic research supervisor and field/site supervisor have reviewed the extended research protocol and IRAS form.

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports,

together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? *How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.*

Total UK sample size: 10

Total international sample size (including UK): 10

Total in European Economic Area: 0

Further details:
Purposive sampling will be used to recruit a predicted maximum number of 10 participants (as suggested by Interpretative Phenomenological Analysis guidelines). This purposive sampling is based upon participants being diagnosed with both a 'learning disability' and 'personality disorder'.

A60. How was the sample size decided upon? *If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.*

IPA suggests between 4-10 participants due to the ethos being on exploring a participant's experience in a greater depth of analysis. Beyond this size, analysis can become more descriptive like Thematic Analysis.

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Interpretative Phenomenological Analysis will be employed for this research. Codes and themes will be interpreted by the lead researcher, and reviewed by the other members of the research team for quality assurance. Themes will then be offered to be taken back to participants for member checking, in order to cross-check understanding and meaning.

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6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. *Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.*

	Title Forename/Initials Surname Dr Suzanne Hodge
Post	Lecturer/Researcher
Qualifications	PhD
Employer	Lancaster University
Work Address	Faculty of Health and Medicine
	Furness College
	Lancaster University
Post Code	LA1 4YG
Telephone	01524 592712
Fax	
Mobile	
Work Email	s.hodge@lancaster.ac.uk

	Title Forename/Initials Surname
Post	███████████████
Qualifications	███████████████

Employer	
Work Address	
Post Code	
Telephone	
Fax	
Mobile	
Work Email	

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor

Status:
- ○ NHS or HSC care organisation
- ● Academic
- ○ Pharmaceutical industry
- ○ Medical device industry
- ○ Local Authority
- ○ Other social care provider (including voluntary sector or private organisation)
- ○ Other

Commercial status: Non-Commercial

If Other, please specify:

Contact person

Name of organisation	Lancaster University
Given name	Becky
Family name	Gordon
Address	Research Services
Town/city	Lancaster University
Post code	LA1 4YG
Country	UNITED KINGDOM
Telephone	01524592981
Fax	
E-mail	ethics@lancaster.ac.uk

A65. Has external funding for the research been secured?

Please tick at least one check box.

- ☐ Funding secured from one or more funders
- ☐ External funding application to one or more funders in progress

ETHICS DOCUMENTS

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☑ No application for external funding will be made

What type of research project is this?
○ Standalone project
○ Project that is part of a programme grant
○ Project that is part of a Centre grant
◉ Project that is part of a fellowship/ personal award/ research training award
○ Other

Other – please state:

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? *Please give details of subcontractors if applicable.*

○ Yes   ◉ No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

○ Yes   ◉ No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

Organisation
Address

Post Code
Work Email
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: http://www.rdforum.nhs.uk

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A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/10/2018
Planned end date: 31/05/2019
Total duration:
Years: 0 Months: 7 Days: 31

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A71-1. Is this study?

◯ Single centre
⦿ Multicentre

A71-2. Where will the research take place? *(Tick as appropriate)*

☑ England

☐ Scotland

☐ Wales

☐ Northern Ireland

☐ Other countries in European Economic Area

Total UK sites in study 2

Does this trial involve countries outside the EU?
◯ Yes   ⦿ No

A72. Which organisations in the UK will host the research? *Please indicate the type of organisation by ticking the box and give approximate numbers if known:*

☑ NHS organisations in England   2

☐ NHS organisations in Wales

☐ NHS organisations in Scotland

☐ HSC organisations in Northern Ireland

☐ GP practices in England

☐ GP practices in Wales

☐ GP practices in Scotland

☐ GP practices in Northern Ireland

☐ Joint health and social care agencies (eg community mental health teams)

☐ Local authorities

☐ Phase 1 trial units

☐ Prison establishments

☐ Probation areas

☐ Independent (private or voluntary sector) organisations

☐ Educational establishments

☐ Independent research units

☐ Other (give details)

Total UK sites in study: 2

A73-1. Will potential participants be identified through any organisations other than the research sites listed above?

◯ Yes   ⦿ No

A74. What arrangements are in place for monitoring and auditing the conduct of the research?

There will use of regular supervision between the lead researcher and academic research supervisor and clinical field supervisor to monitor appropriate conduct during the research. The research sponsor at Lancaster University will be following detailed guidelines as set out by the university. The two NHS Trusts involved in the research will also be registering the research and monitoring the progress and outcome of the research via their R&D departments.

A76. Insurance/ indemnity to meet potential legal liabilities

Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the _management_ of the research? *Please tick box(es) as applicable.*

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (NHS sponsors only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the _design_ of the research? *Please tick box(es) as applicable.*

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

☐ NHS indemnity scheme will apply (protocol authors with NHS contracts only)

☑ Other insurance or indemnity arrangements will apply (give details below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the _conduct_ of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

☑ NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)

☐ Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Lancaster University legal liability cover will apply

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

ETHICS DOCUMENTS

⦿ Yes ◯ No ◯ Not sure

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PART C: Overview of research sites

Please enter details of the host organisations (Local Authority, NHS or other) in the UK that will be responsible for the research sites. *For further information please refer to guidance.*

Investigator identifier	Research site	Investigator Name	
IN1	◉ NHS/HSC Site ○ Non-NHS/HSC Site	Forename	James
		Middle name	Stephen
		Family name	Taylor
	Organisation name	Email	j.taylor23@lancaster.ac.uk
	Address	Qualification (MD...)	BSc (Hons), MSc, Trainee Clinical Psychologist
	Post Code Country	Country	UNITED KINGDOM
IN2	◉ NHS/HSC Site ○ Non-NHS/HSC Site	Forename	James
		Middle name	Stephen
		Family name	Taylor
	Organisation name	Email	j.taylor23@lancaster.ac.uk
	Address	Qualification (MD...)	BSc (Hons), MSc, Trainee Clinical Psychologist
	Post Code Country	Country	UNITED KINGDOM

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PART D: Declarations

D1. Declaration by Chief Investigator

1. The information in this form is accurate to the best of my knowledge and belief and I take full responsibility for it.

2. I undertake to fulfil the responsibilities of the chief investigator for this study as set out in the UK Policy Framework for Health and Social Care Research.

3. I undertake to abide by the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research.

4. If the research is approved I undertake to adhere to the study protocol, the terms of the full application as approved and any conditions set out by review bodies in giving approval.

5. I undertake to notify review bodies of substantial amendments to the protocol or the terms of the approved application, and to seek a favourable opinion from the main REC before implementing the amendment.

6. I undertake to submit annual progress reports setting out the progress of the research, as required by review bodies.

7. I am aware of my responsibility to be up to date and comply with the requirements of the law and relevant guidelines relating to security and confidentiality of patient or other personal data, including the need to register when necessary with the appropriate Data Protection Officer. I understand that I am not permitted to disclose identifiable data to third parties unless the disclosure has the consent of the data subject or, in the case of patient data in England and Wales, the disclosure is covered by the terms of an approval under Section 251 of the NHS Act 2006.

8. I understand that research records/data may be subject to inspection by review bodies for audit purposes if required.

9. I understand that any personal data in this application will be held by review bodies and their operational managers and that this will be managed according to the principles established in the Data Protection Act 1998.

10. I understand that the information contained in this application, any supporting documentation and all correspondence with review bodies or their operational managers relating to the application:

    ○ Will be held by the REC (where applicable) until at least 3 years after the end of the study; and by NHS R&D offices (where the research requires NHS management permission) in accordance with the NHS Code of Practice on Records Management.
    ○ May be disclosed to the operational managers of review bodies, or the appointing authority for the REC (where applicable), in order to check that the application has been processed correctly or to investigate any complaint.
    ○ May be seen by auditors appointed to undertake accreditation of RECs (where applicable).
    ○ Will be subject to the provisions of the Freedom of Information Acts and may be disclosed in response to requests made under the Acts except where statutory exemptions apply.
    ○ May be sent by email to REC members.

11. I understand that information relating to this research, including the contact details on this application, may be held on national research information systems, and that this will be managed according to the principles established in the Data Protection Act 1998.

12. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named below. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

Contact point for publication(Not applicable for R&D Forms)
NRES would like to include a contact point with the published summary of the study for those wishing to seek further

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information. We would be grateful if you would indicate one of the contact points below.

⦿ Chief Investigator

◯ Sponsor

◯ Study co-ordinator

◯ Student

◯ Other – please give details

◯ None

Access to application for training purposes *(Not applicable for R&D Forms)*
Optional – please tick as appropriate:

☑ I would be content for members of other RECs to have access to the information in the application in confidence for training purposes. All personal identifiers and references to sponsors, funders and research units would be removed.

This section was signed electronically by Mr James Taylor on 07/12/2018 14:16.

Job Title/Post:	Trainee Clinical Psychologist
Organisation:	Lancashire Care NHS Trust / Lancaster University
Email:	j.taylor23@lancaster.ac.uk

D2. Declaration by the sponsor's representative

If there is more than one sponsor, this declaration should be signed on behalf of the co-sponsors by a representative of the lead sponsor named at A64-1.

I confirm that:

1. This research proposal has been discussed with the Chief Investigator and agreement in principle to sponsor the research is in place.

2. An appropriate process of scientific critique has demonstrated that this research proposal is worthwhile and of high scientific quality.

3. Any necessary indemnity or insurance arrangements, as described in question A76, will be in place before this research starts. Insurance or indemnity policies will be renewed for the duration of the study where necessary.

4. Arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed.

5. Arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts.

6. The responsibilities of sponsors set out in the UK Policy Framework for Health and Social Care Research will be fulfilled in relation to this research.

   Please note: The declarations below do not form part of the application for approval above. They will not be considered by the Research Ethics Committee.

7. Where the research is reviewed by a REC within the UK Health Departments Research Ethics Service, I understand that the summary of this study will be published on the website of the National Research Ethics Service (NRES), together with the contact point for enquiries named in this application. Publication will take place no earlier than 3 months after issue of the ethics committee's final opinion or the withdrawal of the application.

8. Specifically, for submissions to the Research Ethics Committees (RECs) I declare that any and all clinical trials approved by the HRA since 30th September 2013 (as defined on IRAS categories as clinical trials of medicines, devices, combination of medicines and devices or other clinical trials) have been registered on a publically accessible register in compliance with the HRA registration requirements for the UK, or that any deferral granted by the HRA still applies.

This section was signed electronically by An authorised approver at ethics@lancaster.ac.uk on 12/12/2018 09:19.

Job Title/Post:	Deputy Head of Research Services
Organisation:	Lancaster University
Email:	b.gordon@lancaster.ac.uk

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D3. Declaration for student projects by academic supervisor(s)

1. I have read and approved both the research proposal and this application. I am satisfied that the scientific content of the research is satisfactory for an educational qualification at this level.

2. I undertake to fulfil the responsibilities of the supervisor for this study as set out in the UK Policy Framework for Health and Social Care Research.

3. I take responsibility for ensuring that this study is conducted in accordance with the ethical principles underlying the Declaration of Helsinki and good practice guidelines on the proper conduct of research, in conjunction with clinical supervisors as appropriate.

4. I take responsibility for ensuring that the applicant is up to date and complies with the requirements of the law and relevant guidelines relating to security and confidentiality of patient and other personal data, in conjunction with clinical supervisors as appropriate.

Academic supervisor 1

This section was signed electronically by Dr Suzanne Hodge on 07/12/2018 14:58.

Job Title/Post:

Organisation:

Email:

Academic supervisor 2

This section was signed electronically by Dr Alex Cookson on 07/12/2018 14:24.

Job Title/Post:

Organisation:

Email:

What do people using community learning disability services think about their label of 'personality disorder'? Proposal Form - Version 0.3

Lead Researcher: James Taylor, Trainee Clinical Psychologist, Lancaster University

Research Supervisor: Dr Suzanne Hodge (Lancaster University)

Field Supervisor: Dr Alex Cookson (   )

Introduction

Over the past decade, there has been increasing interest in researching the area of learning disabilities and mental health. There is now an acceptance that people with learning difficulties are at more risk of psychological stress and mental health difficulties compared to the general population (Alexander, Tajuddin & Gangadharan, 2007). Despite calls for greater service user inclusion (Department of Health, 2009) and the increased likelihood of further difficulties within learning disability populations, little research has been conducted with service users themselves. This suggests there is still a divide between clinical practice and policy when working with people with a learning disability, with this population experiencing marginalisation (Robinson, Escopri, Stenfert Kroese & Rose, 2016; Young & Chesson, 2006).

The diagnosis of personality disorder within a learning disability population remains controversial (Naik, Gangadharan & Alexander, 2002). There is disagreement over the construct of personality, and challenges to the assessment and classification of diagnosis (Chester, 2010). Furthermore authors have found high co-morbidity between learning disabilities and personality disorder (between 1% and 91% in community samples) questioning the clinical usefulness (Alexander & Cooray, 2003). The clinical diagnosis of

'personality disorder' is usually limited to service users with a mild-to-moderate learning disability, and within one NHS learning disability community service the prevalence was 7% (Naik et al. 2002). Within secure learning disability settings, this prevalence rate can increase to approximately 50% (Alexander, Chester, Gray & Snowden, 2012). The community prevalence is likely to continue to increase due to the Transforming Care agenda (NHS England, 2015) highlighting service users should be more efficiently moved back to community settings from inpatient services. Another perspective offered by Raghavan (2004) suggests services are too focused on prevalence rates, whereas it would be more clinically useful to develop a knowledge base about the life events and experiences of those with learning disabilities and mental health difficulties. Historically, dual diagnosis of personality disorder and learning disability was attributed to the learning disability affecting personality development (Chester, 2010). However, motivation and personality are affected in those with learning difficulties by the same societal factors and life events as others (Zigler, Bennett-Gates, Hodapp & Henrich, 2002).

O'Brien and Rose (2010) highlighted the experiences of mental health support given to people with learning disabilities. Service users valued a person-centred service in which they felt professionals listened, showed them respect, and were caring and genuine in their ability to help. Life experiences of bullying and injustice are important issues that these individuals continued to face (Robinson et al. 2016). However, people with a diagnosis of personality disorder are more likely to experience restrictive support (Reis, 1994), be viewed as 'untreatable' (Pridding & Proctor, 2008) or to divide opinion within teams (Mavromatis, 2000). Therefore, such a diagnosis may have a negative impact on both the individual and their experiences of services and interventions. Despite the recent surge in research regarding effective interventions and support for people with a 'personality disorder' diagnosis, little has been surrounding those also with a learning disability (Chester, 2010). Therefore, more

research is needed around intervention effectiveness for those with a learning disability and 'personality disorder' diagnosis along with the views of those services users regarding their needs and experiences of services and interventions.

Despite research into the prevalence rates and the emotional impact of working with people with the diagnosis on staff members, teams and services, no research has looked into the views of those given the label of 'personality disorder' within a learning disability population. There has been research exploring the experiences of those with a learning disability and 'psychotic' mental health difficulties within a community service (Robinson et al. 2016) and the experiences of a diagnosis of 'schizophrenia' on those within learning disabilities within a secure setting (Cookson & Dickson, 2010). A recent systematic review of personality disorder, offending behaviour and learning disabilities has called for more qualitative research into the experiences of those accessing community services (Rayner, Wood, Beail & Nagra, 2015). Therefore, little is currently known about how service users come to attract the diagnosis of personality disorder, the impact of a personality disorder diagnosis on the person themselves and on their understanding of their difficulties relationally, emotionally and behaviourally. After the Winterbourne View scandal, the Transforming Care agenda (NHS England, 2015) suggested major revisions to care services offered to those with a learning disability. One of these suggestions included helping those with a learning disability to move back to the community more quickly and efficiently from inpatient or secure settings. Residential and supported living accommodation within the community allows for more freedom, independence and potential opportunities. However, environmentally it less intensely supported and protective compared to inpatient settings (Robinson et al. 2016). Therefore, more people with a learning disability and a diagnosis of 'personality disorder' will be living in the community and accessing local healthcare services. Little is known about these individuals' experiences of their diagnosis, their needs and

support. Therefore, this research aims to use interpretative phenomenological analysis (IPA; Smith, Flowers & Larkin, 2009) to explore the lived experiences of those given the label of 'personality disorder', how they have made sense of it and possible implications this has had regards services and support offered. The results will add a service user perspective to current on-going debates regarding clinical usefulness of diagnosis and the way services are set up for service users with learning disabilities. It will also provide greater understanding of the needs of this population in order to allow for more effective, person-centred support.

Research Questions

How do people with a diagnosis of learning disability and personality disorder:

1. Understand their experiences and relationships in the context of the label?

Design

The proposed research will use a qualitative design. The information will be collected via a series of one-to-one semi-structured interviews. The length of the interviews will need to be flexible to meet the potentially differing needs of each participant, however will aim to last for approximately one hour. A topic guide for the interview will be co-developed and reviewed by individuals with a learning disability diagnosis, and potentially those with a diagnosis of 'personality disorder'. The interviews intend to ask open questions as a way of exploring participants' experiences in the context of their diagnosis, with the topic guide acting as a scaffold to cover specific topics and areas. The data collected will be analysed using IPA (Smith et al. 2009).

Participants

Atkinson (1988) argues that individuals diagnosed with learning disabilities are "best placed to describe their own social situation, their experience of it and their feelings about it"

(p. 76) rather than supporting professionals that can, to some extent, restrict the lives of people with learning disabilities. Therefore, this research will recruit participants currently under the care of UK learning disabilities services and have been diagnosed or received a diagnosis of 'personality disorder'. Inclusion criteria are individuals who are accessing services as part of a community-based learning disability service who have also received a diagnosis of both a 'learning disability' and 'personality disorder'. Potential participants will need to be competent in verbal English due to limited resources available. The aim is to recruit participants from Community Learning Disabilities Teams within two NHS Trusts in the North-West of England. These services work with individuals who may have previously used inpatient or secure services, and also facilitate group interventions such as Mentalisation-Based Therapy and Dialectical Behaviour Therapy which individuals with a diagnosis of 'personality disorder' are more likely to access. As such, there is a group of individuals from which to purposively sample between four and ten participants, as recommended by Smith et al. (2009).

Ethics

As this research will be interviewing participants who are currently involved with NHS Community Learning Disability Teams, ethical approval will be sought via the Health Research Authority (HRA) Integrated Research Application System (IRAS). The Research and Development (R&D) departments of the NHS Trusts involved in the research will be contacted prior to ethics application.

In order to maintain anonymity throughout the research, all participants will be given a numerical identifier in place of their name on transcripts and a pseudonym will be used within the paper itself when referring to specific quotes. Confidentiality cannot be guaranteed to all participants due to quote excerpts being used within the paper to illustrate themes. Anonymity and the right to withdraw data will be documented within the easy-read

ETHICS DOCUMENTS

Participant Information Sheet and Consent Form, co-developed with Experts by Experience (EbE).

Ethical approval will be sought through the NHS IRAS system. Participants will be asked about their experiences and sense making as part of having a diagnosis of 'personality disorder'. Due to the personal nature of the questioning, it is acknowledged that participants may experience distress during and/or after the interview process. Should any distress by participants be experienced during interviewing, participants will be asked if they would like a break or carry on with the interview. Any concerns about the distress experienced by a participant will be raised with the professional involved in that person's care, as well as the Field Supervisor. Prior to the start of interviewing, all participants will be informed of the limits of confidentiality and safeguarding procedures in the event of disclosure of risk-related information regarding themselves or others. If information that is concerning is disclosed during an interview, the interview will be stopped immediately and the participant informed and consulted on their preferred way to refer the information on to their care co-ordinator or safeguarding team. The Participant Information Sheet will also share contact details for participants who would like further information or to discuss their interview further. Services that offer support, such as Samaritans, will also be detailed on the Participant Information Sheet.

In regards to the interviewer, they will follow the Lone Working policy of the Trusts involved when conducting interviews as they are likely to occur in non-clinical settings. However, these are still likely to be staffed premises. Staff on the premises will be informed regarding the nature of the interviews. In case of emergencies, the interviewer will sit nearest the door in case participants become distressed or agitated and they will be aware of the nearest fire exits. The lead researcher will inform the on-site support supervisor and field

supervisor of the interview schedule and will make contact once the interview is complete. If neither is available, the learning disability service's main reception number will be contacted.

To avoid risk of coercion, care co-ordinators will go through the participant information sheet and consent form with the potential participant, which details the right to say 'no'. These leaflets will be left with the individual in order to give them time to reflect on whether they would like to participate and give consent for their contact information to the lead researcher. Participants will also have contact information for the lead researcher, field supervisor and Lancaster University in case they have any queries or complaints. If they would like to participate when care co-ordinators make contact with the individual again, the care co-ordinator will discuss the individual with the lead researcher to assure appropriateness and give contact information. The lead researcher will then make contact to arrange a meeting, in which the consent form and purpose of the study will be discussed and completed. Participants' rights will be continually reinforced throughout the recruitment process.

Procedure

Participants will be recruited via professionals in participating services. Advertisement and information about the research will be sent out to care co-ordinators within the two NHS Trusts. The researcher will also meet with the services contacted as part of the research in order to discuss the project further and to distribute the Participant Information Sheet. This will most likely be done as part of a weekly team meeting in which the majority of the team will be present. An e-mail will also be sent to team members highlighting the purpose of the research and instructions on how they can be involved. Individual service users that meet the inclusion criteria will then be identified by professionals working within these services. The professional involved will explain the purpose of the research and share a copy of the Participant Information Sheet for further

information with each individual identified as meeting the inclusion criteria. Participants will be provided with accessible, 'easy-read' information sheets and consent forms; therefore, ability in reading English is required. In cases where this is not present, consent will need to be gained verbally through either a care co-ordinator or the lead researcher after explaining the purpose of the research. Copies of both forms will be given to all participants. Individuals identified will be left with the materials and given a week to decide whether they would like to participate. If they agree, care co-ordinators will ask if they consent to pass their contact information on to the lead researcher, who will then arrange a visit or phone call to further explain the study and gain consent. When participants have registered an interest in the study, they will be contacted by the researcher to arrange a time for the interview to take place. The location of the interview will be flexible to meet the needs of the participant, however it is expected that interviews will take place at a Trust-owned non-clinical, more informal venue within the community, e.g. a community wellbeing centre.

Immediately prior to the start of interviewing, participants will be asked to complete the Consent Form in order to provide formal, written consent for their participation in the study. All interviews will be audio recorded with a university-issued Dictaphone. These audio recordings will be uploaded as a password protected file to a secure drive on the Lancaster University network server, and then deleted from the Dictaphone. The audio recordings will be deleted off the secure drive once the completed thesis has passed examination. Any physical data will be kept in a locked cabinet within the lead researcher's home before being transferred to Lancaster University. The interviews will be transcribed and anonymised as soon as possible following interviews by the researcher.
Transcripts and details of the analysis will be stored electronically, in password protected file space on a secure Lancaster University server. The lead researcher will be the only person capable of accessing this information, but will allow access to both supervisors to review

transcripts and interview recordings via an encrypted, cloud-based storage system (Box). Following analysis, this information will be transferred to the Lancaster Doctorate in Clinical Psychology Research Co-Ordinator via Box who will save the files as a password protected file on the secure university drive. These will be kept for 10 years after completion of the thesis before being deleted by the Research Co-ordinator.

Materials

A Dictaphone will be used to audio record interviews with all the participants. A reflective journal will be kept throughout undertaking of the research as part of the IPA process. All materials used for recruitment (participant information sheet and consent form) in addition to the semi-structured interview will be co-produced and reviewed by individuals with a learning disability and, where possible, a diagnosis of 'personality disorder'.

Proposed analysis

This researcher intends to use IPA (Smith, Flowers & Larkin, 2009) to analyse data collected through the interviews. IPA posits going beyond reporting statements made by participants and aiming to describe the relationship between their spoken word, cognition and behaviour. Therefore, it enables exploration of the participant's world and their understanding, whilst attempting to adopt an insider perspective. It is particularly pertinent in this proposed research due to IPA's stance that "the primary interest is the person's experience of the phenomenon and the sense they make of their experience rather than the structure of the phenomenon itself" (Eatough & Smith, 2017).

IPA acknowledges that it is not possible to fully access the participant's world as the researcher's own assumptions and experiences will impact on their understanding of the participant's world. The researcher will attempt to overcome this by taking a reflective stance, recognising my own role as an active participant in the interviews and in the relational dynamics between each participant and the interviewer. Therefore, it is imperative to use

supervision between all researchers involved in the study to review the transcripts, initial themes and ideas and eventually the finalised overarching themes. The research will also aim to feedback initial themes to participants to crosscheck understanding, meaning and intention of participants' words.

As part of the analysis process, one interview transcript will be read and re-read several times and then analysed in full to construct initial ideas, emerging themes, and overarching themes. This will be then reviewed by both the Research Supervisor and Field Supervisor. Once in agreement with the initial analyses, the remaining transcripts will be analysed in the same way. Once all transcripts have been coded, the researcher will note any perceived patterns of similarity or difference in the themes both within and between participants' data. These themes will then be condensed into a framework for understanding participants' experiences, based on occurrence in the data, relevance to the research question and interpretations made based on the researcher's sense making of the participants' experiences. Both the Research Supervisor and Field Supervisor will have access to the audio recordings and transcripts in order to aid in the analysis process. Before writing the analysis for the report, both supervisors will review the final document of superordinate themes, to ensure fidelity to the IPA process.

Practical issues

Room bookings for interviews will need to be made through the appropriate Trust's booking policy and procedure. If participants are unable to travel for interviewing, interviews may be potentially held at the participant's home. This will be in conjunction with the appropriate Trust's lone working policies. The Field Supervisor will be informed of the scheduling of interviews including the dates, times and locations. On completion of interviews, the researcher will contact the Field Supervisor to inform them that interviews have ended. Full details of location and methods of contacting the researcher will be given to

the Field Supervisor and a designated back-up (in case Field Supervisor is absent or otherwise engaged). If within a specified time of the end of the interviews or situations in which there is concern over the researcher, a designated person would be able to locate the researcher using this information.

Probable costs include funds for EbE contributions, travel expenses for participants (up to a maximum of £20 per person in accordance with Lancaster University Clinical Psychology Doctorate's guidelines on research expenses) and participants will be invited to enter a prize draw to win a £50 Amazon voucher.

Timescales

March 2018 – Submit proposal

July - 2018 – agrees timetable/research contract

July – August 2018 - ethics

October – December 2018 – data collection and start analysis

October – December 2018 – systematic review

January – March – analysis and write up of research paper (intro/method)

March – May 2019 – write up final paper

References

Alexander, R., Chester, V., Gray, N., & Snowden, R. (2012). Patients with personality disorders and intellectual disability – closer to personality disorders or intellectual disability? A three-way comparison. *Journal of Forensic Psychiatry & Psychology*, *23*(4), 435-451. doi:10.1080/14789949.2012.694462

Alexander, R., & Cooray, S. (2003). Diagnosis of personality disorders in learning disability. *The British Journal of Psychiatry, 182*(44), 28-31. doi:10.1192/bjp.182.44.s28

Alexander, R., Tajuddin, M., & Gangadharan, S. (2007). Personality disorders in intellectual disability: approaches to pharmacotherapy. *Mental Health Aspects of Developmental Disabilities. 10(*4), 129-136. Retrieved from http://go.galegroup.com/ps/anonymous?id=GALE%7CA172169646&sid=googleScholar&v=2.1&it=r&linkaccess=abs&issn=15575187&p=AONE&sw=w

Atkinson, D. (1988). Research interviews with people with mental handicaps. *Mental Handicap Research, 1*(1), 75-90. doi:10.1111/j.1468-3148.1988.tb00006.x

Chester, R. (2010). Diagnosing personality disorder in people with learning disabilities. *Learning Disability Practice*, *13*(8), 14-19. doi:10.7748/ldp2010.10.13.8.14.c8017

Cookson, A., & Dickson, J. (2010). The Subjective Experiences of People with an Intellectual Disability and Diagnosis of Schizophrenia Who are Detained in a Medium Secure Unit. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 379-389. doi:10.1111/j.1468-3148.2010.00554.x

Department of Health, (2009). *The Bradley Report: Lord Bradley's Review of People with Mental Health Problems or Learning Disabilities in the Criminal Justice System.* Department of Health: London

Eatough, V. & Smith, J. (2017). Interpretative phenomenological analysis. In C. Willig & W. Rogers (Eds.) *The SAGE Handbook of qualitative research in psychology* (pp. 193-209). London: SAGE Publications Ltd.

Mavromatis, M. (2000). The diagnosis and treatment of borderline personality disorder in persons with developmental disability: Three case reports. *Mental Health Aspects of Developmental Disabilities, 3*(3), 89-97. Retrieved from http://www.worldcat.org/title/mental-health-aspects-of-developmental-disabilities/oclc/926214983/editions?editionsView=true&referer=br

Naik, B.I., Gangadharan, S., & Alexander, R.T. (2002). Personality disorders in learning disability – the clinical experience. *The British Journal of Developmental Disabilities, 48*(95), 95-100. doi:10.1179/096979502799104210

NHS England. (2015). Transforming Care for People with Learning Disabilities – Next Steps [PDF file]. Retrieved from https://www.england.nhs.uk/wp-content/uploads/2015/01/transform-care-nxt-stps.pdf

O'Brien, A., & Rose, J. (2010). Improving mental health services for people with intellectual disabilities: service users' views. *Advances in Mental Health and Intellectual Disabilities, 4(*4), 40-47. doi:10.5042/amhid.2010.0674

Pridding, A., & Procter, N. (2008). A systematic review of personality disorder amongst people with intellectual disability with implications for the mental health nurse practitioner. *Journal of Clinical Nursing*, *17*(21), 2811-2819. doi:10.1111/j.1365-2702.2007.02269.x

Rayner, K., Wood, H., Beail, N., & Nagra, M. (2015). Intellectual disability, personality disorder and offending: A systematic review. *Advances in Mental Health and Intellectual Disabilities*, *9*(2), 50-61. doi:10.1108/amhid-04-2014-0007

Reiss, S. (1994). *Handbook of challenging behaviour*. Worthington, Ohio: IDS Publishing.

Robinson, L., Escopri, N., Stenfert Kroese, B., & Rose, J. (2016). The subjective experience of adults with intellectual disabilities who have mental health problems within community settings. *Advances in Mental Health And Intellectual Disabilities*, *10*(2), 106-115. doi:10.1108/amhid-04-2015-0017

Smith, J.A., Flowers, P. & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, method and research*. London: Sage.

Young, A.F., & Chesson, R.A. (2006). Obtaining views on health care from people with intellectual disabilities and severe mental health problems. *British Journal of Learning Disabilities, 34(*1), 11-19. doi:10.1111/j.1468-3156.2005.00337.x

Zigler, E., Bennett-Gates, D., Hodapp, R., & Henrich, C. (2002). Assessing Personality Traits of Individuals With Mental Retardation. *American Journal on Mental Retardation*, *107*(3), 181. doi:10.1352/0895-8017(2002)107<0181:aptoiw>2.0.co;2

Appendix 4-A: NHS REC Provisional Opinion

NHS
Health Research Authority
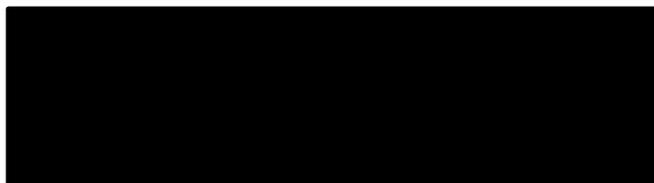
29 November 2018

Mr James Taylor
Trainee Clinical Psychologist
Lancashire Care NHS Foundation Trust
Sceptre Point
Sceptre Way
Walton Summit, Preston
PR5 6AW

Dear Mr Taylor

Study Title: What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

REC reference: 18/NW/0787
Protocol number: N/A
IRAS project ID: 250921

The Research Ethics Committee reviewed the above application at the meeting held on 15 November 2018. Thank you for attending to discuss the application.

Provisional opinion

The Committee would be content to give a favourable ethical opinion of the research, subject to receiving a complete response to the request for further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair, together with the Lead Reviewer, Mr Mike Davis.

Further information or clarification required

1. Allow participants to decide which term they felt was most appropriate by asking at the beginning of the interview – please include this as an item in the Interview Schedule.
2. Store Informed Consent Forms at the university in a secure location
3. Retain confirmation of ability to consent from care coordinator

4. Provide evidence of training for the taking of informed consent
5. Remove Mr Taylor James as Chief Investigator of the study and replace with one of the academic supervisors listed in the IRAS form.
   *Please note, this will require the reauthorisation of the IRAS form by all parties.

   6. Please Put the IRAS number on the participant information leaflet and informed consent form.

When submitting a response to the Committee, the requested information should be electronically submitted from IRAS. Please refer to the guidance in IRAS for instructions on how to submit a response to provisional opinion electronically.

Please submit revised documentation where appropriate underlining or otherwise highlighting the changes which have been made and giving revised version numbers and dates. You do not have to make any changes to the REC application form unless you have been specifically requested to do so by the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points.   A response should be submitted by no later than 29 December 2018.

Extract of the meeting minutes

Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity

The Committee asked whether consent forms would be stored at the researcher's home address.

Mr Taylor explained that this was subject to change and he had been considering where it could be stored securely. Mr Taylor believed it could be kept at the University but that Consent forms may be stored at home in-between visits to the university.

The Committee agreed that effort should be made to ensure that consent forms were kept securely by taking regular trips to the university to keep Consent forms locked up there.

The Committee was concerned that the interview schedule used the word 'label' as opposed to a more neutral term.

Mr Taylor explained that it originally said diagnosis but that it went to a service user group and they had responded negatively to the word 'diagnosis'.

The Committee agreed that diagnosis was a more neutral term but felt it might be best to ask participants which term they might prefer at the beginning of the interview and then use that.

Informed consent process and the adequacy and completeness of participant information

The Committee queried how appropriate the Participant Information Sheets was for the participants and whether or not the images were infantilising.

Mr Taylor indicated that this varied depending on the individual and that sometimes pictures were helpful. Mr Taylor advised that the Service User group they had used were happy with it; however, this group had not been diagnosed with personality disorder and may have a different perspective. Mr Taylor emphasised that he had wanted an easy read format for the Participant Information Sheet so as not to exclude participants and recognised that often patients with personality disorders were excluded from these types of studies.

The Committee asked how these participants would be assessed for capacity to consent and by whom.

Mr Taylor advised that the care coordinator would identify participants and assess their ability to consent. Their consent would be assessed at various stages throughout the process and if they found it particularly difficult at any point they would be able to withdraw.

The Committee asked that ability to consent was communicated in writing and kept for study records. The Committee agreed that consent should be taken by a trained individual and asked that evidence of training for the taking of consent could be provided.

Suitability of the applicant and supporting staff

The Committee noted that Mr James Taylor was listed as the Chief Investigator and asked that justification was provided.

Mr Taylor explained that the student was usually the Chief Investigator at his University.

The UK Policy Framework for Health and Social Care research states that students should not normally take the role of chief investigator at any level of study, as this function should be undertaken by academic supervisors or course leaders. It was therefore decided that Mr Taylor should request that an Academic Supervisor acted as the Chief Investigator.

Other general comments

Mr Taylor indicated that the proportionate review Sub-Committee had identified the amazon voucher as an ethical issue and asked the Committee whether they had also had concerns.

The Committee agreed that they had not had concerns with the inclusion of the amazon voucher as it was felt that this was a 'thank you' for participants' time, rather than an incentive. Upon reflection, the Committee agreed that perhaps it was ultimately unnecessary but it was a nice gesture and there were budget limitations to getting one for each participant.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Documents reviewed

The documents reviewed at the meeting were:

Document	Version	Date
Copies of advertisement materials for research participants [Recruitment email]	0.1	14 September 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Negligence Insurance]		19 July 2018
Interview schedules or topic guides for participants [Interview Schedule]	0.1	14 September 2018
IRAS Application Form [IRAS_Form_11102018]		11 October 2018
IRAS Checklist XML [Checklist_11102018]		11 October 2018
Letter from sponsor [Sponsorship letter]		01 October 2018
Other [Public Liability and Employer Liability Information]		19 July 2018
Participant consent form [Consent Form]	0.2	14 September 2018
Participant information sheet (PIS) [PIS]	0.2	14 September 2018
Research protocol or project proposal [Protocol]	0.3	14 September 2018
Summary CV for Chief Investigator (CI) [CV]		27 September 2018
Summary CV for supervisor (student research) [Research supervisor cv]		
Summary CV for supervisor (student research) [Clinical supervisor cv]		

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

18/NW/0787	Please quote this number on all correspondence

Yours sincerely

PP

Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments.

Copy to: Becky Gordon

Appendix 4-B: NHS REC Favourable Opinion

NHS
Health Research
Authority

Please note: This is the
favourable opinion of the
REC only and does not allow
you to start your study at NHS
sites in England until you
receive HRA Approval
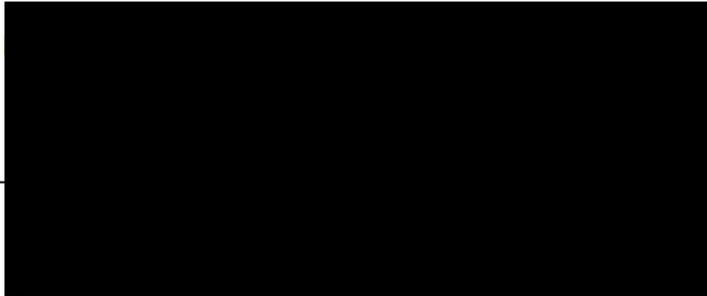
30 January 2019

Dr Suzanne Hodge
Faculty of Health and Medicine
Furness College
Lancaster University
LA1 4YG

Dear Dr Hodge

Study title: What do people using community learning disability
teams think about their diagnosis of 'personality
disorder'?
REC reference: 18/NW/0787
Protocol number: N/A
IRAS project ID: 250921

Thank you for your letter of 22nd January 2019, responding to the Committee's request for further
information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website,
together with your contact details. Publication will be no earlier than three months from the date of
this opinion letter. Should you wish to provide a substitute contact point, require further
information, or wish to make a request to postpone publication, please contact
hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be

registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date	
Copies of advertisement materials for research participants [Recruitment e-mail]	0.1	14 September 2018	
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Negligence Insurance]		19 July 2018	
Interview schedules or topic guides for participants [Interview Schedule]	0.2	30 November 2018	
IRAS Application Form [IRAS_Form_11102018]		11 October 2018	
IRAS Application Form [IRAS_Form_22012019]		22 January 2019	
Letter from sponsor [Sponsorship Letter]		01 October 2018	
Other [Public Liability and Employer Liability Information]	0.1	19 July 2018	
Other [Field Clinical Supervisor CV]	0.1	12 October 2018	
Other [Evidence of training in informed consent]	0.1	23 September 2018	
Other [Covering Letter Response to REC Provisional Opinion Letter]	0.1	07 December 2018	
Participant consent form [Easy-read Consent Form]	0.3	30 November 2018	
Participant consent form [Consent Form with no pictures]	0.1	30 November 2018	
Participant information sheet (PIS) [Easy-read Participant Information Sheet]	0.3	30 November 2018	
Participant information sheet (PIS) [Participant Information Sheet with no pictures]	0.1	30 November 2018	
Research protocol or project proposal [Research Protocol]	0.3	14 September 2018	

Summary CV for Chief Investigator (CI) [CI Research CV]		27 September 2018	
Summary CV for supervisor (student research) [Clinical supervisor cv]			
Summary CV for supervisor (student research) [Research Supervisor CV]		12 October 2018	

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at
http://www.hra.nhs.uk/hra-training/

18/NW/0787	Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

Enclosures:	"After ethical review – guidance for researchers"
Copy to:	

Appendix 4-C: HRA Approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr James Taylor
Trainee Clinical Psychologist
Lancashire Care NHS Foundation Trust
Sceptre Point
Sceptre Way
Walton Summit, Preston
PR5 6AW

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

31 January 2019

Dear Mr Taylor

HRA and Health and Care
Research Wales (HCRW)
Approval Letter

Study title:	What do people using community learning disability teams think about their diagnosis of 'personality disorder'?
IRAS project ID:	250921
Protocol number:	N/A
REC reference:	18/LO/1931
Sponsor	Lancaster University

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	250921

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Ms Becky Gordon
Email: ethics@lancaster.ac.uk

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **250921**. Please quote this on all correspondence.

IRAS project ID	250921

Yours sincerely

Thomas Fairman
HRA Assessor

Email: hra.approval@nhs.net

Copy to:

IRAS project ID	250921

ETHICS DOCUMENTS

Appendix 4-D: R&D Approval

Dear Mr Taylor

Confirmation of Capacity and Capability

Trust Ref	2019/14
Chief Investigator	Mr James Taylor
Full title	What do people using community learning disability teams think about their diagnosis of "personality disorder"?
IRAS	250921
REC Ref:	18/LO/1931
HRA Approval	31st January, 2019
Sponsor	Lancaster University

This email confirms that ███████████████ has the capacity and capability to deliver the above study within the Trust.

The study will be supported by the learning disability service and ███████████████ ██.

This support is subject to the research team adhering to all statements in the IRAS application. In order to securely protect participant information and comply with Data Protection Act legislation it is vital that any personal identifiable information is held as per IRAS application. Dropbox accounts should never be used to store personal information as they do not provide adequate security and are hosted outside the European Union. Any potential data breach must be reported immediately to the Trust. If you are unsure about using, storing or sharing information please contact the R&D team in the first instance on 0151 471 2638 for advice.

We agree to start this study on the 29th March 2019.

The trust is monitored on how quickly it recruits the first participant and the ████████ ████████████████████████ requires trusts within its footprint to recruit the first participant within 30 days from Confirmation of Capacity and Capability. Accordingly, the trust's deadline for first recruit is the 27th April, 2019.

ETHICS DOCUMENTS

The trust has not agreed a recruitment target but notes that you aim to recruit 10 participants.

Amendments

Please note it is the CI's responsibility to ensure the R&D department is informed in a timely manner when amendments have been submitted and provided with a summary of the amendment and any updated documentation. For information regarding how to notify the trust of any amendments to your study please refer to the amendments guidance found on the hra website: https://www.hra.nhs.uk/approvals-amendments/amending-approval

Publication

The Trust supports the publication and dissemination of study results to relevant wider audiences but requests that this be completed in a timely manner. Whilst the Trust appreciates that the time taken to analyse results and write up findings for publication can be lengthy, we request this is completed within 2 years of the end of data collection. This allows for a real time and current representation of the service which is imperative given the continuous aim of striving for ███████████████████████████████ aspires to.

Event reporting

You are reminded you must report any adverse event or incident whether or not you feel it is serious, quoting the study reference number. This requirement is in addition to informing the Chairman of the relevant Research Ethics Committee.

If you wish to discuss further, please do not hesitate to contact ██████████.

Extension

If you require any extension to the project, please inform the department. For further information regarding notification of amendments, please visit: http://www.hra.nhs.uk/research-community/during-your-research-project/amendments.

Kind regards,

██████

Appendix 4-E: Participant Information Sheet

Participant Information Sheet – Version 0.3

What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

My name is James and I'm a trainee psychologist studying at Lancaster University.

- I would like to ask you to help with my research.

- Before you decide whether you would like to take part in my research, it is important for you to know what it is about and what it will involve.

- You can stop me at any time if you do not understand or have any questions.
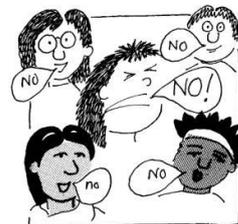
- You do not have to take part.

- You can say 'no' at any time.

- I am asking you to take part in my research as you are using services and have been given a diagnosis of 'personality disorder'

- I would like to know your thoughts and feelings about this diagnosis

- This will involve talking about your experiences of having this diagnosis or label

- I need to talk to people in an interview, which will last about 60 minutes

- You can have a break at any time

- I will record our conversation on an audio recorder

- If you say anything that make me worried about you or others, I will stop the interview and explain what needs to happened and who we tell

- The recording will be password protected and moved to a secure, computer drive at Lancaster University

- Your name will not be written down or used in the results

- If you agree to take part and then you change your mind, it is OK

- You will be invited to take part in a raffle to win a £50 Amazon voucher

- Once the study is over, I would like to talk to you again to about the results

- You do not have to meet me if you do not want to

- I will type the results up into a paper so others can read and learn from what we did

- I will give you a different name if your words are used in the final paper

- If you decide to take part, let your team know and I will be in touch

- You will be given a copy of this leaflet and the consent form to keep

- The consent form will be kept in a locked cabinet at the team office. Once the study is finished, this will be moved to Lancaster University and held by the Research Co-ordinator.
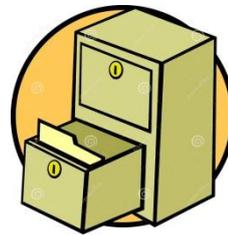
If you would like to talk about taking part in the survey or have any questions, please contact James Taylor on:

j.taylor23@lancaster.ac.uk

0151 737 4800

If you would like to make a complaint or have any concerns about the survey, please contact the following people at Lancaster University:

Dr Bill Sellwood

b.sellwood@lancaster.ac.uk

01524 593998

Or:

Professor Roger Pickup

📞 01524 593746

If you feel upset or worried during or after the interview, you can:

- Speak to James during the interview

- Email or phone either James or Alex to arrange a meeting

- Speak to your nurse or another member of staff in your team

- If you cannot speak to anyone or if it is an emergency - contact your GP, go to your local A&E hospital or contact the Samaritans:

  📞 116 123

  🖥 jo@samaritans.org

Health Research Authority Transparency Information

- Lancaster University is the sponsor for this study. They are responsible for looking after your information and using it properly. They will keep this information for 10 years after the study has finished, until 2029.

Lancaster University   2029

• Lancaster University will manage your information in specific ways so that the research stays true and reliable. This means your rights to seeing or changing information is limited.

• If you withdraw from the study, we will keep the information about you that we have, but use the least information possible. You or your information will not be made known.

• You can find out more about how we use your information by contacting Bill or Roger at Lancaster University using the information above.

• Your team will keep your name and contact details confidential, and will not pass this information to Lancaster University.

• Your team will use your information to contact you about the research and write about you taking part.

• Certain individuals from Lancaster University and regulatory organisations may look at your records to check the accuracy of the research study.

• Lancaster University will only receive information that does not identify you. They will not be able to find out your name or contact details.

Thank you for reading this leaflet

Appendix 4-F: Consent Form

Consent Form – Version 0.3

Study Title: What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

Name of researcher: James Taylor (Trainee Clinical Psychologist)

Please initial the boxes

1. I have read the information sheet or the information sheet has been read to me
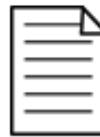
2. I have been given time to ask questions about the study

3. I understand that I will take part in an interview

4. I understand that I will be asked questions by James Taylor
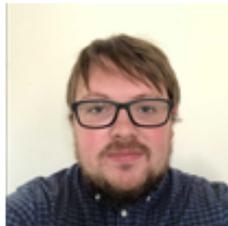
5. I understand what I say in the interview will be recorded

IRAS Project ID: 250921   30/11/2018

6. I understand that the recording will be kept on a secure computer until the study is marked

7. I know that others might read or listen to my answers

8. I understand that other people will not know my name

9. I know that I can say 'no' or stop at any point in the interview
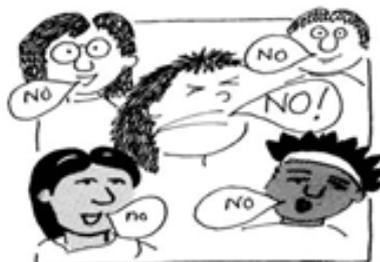
10. I know I can change my mind to take part at any point of the study, up until 1st April 2019

11. I understand that the interviews will be typed up and might be published for other people to read

12. I know that the typed interviews and consent forms will be kept at Lancaster University for 10 years

13. I understand that people will not know my name, but I agree to things I say being published

14. I understand that James may want to meet again to talk about the interview results. I can say no if I don't want to meet.

15. I would like to take part in the interview and the study

16. I would like to enter the raffle to win £50 Amazon voucher

17. I agree to give my e-mail address to be contacted about the raffle

Email address:

Name of Participant: Signature: Date:

Name of Researcher: Signature: Date:

What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

<u>Interview Schedule – Version 0.2</u>

Key objectives:

- To understand how participants view their experiences in light of a diagnosis of 'personality disorder'
- To understand the impact of the diagnosis on their identity or relationships with themselves, others and services
- To understand the changes from before diagnosis to afterwards

Topics for discussion (questions)	Interviewer notes (prompts)	Timing (approx.)
1. Welcome and introduction to interview		**5 min.**

• Welcome participant to interview
• Explain aim of interview:
 	
  - To learn more about what it is like to have a 'personality disorder' diagnosis.
 	
  - Due to differences over the appropriateness of language, ask participant how they would like the interviewer to refer to 'personality disorder', e.g. 'term', 'label', 'diagnosis', just 'personality disorder', or their own suggestions
 	
• Remind participant:
 	
  - Who researcher is (name, job, university, etc.)
 	
  - Ok for someone else present if wanted
 	
  - Confidentiality – won't discuss details of what is said with anyone in the team, unless concerns about harm or risk to self or others
 	
  - Ok to stop or pause the interview at any time		

- Directions for fire exits, toilets, refreshments etc. - Interview will last for around 1 hour - Need to audio-record interview • Sign consent form if not already complete • Answer any questions before starting		4-71
2. Introduction to the participant		**5 min.**
• Preferred name? • How did you get here today? • What else have you done today / plan to do later? • Can you tell me a little about yourself? • How old are you? • Who do you live with? • How long have you lived there? • Where did you grow up? (Live as a child?) • Do you have any family? • Do you have a support worker? • Do you have anyone else who helps you to do things?	Introductory questions which are easy to answer, in order to make participants feel more relaxed and gently introduces the topic.	
3. Knowledge of diagnosis		**10 min.**
- When did you first hear about (the diagnosis/label/term) 'personality disorder'? - Can you remember when the first time it was used about you? - How did you get told about it? - What was it like? Who spoke to you? - Some people do not like the term personality		

disorder and some people do. What do you think about it? - Is there anything you would change about the way you received the diagnosis? - Who did you tell first? - What helped you to tell that person? - Did anything make it hard to tell that person? - Were you worried about telling anyone?		4-72
4. Experience of having diagnosis		**10 min.**
- Does it mean anything to you? - Does the (diagnosis/term/label) say anything about you? - Does it help you with understanding yourself (understanding any other aspects)? - What kind of things did you learn? - Is there anything good about the term? - Is there anything bad about the term? - Why do you think you have been given the diagnosis? Things you do? - How did the diagnosis affect you? - How has having the label affected your relationships with friends/family/staff?		
5. Impact/Stigma		**10 min.**
• Did/Do you know any other people who have been given a 'personality disorder'? • What do you think about others given this? • What do other people say about their personality disorder? • What do your support workers say?		

• What do you think about it? • Do you feel that people treat you any differently now you have been given a diagnosis? Behave differently? • Do they speak to you differently? Family, friends, staff? • Has it changed the way you think about your problems? Difficulties? Relationships? • How do you feel about the future? • Are you happy you received the diagnosis? • Has it helped?		4-73
6. Advice to others		**10 min.**
• What would you tell someone to help if they have been given the label of 'personality disorder' • What advice would you give? • What kind of support / help do you think you need or that others might need? • Is there any support missing at the moment that would be helpful? • Is there anything that people should not do / stop doing if they want to help people with a 'personality disorder' diagnosis?		
7. Conclusions		**10 min.**
• Summarise points raised in interview. • Anything else that you want to speak about that we haven't yet? • Anything important that has been missed? • Debrief - How are you feeling now that the interview is	Final check if interviewer understood correctly and covered all topics important to participant.	

finished? - Any plans for after the interview? • Feedback - Option to meet with participant to check themes emerging from study before final write up - Contact details to speak/meet regarding final findings of study - Confirm researchers' contact detail if participant wants to follow up any topic that was discussed • Thank you for attending and participating. • End of interview.		4-74

Appendix 4-H: Recruitment E-mail to Care Co-ordinators

What do people using community learning disability teams think about their diagnosis of 'personality disorder'?

My name is James Taylor and I am conducting research on the above topic as a student in the Doctorate in Clinical Psychology programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?
The purpose of this study is to investigate learning disability service users' experiences of having a diagnosis of 'personality disorder' and its impact on their thoughts, feelings and relationships. This will be conducted as 1:1 interviews with service users currently under care of your team. The findings may then be used to help develop future clinical practice and support for those diagnosed with both a learning disability and personality disorder.

It is hoped that between six and ten interviews will take place over the next few months. If you are currently working with anyone with a diagnosis of personality disorder who you believe would like to take part, please contact them to discuss my research and give copies of the Participant Information Sheet and Consent Form (attached to this e-mail). When you next meet with the individual, please would you help go through both forms with them in order to determine appropriateness and their consent to engage? If any of your clients agree to participate, please get permission to give their contact details to myself and I will arrange a meeting and interview time with them. If you have any further queries or questions, please do not hesitate to contact either myself or my research supervisor, ▮▮▮▮
▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮

James Taylor, Trainee Clinical Psychologist – j.taylor23@lancaster.ac.uk
▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮▮

Care co-ordinators of individuals to be interviewed for the research will be informed of the date, time and location of the interview once confirmed. I am available to contact for any further information or questions on the above e-mail address, and I will shortly be visiting the team and answer any questions you may have beforehand.

Thank you for your time and I look forward to meeting some of you soon.

Kind regards,

James Taylor
Trainee Clinical Psychologist
Lancaster University

[attachment of Participant Information Sheet] [attachment of Consent Form]