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Valued social roles for people with learning disabilities

Section A:

The impact and experiences of valued social roles within employment, education, and self-advocacy on the lives of people with learning disabilities

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DECLARATION PAGE

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Summary of portfolio

Section A

This literature review explores research pertaining to the impact of valued social roles within employment, education and self-advocacy for people with learning disabilities. It highlights key outcomes, discusses clinical relevance and outlines areas for further research.

Section B

This narrative study explores the impact of being a trainer on the lives and identities of people with a learning disability. Open-ended interviews, conducted with nine participants (three female, six male), were analysed using a structural and positioning narrative analysis approach. The results illustrated that being a trainer contributed to positive changes in most participants' lives, and that participants positioned themselves as trainers in a number of positive roles. The results are discussed in relation to theoretical, research and clinical implications.

Section C

This critical appraisal discusses the primary research skills gained by conducting this project, reflects on what could have been done differently, discusses implications for future clinical practice, and makes suggestions for future research.

Emma Taylor

Section A: Literature review

The impact and experiences of valued social roles within employment, education, and self-advocacy on the lives of people with learning disabilities

Word Count: 5496 (209)

Abstract

People with learning disabilities (PLD) traditionally represent a marginalised and excluded group in society. However, socio-political changes have led to an increased recognition of the need to improve the lives of PLD. The theories of normalisation and social role valorisation highlight the importance of access to 'ordinary patterns of life' for PLD, and valued social roles within a variety of life domains. This paper aims to review the literature pertaining to valued social roles within the domains of employment, education and self-advocacy, and their impact on the lives of PLD.

Literature searches of PsychINFO and ASSIA databases revealed 21 studies included for review. Positive outcomes (e.g. enhanced self-esteem, positive self-identity, quality of life), and practical and personal challenges (e.g. illiteracy, difficulties developing social relationships) were found. However, the results need to be interpreted in light of limitations related to the samples and the paucity of UK-based studies. Clinical and research implications highlight the need for professionals to consider the impact of vocational activities when supporting PLD, and the value of PLD sharing their experiences, to name a few. Further research is required generally, and specifically relating to the roles of researcher and trainer given the paucity of literature.

Introduction

Socio-political context

Social inclusion and enhanced life opportunities for people with learning disabilities (PLD)¹ are at the forefront of UK government policy. Historically, the All Wales Strategy (Welsh Office, 1983) outlined the rights of PLD to ordinary patterns of life within their community; the right to be treated as individuals; and the right to additional help from their community. More recently, Valuing People (DH, 2001) and Valuing People Now (DH, 2009a) emphasised the importance of the views and voices of PLD in shaping their everyday lives, and underscored their rights, independence, choice and social inclusion.

This focus on improving the lives of PLD is a change from their traditional experiences of marginalisation, exclusion, and poorer outcomes compared to physically disabled and non-disabled populations (Emerson, Baines, Allerton, & Welch, 2010). PLD remain less likely to be married (Koller, Richardson, & Katz, 1988), to gain employment (Stephens, Collins, & Dodder, 2005), have smaller social support networks, and participate in fewer community activities than non-disabled individuals (Rosen & Burchard, 1990). Additionally, funding limitations challenge the realisation of relevant policies and PLD continue to be excluded from broader government policies. Therefore, despite these socio-political advances, ongoing challenges remain.

¹ This term is used in line with BPS. However, the author is aware that terms such as intellectual disability are also used.

Theoretical context

This changing socio-political context has been significantly impacted by Normalisation (Nirje, 1980), later renamed Social Role Valorisation (SRV; Wolfensberger, 1983), which attempted to enhance the social image of PLD and address the stigma associated with the identity. It underscored “access to ordinary patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society” (Nirje, 1980, p. 33). Normalisation/SRV proposed that supporting PLD to adopt valued roles (e.g. neighbour, employee etc) would enhance their perceived value in society, resulting in better treatment, greater social opportunities, and enhanced self-esteem and quality of life (Abraham, Gregory, Wolf, & Pemberton, 2002). By applying the principles of normalisation to services, it was hoped that this would result in high quality services fostering high quality lifestyles, and the opportunity for PLD to form valued social identities. Therefore, valued social roles were assumed to afford PLD “the good things in life” by mitigating the stigma and prejudice they experience (Wolfensberger, 2000).

Defining ‘valued social role’.

Wolfensberger (1992) defined a valued social role as “a socially accepted pattern of behaviours, responsibilities, expectations and privileges” (p. 13). Similarly, O’Brien (2006) defined it as “the ways that people belong to each other, participate in exchanges with each other and expect reciprocal responsibility from each other” (p. 5) within the domains of spirituality and religion, work, home and neighbourhood, learning, community inclusion, sport

and fitness, family and friends, and creative expression. O'Brien (2006) also identified specific examples within each domain (e.g. employee within work domain).

Theoretical impact and criticisms.

The influence of Normalisation/SRV in the UK was positively reflected in the closure of long stay asylums, the movement from segregated to community-based living, and the development of community-based services for PLD, to name a few. The latter was largely influenced by O'Brien's (1989) five service accomplishments, which focused on improving services for PLD by underscoring their community presence, choice, competence, respect and community participation.

However, critics argued that normalisation was developed and based on research conducted by non-learning disability academics, originally neglecting the voices of PLD themselves (Walmsley, 2001). Additionally, some argued it negated an appreciation of the factors that contributed to devaluation given the focus on the factors contributing to "ordinary patterns of living" (Myers, Ager, Kerr, & Myles, 1998). Similarly, by focusing on services, it neglected an understanding of the impact of wider social factors, such as public attitudes, on PLD (Walmsley, 2001). The use of 'normative' as a desired outcome and a measure of success was also criticised, and some argued that normalisation "seeks equality through similarity", rather than "equality of difference" (Myers, Ager, Kerr, & Myles, 1998, p. 392). Given the assumption that adopting roles, cultures and expectations of the dominant

group can lead to positive changes, normalisation was also been criticised as leading to a “deconstruction of minority cultures” (Emerson, 1992, p. 13) and a focus on conformity rather than acceptance (Bayley, 1991). Lastly, the assumption that positive changes in one area lead to positive changes in another is overly positivistic and linear. Thus, unsurprisingly, the principles of normalisation have been wrongly applied in areas like supported employment, resulting in a lack of reasonable adjustments for PLD (Wilson, 2003).

Valued social roles within the non-LD population

Valued social roles impact the lives of people without learning disabilities. Employment provides opportunities for engaging in, and contributing to society (Lysaght, 2010), and a positive correlation exists between job satisfaction and psychological health (Tait, Padgett, & Baldwin, 1989). Research with disadvantaged groups, such as people with mental health difficulties, has linked involvement in training to increased belonging (Solomon, 2004), competence and social usefulness (Riessman, 1965). Similarly, people with mental health difficulties involved in undergraduate medical teaching felt validated and empowered (Walters, Buszewicz, Russell, & Humphrey, 2003). Some participants also found talking about their experiences anxiety provoking and distressing, thus highlighting potential challenges of the role. Lastly, people with physical disabilities in recreational and sporting roles evidenced increased quality of life (Zabriskie, Lundberg, & Groff, 2005). Therefore, valued social roles are likely to impact PLD in different ways.

Scope and aim of review

The breadth of domains encompassed by the definition of valued social roles leads to a plethora of roles for potential examination. However, coupled with the current socio-political climate of the UK, specific domains warrant investigation.

The publication of Valuing Employment Now (DH, 2009b) highlighted the need to enhance the employment opportunities of PLD, particularly those with severe to moderate learning disabilities. Community-based paid employment is also vital to social inclusion and enhanced quality of life for PLD (DH, 2000, 2009a, 2009b). Additionally, the current government agenda aims to decrease the number of people on benefits and increase the number of people in employment, including those previously entitled to disability living allowance. Thus, employment roles are particularly relevant at present.

Normalisation has also had a significant influence on the educational roles adopted by PLD. A change in the exclusion of PLD from statutory schooling in the UK prior to 1970 (Walmsley, 2001), and ongoing debates surrounding the value of mainstream versus specialist education (Department for Education and Skills; DfES, 2004) highlight the increased value of traditional roles, such as student for PLD. Normalisation also paved the way for PLD to speak-out about their lives and experiences (Walmsley, 2001), resulting in them adopting educational-related roles that involve imparting knowledge onto others, thus themselves becoming educators. Therefore, educational roles are also worthy of exploration.

These changes are also reflected by the growth of the self-advocacy movement. Self-advocacy is a civil rights movement for PLD that involves speaking up and taking control of their own lives in order to “achieve or regain some of the autonomy they have traditionally been denied” (Holmes, 1995, p. 449). Self-advocacy places significant value on “an individual’s ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions” (cited in Test, Fowler, Wood, Brewer, & Eddy, 2005, p. 41). Therefore, self-advocacy focuses largely on the individual and their capacity for enhanced responsibility, self-determination and empowerment. For this reason, it seemed important to consider it a separate domain from education and employment within this review.

Therefore, this paper aims to critically review the literature pertaining to the impact of valued social roles relevant to employment, education and self-advocacy for PLD. Whilst Normalisation/SRV and the current UK socio-political climate have influenced multiple areas, these domains were considered a useful starting point to review given the variety of potential roles that could be explored, and their relative similarities. Literature within other populations implies that positive outcomes and challenges arise from valued social roles, yet no review pertaining to PLD has been conducted to date².

² As of 23/11/12

Definitions

Learning disability

This review employs the British definition of 'learning disability', characterised by intellectual impairment, impaired social functioning and age of onset before 18 years (referred to as 'Mental Retardation' in the definition by International Statistical Classification of Diseases and Related Problems, 10th revision) (World Health Organisation, 2007).

Employment, education and self-advocacy

The domains of employment and education were partly informed by the definitions within the community participation literature (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009), which was significantly influenced by Normalisation. They are defined as remunerative, non-remunerative, voluntary, formal and informal roles (excluding domestic roles), and informal, vocational training and higher education, respectively. Additionally, education was also defined as encompassing traditional educational roles, such as student, and roles whereby PLD impart knowledge onto others (i.e. educators). O'Brien's (2006) domains of 'work' and 'learning' informed specific valued social roles (e.g. trainer). Self-advocacy has been defined in multiple ways and no one single definition exists. Nevertheless, key themes across the range of definitions include "speaking and standing up for yourself, standing up for your rights, making choices, being independent and taking responsibility for yourself" (cited in Beart, Hardy, & Buchan, 2004, p. 91).

Method

Search strategy

Primary and secondary searches of PsychINFO³ and Applied Social Science Index and Abstracts⁴ (ASSIA) were conducted using variations of the keyword 'intellectual disability' with keywords related to employment, education and self-advocacy, informed by the community participation literature and O'Brien (2006) (Appendix 1). Database thesauruses, references and citing articles were used to identify additional search terms and relevant articles, respectively.

Procedure

English language journal articles were initially retained based on their title and abstract, followed by their full-text if: (1) the sample included PLD aged 18 and over, and (2) they reported outcomes/experiences (i.e. impact) of roles within employment, education or self-advocacy (Appendix 2). Dissertation abstracts, mixed sample studies whereby the results for PLD were not delineated from those without a disability (excluding borderline LD), and studies within the employment domain that reported solely vocational outcomes (i.e. wages, re-employment rates) were excluded. The latter was not deemed relevant to understanding the experiences of PLD.

³ Between 1967 and November 2012, and March 2013

⁴ Between 1969 and November 2012, and March 2013

Search results

Twenty-one studies met the inclusion criteria. Some studies resulted from searches relevant to multiple domains. Thus, the groupings below are somewhat arbitrary for the purpose of this review. Relevant to employment, one review about PLD as supported employees, six quasi-experimental studies that were not included in the aforementioned review, and two quasi-experimental studies about open employment were found. Within the education domain, two reflective accounts about PLD as co-researchers, three about PLD as teachers/trainers, (two qualitative, one reflective account), and four about PLD as students (one qualitative, one mixed-methods, two case studies) were found. Lastly, three qualitative studies about PLD as self-advocates were found.

Given the variety of research methods employed, no set quality criteria were used. Instead, frameworks for assessing the quality of non-randomised studies and qualitative research (i.e. Downs & Black, 1998; Mays & Pope, 2000) were used to identify key methodological issues.

Literature review

Structure

Studies are grouped according to domain and role, and their key findings and methodological limitations are outlined (see summary table Appendix 3). This is followed by a discussion of their results, critique, clinical and research implications.

Employment

Studies within this domain pertain to supported employment (SE), which is reviewed first, followed by open employment (i.e. competitive).

Supported employment.

SE refers to “real jobs, paid at the going rate, with normal job security, vocational profiling, professional job finding, job analysis, job matching, placement plans, and on-the-job training and follow-up” (Beyer, Brown, Akandi & Rapley, 2010, p. 290). Studies are grouped according to outcome, and reviewed chronologically as one is a review.

Quality of life.

Sinnott-Oswald, Gliner, and Spencer (1991) compared perceived quality of life (QOL) for PLD in SE, a sheltered workshop program⁵ (SW), and individuals without disabilities in employment. QOL was measured using a questionnaire that was developed by the authors and based on the Quality of Life Scale (Schalock & Keith, 1993). The results revealed that the number of leisure activities, use of leisure time, self-esteem, involvement in activities, mobility, job skill perceptions, and perceptions regarding changes in income were positively related to SE. However, these results may have been attributed to the part-time status of SE participants and were limited by the use of a self-report QOL measure.

⁵ Refers to segregated vocational and non-vocational programs (e.g. adult activity centres, work activity centers, day treatment centers).

In a systematic review, Jahoda, Kemp, Ridell, and Banks (2008) illustrated that supported employees and their families reported greater QOL (i.e. psychological well-being, satisfaction, self-esteem) compared to PLD in other settings (e.g. sheltered workshops, unemployed). The measures used across the reviewed studies included QOL measures (e.g. Schalock Quality of Life Scale), and other measures pertaining to participants' social networks (e.g. Social Network Guide), life experiences (e.g. Life Experiences Check list), and adaptive behaviour (Vineland Adaptive Behaviour Scales). Whilst some PLD reported greater integration with non-disabled colleagues and enhanced social networks compared to non-supported employees, the quality of their social relationships (i.e. reciprocity, supportiveness) did not differ. The credibility of this review was increased by the exclusive use of peer-review studies. However, workplace or participant variables may have impacted subjective QOL, and the use of observation methods to measure social outcomes in many of the reviewed studies prevented insight into the subjective quality or meaning an individual attached to a social interaction, which could impact outcomes. The direct experiences and voices of PLD were also neglected given the exclusion of qualitative studies.

In contrast, Verdugo, de Urries, Jenaro, Caballo, and Crespo (2006) found no differences for QOL (i.e. competence/productivity, self-determination/independence, satisfaction, social belonging/integration in the community) between supported and sheltered employees in Spain. The measures included the Quality of Life Scale (Schalock & Keith, 1993) and the Typicalness Questionnaire (Mank, Cioffi, & Yovanoff, 1997). Higher job

'typicalness' (i.e. degree to which characteristics of the job e.g. duties, environment, reflect those of non-disabled colleagues) was correlated with higher total QOL, competence/productivity and self-determination/independence for supported employees. Participants with greater levels of direct support, women, and workers with lower training demonstrated lower QOL. Therefore, jobs that closely resembled non-disabled workers' were related to enhanced QOL. However, participants were not randomly selected, the sample comprised mainly of people with mild LD, and the majority of participants lived in the family home, which limits generalisability.

More recently, Beyer, Brown, Akandi, and Rapley (2010) found that supported employees scored higher than enterprise workers⁶ and day service attendees on objective QOL (i.e. material well-being, health, productivity, intimacy, safety, place in society and emotional well-being), but not on quality of work environment (i.e. relationships, personal growth, system maintenance and change). Quality of Life was measured using the Comprehensive Quality of Life Scale for adults (ComQol-A; Cummins, 1997a) or PLD (ComQol-I; Cummins, 1997b). Non-disabled co-workers scored higher on total objective QOL, compared to all PLD. However, supported employees had greater subjective QOL (i.e. the importance of the different domains to the person) than non-disabled workers. Therefore, SE was related to more positive QOL outcomes compared to other forms of activity for PLD. However, a gap between supported employees and non-disabled workers in some areas

⁶ i.e. Those working in social enterprises

remained. These results need to be interpreted with caution given that 70% and 90% of supported and day centre participants were male, and the study employed small samples (i.e. 10 day-service attendees, 10 employment enterprise workers).

Banks, Jahoda, Dagnan, Kemp, and Williams (2010) explored the psychological impact of job breakdown on PLD in SE using the ComQoI-I (Cummins, 1997b). Within nine to 12 months of starting a job, 27% of participants experienced job breakdown that was not related to age, gender, living arrangements, type of school attended or IQ. No differences for QOL (i.e. material well-being, health, productivity, intimacy, safety, place in community, emotional well-being) and psychological well-being (i.e. depression and anxiety) were found for PLD who lost their jobs at follow-up compared to those who retained employment. However, losing one's job left a significant gap in participants' lives, resulting in boredom, laziness and uncertainty about finding another job. This study was strengthened by the use of interviews to access the direct experiences of PLD in employment. However, the mean IQ score of 69 on the Wechsler Abbreviated Scale of Intelligence (WASI) meant that the majority of participants had a mild learning disability, and only five scored below 75.

Adaptive skills.

Stephens, Collins, and Dodder's (2005) longitudinal study illustrated that PLD who moved from unemployment to sheltered, supported and/or competitive employment showed increased adaptive behaviour skills (i.e.

activities of daily living). Where employment status remained constant, so too did participants' level of adaptive skills. However, those who moved from employment to unemployment evidenced decreased adaptive skills. The generalisability of these results was enhanced by the inclusion of people with moderate and severe LD. However, given the longitudinal design, maturation effects may have confounded the results.

Jahoda et al. (2009) explored the relationship between employment and adaptive skills in supported employees prior to their first job starting, and nine to 12 months later. Employment provided purposeful activity, financial reward, increased choice, independence, social activities, status, and self-worth. Challenges pertained to anxiety about starting a new job, job retention, learning and retaining new skills and meeting new people. This was one of the only studies to address the challenges associated with gaining employment for PLD. However, as a proportion of participants had an IQ greater than 70 the results of this study are difficult to interpret in terms of their applicability to PLD.

Open employment.

Kober and Eggleton (2005) found that PLD in open employment (i.e. competitive employment) evidenced higher total quality of life (i.e. satisfaction, competence/productivity, empowerment, social belonging/community integration), individual empowerment/independence and social belonging/community integration compared to PLD in sheltered employment. After splitting the sample based on functional work ability (i.e. work

capabilities and deficiencies), only high functional work ability employees in open employment had higher empowerment/independence, social belonging/community integration, and total quality of life scores. There were no significant differences for total QOL or related domains for low functional work ability individuals based on type of employment. Thus, greater QOL may have been attributable to functional work ability. However, these results were limited by the recruitment of participants from a specific geographical location and the lack of matched samples.

Petrovski and Gleeson (1997) used the spill-over hypothesis, whereby job satisfaction/dissatisfaction influences life satisfaction, to explore the relationship between job satisfaction and psychological health (i.e. self-esteem, stigma, loneliness and aspirations) for PLD in open employment. Participants with high job satisfaction reported low perceived stigma and loneliness at work. However, despite feeling satisfied with their social contacts at work, few participants saw work 'friends' outside of work. No relationship was found between job satisfaction, self-esteem or aspirations, or gender in terms of perceived levels of self-esteem, stigma and aspirations. However, females reported higher loneliness than males at work. Therefore, only certain aspects of psychological health were influenced by job satisfaction for PLD. However, these results were limited by the lack of a control group and it was unclear whether all the measures were validated for use by PLD.

Education

Researcher.

Knox, Mock, and Parmenter's (2000) reflective account of a wider research project about community relationships for PLD, involved six participants who elected to become informants in an emancipatory research⁷ project. Although outcomes of the researcher role were not the focus of this paper, PLD reported feeling heard, legitimised, able to talk about experiences that had not been asked about or heard before, and gained increased knowledge of the research process.

Similarly, Conder, Milner, and Mirfin-Veitch (2011) found that PLD as researchers (i.e. co-facilitating focus groups, data entry) felt more confident in the role of researcher and in supporting others to speak up as a result of their involvement. Co-researchers also felt the individual time offered by supporters helped improve their reading skills. However, when interviewing others, co-researchers found it difficult to read some of the questions and felt they did not have enough time to memorise the material.

Thus, both personal and practical challenges arose from the role of co-researcher. However, the results need to be interpreted with caution given that participants in the first study were self-selecting, and because feedback was gathered informally, rather than empirically.

⁷ This is also referred to as 'inclusive research' and pertains to research whereby PLD are involved as more than just research subjects or respondents (Walmsley, 2001).

Teacher/trainer.

Borisov and Reid's (2010) qualitative study explored the benefits of PLD as teaching assistants in physical education. Observational and semi-structured interview data highlighted positive outcomes including positive affect, connectedness, pride and accomplishment, career aspirations, self-identity as helper, responsibility towards others, being a role model, modification of behaviour (e.g. increased focus, attitudes towards school) and altruism. However, the sample comprised only five participants and the focus on the benefits of the role negated an understanding of the likely challenges.

Black and Roberts (2009) also found positive outcomes for PLD as trainers in a values-based pilot training program delivered to staff. These included feeling positive about "telling people what matters", being listened to, making friends, and personal development (e.g. memory, confidence). Trainers also identified practical challenges, such as reading and mobility. Follow-up interviews revealed perceived increased confidence, competence, and decreased anxiety with experience. Positive changes in staff attitudes and increased awareness of the perspectives of PLD post-training were also found.

Lastly, Weeks, Shane, MacDonald, Hart, and Smith (2006) reported outcomes from a two-day training event delivered by four PLD to PLD from eight UK sites. Although this study was largely descriptive, trainers developed new skills in teaching and running training (e.g. role plays), and increased confidence due to their involvement.

Therefore, the role of trainer had both a short and long-term positive impact on PLD, and positively influenced the perceptions of others towards them. However, as these studies were largely descriptive, they lacked formal measures (e.g. attitude scales) to back-up their results, and their samples were small. Thus, greater methodological rigour is required before drawing firm conclusions about the impact of the trainer role on PLD.

Student.

Paiewonsky's (2011) qualitative study of the experiences of nine college students with LD revealed multiple themes relevant to the impact of the role. 'Having a new identity and feeling different' pertained to increased independence and integration with other students. 'Adjusting to new expectations' meant being treated like an adult and learning to take responsibility for oneself. 'Campus life' referred to increased social opportunities and access to practical resources. Challenges pertained to a lack of access to classes in line with their interests, and a desire for support in making new friendships. Given all participants were aged 19-21 and were drawn from a limited geographical location, the generalisability of these results was limited.

O'Brien et al.'s (2009) qualitative study found that the role of student lead PLD to view themselves in multiple novel roles. These included a 'learner', with increased independence, confidence and communication skills; a friend, with an increased social network and access to activities; and a 'different person', who felt happier, more included and who non-disabled

students perceived as 'ordinary'. Thus, the role of student promoted a positive identity for PLD. However, the study only involved participants from one Irish university, thus limiting generalisability.

Through interviews with 'Megan', her teachers, and seven fellow students, Hamill (2003) found evidence of increased independence, self-esteem and pride for Megan as a student. Fellow students reported learning more about the experiences of people with disabilities. However, Megan also experienced difficulties developing meaningful friendships, which left her feeling excluded and separate from others. She also found it a challenge to understand the procedures regarding coursework and college life.

For 'Jacqueline', a 21 year-old woman with Down syndrome, the role of student resulted in a perception of 'sameness' with fellow students, and fostered a positive relationship with her non-disabled mentor (Casale-Giannola & Kamens, 2006). Fellow students also cited increased positive attitudes towards people with disabilities. However, Jacqueline experienced a lack of meaningful relationships with peers.

Thus, in addition to positive outcomes related to identity, being a student was challenging in terms of social interaction and relationships. However, as the latter two studies employed a case study design, and participants' level of LD was unclear, generalisation to the broader LD population is limited.

Self-advocacy

Caldwell (2010) explored leadership development in 13 members of the self-advocacy movement in the USA via semi-structured interviews. Self-advocacy encouraged resistance towards oppression resulting from disability, fostered connections with a disability community, increased self-confidence and self-determination, provided a safe and trusting environment within which to be heard, and facilitated a positive self-identity as a result of developing a personal concept of disability independent of societal beliefs. These results need to be interpreted with caution given the use of snowball sampling as a non-random method subject to significant bias (i.e. participants were chosen based on friendships).

Beart, Hardy, and Buchan's (2004) grounded theory model entitled 'Changing selves' illustrated that self-advocacy resulted in a change in self-concept, including increased confidence, autonomy, status and skills. Being in a group provided a positive social environment, new friendships, support and help. However, changes in self-concept led to a reflection on past painful experiences, such as bullying, feelings of powerlessness, and a lack of support. Participants also cited positive reactions from others, including family, friends and professionals, arising from their role. However, these results were limited given all participants were White British.

Gilmartin and Slevin (2010) explored the experiences of 13 self-advocates in Ireland. Participants felt self-advocacy helped them feel safe about speaking out, led to enhanced self-determination, confidence, self-

esteem, positive changes in personal identity, expanded social networks and increased individual and collective empowerment. Challenges included not feeling listened to, feeling unable to affect change, nervousness and tension within the group. However, as the level of LD was not reported it was unclear which LD population the results related to.

Discussion

This paper aimed to review the impact of valued social roles within employment, education and self-advocacy for PLD, from which positive outcomes and challenges arose. Consistent with positive outcomes for people with mental health difficulties involved in training, including increased competence, social usefulness and empowerment (Riessman, 1965; Walters, Buszewicz, Russell, & Humphrey, 2003), being a teacher/trainer and student had a positive impact on self-esteem. This is promising given self-esteem is fundamental to subjective well-being (Rosenfield, 1997). These roles also facilitated skills development, positive identities, and positive perceptions of others towards PLD (e.g. staff, fellow students). The latter lends support for the contact hypothesis (Allport, 1954), whereby interpersonal contact between majority and minority group individuals can reduce prejudice. It is also consistent with evidence of decreased negative stereotypes and enhanced positive attitudes amongst medical students towards PLD following user-led training (Thistlethwaite & Ewart, 2003; Biswas, Raju, & Gravestock, 2009).

Given that PLD cite low confidence as a barrier to social inclusion (Abbott & McConkey, 2006), and self-advocacy groups are pushing for more inclusive research with PLD as co-researchers (Paiewonsky, 2011), it was promising that PLD as trainers, self-advocates and researchers gained increased confidence. The large number of studies about PLD as employees was also positive given that PLD cite employment as crucial to their social inclusion (Hall, 2009). Additionally, supported employment can challenge negative societal beliefs about the abilities of people with disabilities in work settings (Wehman, Revell, & Brooke, 2003).

The finding that losing one's job left a significant gap in the lives of PLD was unsurprising given the association between unemployment and poorer mental health outcomes (Warr & Jackson, 1987), and the link between social isolation and long-term unemployment in the general population (Jahoda, 1988). Challenges also arose for some researchers (e.g. illiteracy), self-advocates (e.g. group tension), students (e.g. social integration), and supported employees (e.g. retaining new skills). Additionally, some supported employees did not evidence greater quality of work environment (i.e. relationships, personal growth, system maintenance/change). Therefore, practical and personal difficulties arose. However, consistent with criticisms of normalisation as positivistic in its assumptions, many studies did not report any challenges. Furthermore, the difficulties related to social relationships for students, and the limited social belonging/community integration of supported employees highlighted that valued social roles do not necessarily mediate the stigma associated with being learning disabled. As Ager, Myers, Kerr, Myles,

and Green (2001) state, a community presence does not necessarily result in social inclusion.

Critique

Several factors should be considered when assessing the relevance of these results. Firstly, their applicability to a UK population was limited by the fact that only six of the 20 studies (excluding the review by Jahoda, Kemp, Ridell, & Banks, 2008) were conducted in the UK, with the majority occurring in Australia, New Zealand, and the USA. This may be indicative of different cultural attitudes towards PLD and a differential influence of Normalisation within these countries. This may also reflect the fact that the influence of Normalisation in the UK has decreased in recent years (Walmsley, 2001).

Secondly, few studies referenced Normalisation/SRV, which was surprising given they are likely to have influenced their conception. For example, Walmsley (2001) argues that involving PLD as contributors in research is largely attributed to normalisation, and participatory research is one way of promoting 'valued social roles'.

Sample characteristics also limited the generalisability of the results. Specifically, many studies employed small samples whereby a large proportion of participants lived independently or with family. Thus, they may have been a highly empowered and supported group to begin with, which differs from the general LD population. Many studies also failed to report the level of learning disability of participants, and there was a paucity of studies

involving individuals with moderate to severe learning disabilities. Interestingly, this is consistent with criticisms of supported employment as failing to meet the needs of workers with a severe disability (Lysaght, 2010), and the social model of disability as excluding of individuals with severe and profound LD (Chappell, 1992). This also reinforces the exclusion of PLD with moderate to severe disabilities from research (Nind, 2009), and opposes the values espoused in Valuing People (DH, 2000, 2009a).

Clinical implications

Evidence of positive individual and recipient outcomes resulting from PLD as trainers suggests that professionals should include PLD in the development and delivery of training, particularly given training providers are increasingly being encouraged to involve PLD in training (Levin, 2004). However, professionals need to ensure that PLD are offered appropriate support within this role and all other roles given the aforementioned challenges. Balancing the level of support with a degree of autonomy is also important given that supported employees with high levels of support evidenced lower QOL (Verdugo, de Urries, Jenaro, Caballo, & Crespo, 2006). The prospect of receiving support is also cited as a motivation for PLD to engage in employment-related roles (Andrews & Rose, 2010), and the provision of appropriate formal (e.g. service system) and informal (e.g. family, caregiver) support can enhance social inclusion (Hall, 2009). Equally, professionals should be mindful of making assumptions about the wider impact of valued social roles on the lives of PLD given that some roles did not

necessarily impact areas like social/community integration, or help overcome difficulties establishing social relationships.

Given PLD valued the time to talk about their experiences and be heard, privileging the experiences of PLD about services is vital, particularly as service-user voices provide different perspectives on services, and facilitate the development of appropriate provision (Bowes & Dar, 2000). Despite the increased emphasis on face-to-face contacts driven by Payment by Results in the NHS, it may also be beneficial for professionals to liaise with voluntary and employment agencies to support a holistic care plan for PLD.

The finding that valued roles positively impacted identity is relevant to psychologists working therapeutically with PLD around issues of adjustment to disability, low self-image, and confidence, for example. It also seems vital to understand the impact, or lack thereof, of vocational and other activities for PLD as part of the assessment and formulation process.

Lastly, the emergence of positive outcomes is consistent with the assertion that valued social roles afford individuals “the good things in life”. Thus, it seems vital that Normalisation/SRV continue to inform the development, delivery and evaluation of LD services in the UK. However, given the challenges associated with the aforementioned roles, services should be cautious about making generalisations about the impact of valued social roles for PLD.

Research implications

An obvious implication of this review is the need for further research exploring the impact of valued social roles for PLD generally (including challenges), and relative to the roles of trainer and researcher given the paucity of empirical research. Given PLD in these roles welcomed the opportunity to share their personal experiences, a qualitative method might be appropriate. Narrative methods are an accessible, non-threatening, ethical and empowering research method for PLD (Booth & Booth, 1996). They focus on the meanings participants attribute to specific phenomena through the way they story their experiences (Brown, Dodd & Vetere, 2010), and can “liberate the voices and stories of people who would ordinarily remain silent” (Owens, 2007, p. 299).

Additionally, although the roles of teacher/trainer, self-advocate, and student positively impacted identity, no study explicitly researched this. There was also a lack of theoretical frameworks to explain these results. Social identity theory (Tajfel & Turner, 1978) posits that our sense of self is created according to the social groups to which we belong, and that positive social identities are sought to maintain or enhance self-esteem. This may be a useful framework to explore the relationship between valued social roles and identity. Given narratives are key to how individuals conceive their identity (Ricoeur, 1984), narrative analysis may be a useful starting point.

The finding that some roles positively impacted the perspectives of others towards PLD (i.e. students, family) highlights another area of further

research focusing on the systemic impact of valued social roles. Similarly, the paucity of literature pertaining to individuals with moderate to severe learning disabilities underscores the need for further research with these populations. Given the drive towards increasing the employment opportunities of these groups (DH, 2009b), research may be a useful starting point. Therefore, the following questions could be addressed in further research:

- What do the narratives of PLD who are trainers reveal about the impact of the role on their lives and identities?
- How do valued social roles of PLD impact their significant others?
- What are the experiences of people with moderate to severe learning disabilities in employment?

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Emma Taylor

Section B: Empirical paper

A narrative analysis of the impact of being a trainer
on the lives and identities of people with learning
disabilities

For submission to the British Journal of Learning Disabilities

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Accessible summary

- Being a trainer affected the lives of people with learning disabilities in different ways
- Some participants said that being a trainer improved their lives
- Other participants said that life before being a trainer was positive
- Being a trainer made participants see themselves and others differently
- This research shows that being a trainer is a valuable role for people with learning disabilities

Summary

Social identity theory maintains that individuals define themselves according to their social groups, which in turn impacts self-esteem. Valued social roles are assumed to influence identity and self-concept. Being a trainer represents a valued social role for people with learning disabilities (PLD) and research suggests it impacts identity. However, there is a paucity of empirical literature explicitly exploring this relationship in learning disabled trainers. Using narrative analysis, this study explored how being a trainer impacted the lives and identities of nine PLD.

Being a trainer contributed to progression and stability in participants' lives and they positioned themselves as trainers in different positive roles (e.g. go-getter, helper). This study highlights the value of the trainer role for PLD, suggests a role for clinical psychologists in contributing to the sustainability of training organisations, and highlights a need for further research employing standardised measures, longitudinal and comparative designs.

Keywords: Intellectual disabilities, training, valued social roles, social identity theory

Introduction

Social identity theory (Tajfel & Turner, 1978) posits that individuals define themselves in terms of their social group membership, and that their sense of self is created according to the groups to which they belong. Individuals attempt to maintain a positive social identity to enhance their self-esteem. This is achieved through social categorisation and social comparison processes whereby individuals assess their group's value by comparing it to other groups, the outcome of which impacts self-esteem. A person who belongs to a group they perceive to be superior to other groups will feel better about themselves. If an individual feels devalued as part of their group they may leave it or create a positive social identity for it (Brown, 2000).

People with a learning disability (PLD)⁸ traditionally face marginalisation, exclusion, and poorer outcomes compared to physically disabled and non-disabled populations (Emerson, Baines, Allerton, & Welch, 2010). They are less likely to be married (Koller, Richardson, & Katz, 1988), to gain employment (Stephens, Collins, & Dodder, 2005), have smaller social support networks, and participate in fewer community activities than non-disabled individuals (Rosen & Burchard, 1990). Therefore, PLD represent a stigmatised social group who face significant challenges in everyday life.

⁸ This term is used in line with British definition of 'learning disability' (World Health Organisation, 2007). However, the author is aware that other terms, such as intellectual disability, are also used.

Normalisation/Social role valorisation

Normalisation (Nirje, 1980), later renamed Social Role Valorisation (SRV; Wolfensberger 1983), attempted to enhance the social image of PLD and address the stigma associated with the identity. It underscored “access to ordinary patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life or society” (Nirje, 1980, p. 33). It also emphasised the notion of valued social roles, which refer to “socially accepted patterns of behaviours, responsibilities, expectations and privileges” (Wolfensberger, 1992, p. 13). Normalisation/SRV proposed that supporting PLD to adopt valued roles (e.g. neighbour, employee etc) would enhance their perceived value in society, resulting in better treatment, greater social opportunities, enhanced self-esteem and quality of life (Abraham, Gregory, Wolf, & Pemberton, 2002). It was hoped that applying the principles of normalisation to services would result in high quality services fostering high quality lifestyles, with opportunities for PLD to form valued social identities. Therefore, valued social roles were assumed to afford PLD “the good things in life” by mitigating the stigma and prejudice they can experience (Wolfensberger, 2000).

The picture that emerged in the wake of normalisation was complex. In the UK, it was positively reflected in, amongst other things, the closure of long stay asylums, the movement from segregated to community-based living, and the development of community-based services for PLD. The latter were significantly impacted by O'Brien's (1989) five service accomplishments. Positive service user outcomes associated with deinstitutionalisation included

increased engagement (e.g. participation in leisure/domestic activities), community participation (e.g. use of facilities), and satisfaction with services and lifestyle compared to PLD in hospitals or specialist units (Emerson & Hatton, 1996). PLD as employees and students evidenced enhanced quality of life and self-esteem (Jahoda, Kemp, Ridell, & Banks, 2008; Paiewonsky, 2011).

However, critics argued that Normalisation/SRV “sought equality through similarity”, rather than “equality of difference” (Myers, Ager, Kerr, & Myles, 1998, p. 392), and negated an appreciation of the valued characteristics of PLD by focusing on conformity rather than acceptance (Bayley, 1991). Some PLD in community-based living did not evidence significant changes in their lives compared to hospital-based living (Emerson & Hatton, 1996). Furthermore, subsequent gains following initial positive outcomes were limited (Cambridge, Hayes, & Knapp, 1993), and the principles of normalisation were wrongly applied in areas such as supported employment, resulting in a lack of reasonable adjustments for PLD (Wilson, 2003). Therefore, valued social roles do not necessarily have a uniformly positive impact on the lives of all PLD.

Identity in PLD

Normalisation was based on an assumption that being labelled ‘learning disabled’ negatively impacts identity and self-esteem. In support, Szivos-Bach (1993) found that PLD who had the greatest experiences of stigma evidenced the lowest self-esteem. Jahoda, Markova, and Cattermole

(1988) found that PLD were aware of the stigma associated with the LD label and coped by describing themselves as similar to people without learning disabilities, or by comparing themselves to people with a more severe learning disability. Craig, Craig, Withers, Hatton, and Limb (2002) found that PLD portrayed themselves as not disabled, or as 'better off' than other disabled individuals. Booth and Simons (1989) noted that participants spoke in the third person when asked about the meaning of 'learning disability', Davies and Jenkins (1997) found that participants used criteria that excluded themselves, and Finlay and Lyons (2005) found that some participants alluded to individuals with physical disabilities and visible impairments due to uncertainty about the meaning of the label.

However, lower self-esteem was not found in individuals who admitted the label compared to those who rejected it (Finlay & Lyons, 1998). Moreover, some PLD who integrated the label into their self-concept demonstrated positive self-esteem and social acceptance (Glenn & Cunningham, 2001), and said their learning disability enriched their lives and highlighted their strengths (Olney & Brockelman, 2003). Fine and Asch (1988) argue that it is erroneous to assume that the LD identity is core to self-concept because PLD have multiple social identities. Therefore, the relationship between stigma, identity and self-esteem in PLD is complex. PLD negotiate their learning disabled identity in different ways and it is not necessarily salient/internalised, or detrimental to self-esteem.

Involvement in training about learning disabilities

In this context, a particularly interesting group is PLD who have adopted the role of training others about their experiences and needs. Due to impairments in intellectual and adaptive/social functioning (World Health Organisation, 2007), many PLD require support from professionals and non-professionals (e.g. carers) to negotiate everyday life. In turn, these people require training in order to offer effective support. In line with the idea that PLD are experts in their own experience, training providers are increasingly encouraged to involve them in training (Levin, 2004).

Being involved in training has been found to impact identity and self-concept in other disadvantaged groups, such as people with mental health difficulties. Findings include increased belonging (Solomon, 2004), competence, social usefulness (Riessman, 1965), validation and empowerment (Walters, Buszewicz, Russell, & Humphrey, 2003). Some participants in this study found their experience anxiety provoking and distressing, highlighting that being a trainer can also be challenging, and has potentially detrimental effects.

A limited number of studies have explored PLD who take on the ostensibly 'valued social role' of trainer. Being a trainer has been found to support PLD to feel positive about "telling people what matters", be listened to, and become more confident (Black & Roberts, 2009; Weeks, Shane, MacDonald, Hart, & Smith, 2006). It has also been linked to increased connectedness, pride, accomplishment, responsibility, self-esteem, and a

positive identity (Borisov & Reid, 2010). However, two of the aforementioned studies were reflective accounts (Black & Roberts, 2009; Weeks, Shane, McDonald, Hart, & Smith, 2006), and all three employed small sample sizes. Furthermore, no studies to date⁹ have specifically explored the identities of trainers with a learning disability. Given the complex aforementioned findings about how PLD negotiate their 'learning disabled' identity, mixed findings about the impact of being a trainer on the identities of other groups, and the increased emphasis on involving PLD as trainers, it seemed vital to further investigate the experiences and identities of trainers with learning disabilities.

Narrative analysis

In Black and Roberts' (2009) study learning disability trainers particularly valued the opportunity to share their personal experiences, thus highlighting the value of a qualitative methodology. Narrative analysis (NA) explores the meaning people attribute to specific phenomena through the way they talk about their experiences. It is concerned with how individuals represent themselves and their worlds to themselves and others (Lawler, 2002), and is appropriate for exploring identity given that narratives are central to how we conceive identity (Ricoeur, 1984). As an accessible, non-threatening and ethical method of research for PLD (Booth & Booth, 1996) that can "liberate the voices and stories of people who would ordinarily remain silent" (Owens, 2007, p. 299), NA is consistent with Valuing People (DH, 2000, 2009).

⁹ As of 5th April 2013

Research questions

This study addressed the following research questions:

1. What do participants' narratives reveal about the impact of being a trainer on their lives and identities?

a. How do people with a learning disability who are trainers tell their story about being a trainer in the context of their lives?

b. How do participants position themselves within their narratives and what does this reveal about the way they see themselves and others?

Addressing these questions was seen as potentially contributing to an understanding of the social groupings of PLD, the implications of the social identity as a trainer on self-concept, and an understanding of the importance of valued roles for PLD, in line with Normalisation/SRV (Wolfensberger, 1983). This research aimed also to highlight the value of listening to (the stories of) PLD, in line with Valuing People (DH, 2001, 2009), and to underscore the importance of research with PLD.

Method

Epistemological position

NA falls within a social constructionist approach whereby meaning is constructed through language. Narratives construct versions of reality rather than objective truths, and are shaped by social context (Smith, 2007). The term 'narrative' will be used interchangeably with 'story' to reflect participants' construction and meaning of their lives, and the events within it. Given narration is useful during times of change (Murray, 2003), this seemed relevant to becoming a trainer.

Participants

Nine adults aged 18+ were recruited from three training services for PLD. A trainer was defined as someone who talks to/educates others about having a learning disability. The inclusion criterion was self-identified trainers with a learning disability (participants required this diagnosis to join the training organisations). Three participants were female and six were male. Seven were White British and two were Black British. The age range was 27-55 years. Three participants lived independently and five lived with family. Although there is limited guidance on sampling numbers for NA, a recent study by Brown, Dodd, and Vetere (2010) employed six participants.

Recruitment. A project supervisor in contact with the participating organisations gained consent for the lead researcher to distribute information sheets (Appendix 4) and consent forms (Appendix 5) to managers, who

distributed them to trainers. Following significant interest from one organisation, the researcher conducted a presentation before gaining informed consent from five participants. As three individuals within the second organisation had already read the information sheets and consented to participate via their manager, a presentation was not conducted. The ninth participant was linked with the university and volunteered to participate.

Procedure

Open-ended interviews were conducted at participants' workplace. An aide-memoire (Appendix 6) and McAdams' (1995) life story interview guided topic areas relevant to the research questions. Interviews lasted between thirty-six and sixty-five minutes.

Ethical considerations

Full ethical approval was granted by Salomons (Canterbury Christ Church University) Research and Ethics board (Appendix 7) given the participating organisations were non-NHS affiliated. Ethical considerations included informed consent, risk, confidentiality and data protection.

Informed Consent. The researcher followed Nind's (2008) suggestions for obtaining informed consent in qualitative research with PLD by ensuring all information was accessible, participants were aware of their right to withdraw (up to July 2013), and could ask questions prior to interview via email or answer-phone. Participants were also encouraged to inform carers/parents/significant others of their participation. The researcher was

alert for positive (e.g. eye contact, relaxed body language, relevant elaboration) and negative indicators of consent (e.g. low engagement, ambivalence) and acquiescence (Nind, 2008). Participants were offered the option of consenting in the company of a trusted individual (Cameron & Murphy, 2007), and the researcher planned to contact them to confirm/disconfirm participants' willingness to participate if concerns about their capacity to consent arose.

Risk. The interviewer attempted to build a rapport with participants prior to interview (i.e. joining in with lunch/breaks), invited participants to talk about themselves before commencing formal interviewing, and adopted an informal interviewing style to reduce potential distress (Booth & Booth, 1996). The researcher was prepared to stop interviews any time, provide advice and contact details for relevant agencies (e.g. visit GP, helpline numbers), and encouraged participants to nominate a carer/friend/professional to inform should concerns arise. The potential for distress was explained in the information sheet and prior to gaining consent.

Confidentiality and data protection. Identifiable information was removed from transcripts, and digital recordings of interviews, transcripts, and analyses were stored electronically on a password-protected computer, in accordance with Data Protection Act (1998). No paper copies of data were kept. Pseudonyms were used to ensure anonymity.

Data analysis

In contrast to other qualitative approaches, NA focuses on content (i.e. what is said), structure (i.e. how it is said), and performance (i.e. positioning of self and others). This study employed an integrative NA framework drawing on Murray's (2003), and Gergen and Gergen's (1983) structural approaches, and Bamberg's (1997) performance approach. There is no set of procedures for NA analysis (Riessman, 1993). The process for each method is outlined below.

This researcher listened to the recordings and read the transcripts multiple times before preparing a summary of participants' beginning (i.e. childhood, early adulthood), middle (i.e. current life) and end (future) narratives, in line with Murray's (2003) interpretation of narratives as a sequence of events that bring 'order to disorder' (Appendix 8). This approach increased familiarity with the narratives before formal analysis commenced.

Gergen and Gergen (1983) propose three basic structures of narratives that illustrate temporality over time. Progressive narratives illustrate advancement and success, regressive narratives pertain to deterioration/decline, and stable narratives illustrate life as unchanged (see Appendix 9 for illustration). Stable narratives can be either positive or negative. These structures were mapped onto participants' narrative summaries to explore how they told their story of being a trainer (as per Appendix 8).

Transcripts were then analysed using Bamberg's (1997) positioning approach whereby narratives serve as a platform for preferred identities (Langellier, 2004). The researcher was guided by the following questions:

- How does the narrator position characters in relation to one another and themselves?
- How does the narrator position themselves to themselves and the audience (i.e. who are they)?

For example, narrators may position themselves as victims and others as perpetrators. Positions can change throughout the narrative and are indicative of identity (Gubrium & Holstein, 2002). This approach was considered relevant to exploring how participants viewed themselves and others, and was conducted in two stages. Firstly, all transcripts were read with the above questions in mind and roles related to specific content and the overall narrative were identified (Appendix 10). A master list of roles across participants was then created and condensed into a final framework (see Appendix 11 for positioning analysis stages). The second stage involved reviewing participants' narrative summaries and mapping their roles onto each narrative section (Appendix 12).

Quality assurance

In line with Elliot, Fischer and Rennie's (1999) criteria for quality in qualitative research, the researcher owned her perspective by keeping a research diary (Appendix 13), and conducted a bracketing interview to reflect

on her motivations, assumptions and beliefs relevant to the project. To ensure credibility, coherence and the resonance of the results with the reader, direct quotations are used to illustrate the results, and research supervisors were involved in analysis, and/or facilitated discussions about preliminary analyses. In line with Riessman (1993), participant feedback was not obtained. However, the researcher worked hard to ensure the credibility of the results.

Results

The results are presented as: participants' narrative summaries with reference to their structure (1), the positions/roles adopted across participants' narratives and their relationship to each narrative section (2), and a synthesis section discussing the findings in relation to research questions a and b (3).

Narrative summaries and structure

Sarah (1). A story of fighting. Sarah's beginning narrative conveyed negative stability related to being restricted by her parents, followed by progression by fighting to live independently, "*my parents kept putting me off, 'you can't do this, you've got a disability', and I said 'I'll fight this right the way through'*". The middle and end of Sarah's narrative conveyed stability as she detailed her current life and experience of being a trainer without regression or progression, and outlined her desire to gain more experience of training.

John (2). A story of ongoing struggles. John's beginning narrative conveyed negative stability marked by bullying and segregation at school,

followed by progression upon securing his first job. Being made redundant marked a period of regression, before becoming a trainer marked further progression in his middle narrative, *“coming as a trainer, it’s turned my life round a hell of a lot. I’ve got no more worries”*. John’s end narrative conveyed stability given his desire to continue training, and the potential for regression given his anxiety about future care when his parents die.

Oliver (3). A story of helping others. Oliver’s beginning narrative outlined enjoyable experiences at school, work, and college, indicative of positive stability, *“before I became a trainer I just sort of worked normally”*. His middle narrative also described positive stability given his enjoyment of helping others and training in different subjects, *“I try and be helpful and kind and considerate to whatever they need help with”*. Oliver’s end narrative conveyed further stability given his desire to continue training if needed, or to work for his parents. Regardless of his role, Oliver was adamant about continuing to see friends.

Mary (4). A story of personal development. Mary’s beginning narrative conveyed negative stability related to physical abuse, segregation at school, and mental health difficulties. However, her middle narrative conveyed progression linked to positive changes in self-perception by becoming a trainer, *“I used to be really really shy and closed...I’m really more confident now to the extent where when I first came here I wouldn’t speak to anybody”*. Her end narrative also conveyed progression given her desire to be a full-time trainer.

Charlie (5). A story of expertise and experience. Charlie's beginning narrative focused on discrimination, bullying, and physical health difficulties, indicative of negative stability. However, his middle narrative conveyed progression marked by overcoming anger, and gaining expertise in training professionals, *"I'm going to go for an interview at a hospital to actually become a member of staff there to help to teach the medical staff to how to talk to people with physical and learning disabilities"*. Charlie's end narrative also conveyed progression given he wanted to "sink my teeth into" the role.

Justin (6). A story of self-worth. Justin's beginning narrative conveyed negative stability marked by isolation, speech difficulties and feeling unfulfilled. His middle narrative conveyed progression given positive changes in his life and self-perception linked to his trainer role, *"I used to sit at home with nothing to do but now I get to do what I want to do....it just makes me realise that I'm a grown intelligent hard-working positive guy"*. Justin's end narrative portrayed stability given his desire to continue training.

Tom (7). A story of wisdom. Tom's beginning narrative conveyed negative stability related to health problems, ignorance about his disability, and progression related to attending activity groups, college and gaining employment. His middle narrative marked further progression linked to increased insight into life, *"if I allow people to stop me from doing some things then I'm going to allow them to win"*. Tom's end narrative suggested further progression given his desire to continue training or other related activities (e.g. work experience, employment).

Erica (8). A story of support. Erica's beginning narrative conveyed positive stability in terms of enjoying school, home life and being with friends. Her middle narrative conveyed regression associated with bereavement, followed by progression resulting from support from fellow trainers, friends and family, and her trainer role, "*the trainer makes you feel confident to know everything....training is really good, really good be a trainer*". Erica's end narrative indicated stability given her desire to gain more 'practice' as a trainer.

Peter (9). A story of coping. Peter's beginning narrative conveyed regression following a head injury, negative stability linked to bullying and physical health difficulties, and progression related to enjoyment at school. His middle narrative conveyed progression related to positive changes in self-perception as a trainer, "*I'm a happy go jolly person now whereas before I used to be stuck in my ways*". His end narrative alluded to further progression given his desire to undertake greater responsibility as a trainer.

Positioning analysis

Table 1 illustrates the roles participants adopted within their narratives and their occurrence within participants' beginning, middle and end narratives. Each role is described and illustrated below using narrative content.

Empowered/strength-based roles.

Fighter. Seven participants positioned themselves as demonstrating strength, agency and resilience in relation to moving out, bullying, speech and

physical difficulties, bereavement, and abuse. This occurred in participants' beginning and middle narratives suggesting the role related to personal and trainer-related experiences:

"I said 'no, I'm moving out' and my dad was horrified. He said 'you can't do that' and I said 'you watch me' and I did and he didn't like it. I stood my ground" (Sarah).

"I had the need to talk about the abuse and stuff years ago but found it very hard to talk about but when I become a trainer I didn't realise how easy it would be talking about them so now I talk about them the easier it gets" (Mary).

Go-getter. Eight participants positioned themselves as seeking out opportunities/challenges in life (e.g. work experience, training, college) and directing life according to their own agenda. This occurred within some participants' beginning narratives but occurred most often within their middle and end narratives in relation to their trainer role and future ambitions:

"I wanted a new experience and also I was offered the work. It gets me out and about, it gives me something to do because really I don't like being cooped up at home all the time" (Charlie).

"I wanted a full-time job doing what I wanted to do, not what my parents wanted me to do in my life" (John).

“It’s [training] made me feel that I can do something to the extent that I’d love to do it as a full-time job” (Mary).

Able. Eight participants positioned themselves as capable, in relation to a capacity to learn and their disability. This occurred within some participants’ beginning narratives, and their middle narratives, indicative of an association with historical experiences and the trainer role:

“It [training] makes me feel I can actually do something” (Mary).

“I can take over there, what do you need me to do and they just say, stick the person over there and talk to the medical student doctors and teach them how to talk to people with physical and learning disabilities. I could do it just like that” (Charlie).

Independent. Five participants positioned themselves as self-sufficient. This occurred across the narrative sections and was not associated with the trainer role:

“I’m the kind of person who would say why are you helping me when I haven’t asked you to help me because I don’t like people trying to help me when I don’t need it” (Charlie).

“I can go shopping on my own now, I can go travelling on my own” (Peter).

Table 1: Participant roles by narrative section

	Past (beginning narrative)									Present (middle narrative)									Future (end narrative) ¹⁰								
	1	2	3	4	5	6	7	8	9	1	2	3	4	5	6	7	8	9	1	2	3	4	5	6	7	8	9
Fighter	◆	◆				◆	◆		◆				◆*				◆										
Go-getter	◆	◆	◆							◆*	◆*		◆*	◆*	◆*	◆*		◆*	◆*	◆*		◆	◆*	◆*	◆*		◆*
Able	◆		◆			◆			◆	◆*	◆*	◆*	◆*	◆*	◆*	◆*		◆*									
Independent	◆		◆							◆				◆		◆		◆			◆						
New me											◆*	◆*	◆*	◆*	◆*		◆*	◆*									
Ambivalent										◆	◆	◆	◆	◆*			◆										
Defensive					◆						◆*		◆*				◆	◆*									
Educator/ expert										◆*	◆*	◆*		◆*	◆*		◆*										
Wise												◆*		◆*	◆	◆		◆									
Valued individual			◆							◆*		◆*	◆*	◆*			◆*										
Moralistic										◆*	◆*	◆*		◆*		◆											
Belonging						◆	◆		◆	◆*				◆*				◆*									
Advocate										◆*	◆*	◆*	◆*	◆*				◆*									
Supporter/helper									◆			◆*	◆*	◆*		◆*	◆*	◆*									
Enabled	◆	◆	◆		◆	◆	◆						◆*	◆*	◆	◆	◆	◆									
Dependent	◆	◆				◆	◆	◆	◆		◆*			◆			◆										
Victim	◆	◆	◆	◆	◆	◆	◆		◆	◆																	
Rejected	◆	◆		◆			◆		◆		◆*																
Disabled	◆	◆		◆	◆	◆	◆		◆	◆*			◆*	◆*													

¹⁰ Participants were explicitly asked about their future as a trainer but this was not the primary focus of interviews
 *Roles linked to being a trainer

New me. Seven participants described changes in self-perception (e.g. confidence, assertiveness) strongly linked to being a trainer, as indicated by its occurrence in participants' middle narratives only:

"I just feel so much different to the way I used to be...it makes me realise that I've got everything that I want so I couldn't be more happier". (Justin)

"It makes me how to speak up more, how to have a conversation to people" (Erica).

Ambivalent roles.

Ambivalent about self as (learning) disabled. Six participants positioned themselves as having mixed feelings about their learning disability, which occurred in participants' middle narratives, independent of their trainer role. Participants acknowledged this identity in part, or described ambivalence about revealing it in certain settings:

"I said to myself I haven't got a disability, I can't read and write but I haven't got a problem with health and stuff" (John).

"I don't think if I was in town or something I would be open with it [learning disability] but in the training session I feel comfortable. I know I'm not going to be stigmatised" (Mary).

Defensive. Five participants positioned themselves as defensive about their learning disability, most often within their middle narratives, but not as a trainer. This manifested as denial about its impact, judgements about more disabled individuals, or a desire to hide it:

“I’ve gone on from a having a LD and I don’t think about that anymore. I never thought about that at all so I don’t think about that really” (John).

“I suppose in one way the power hides a lot of the learning difficulty sides of it” (Mary)

“You want to be around people that are like you, that are on the ball, on the go and they know what they’re doing but they might just have a mild learning disability” (Peter).

Knowledge-based roles

Educator/expert. Six participants positioned themselves as imparting knowledge to others, and positioned others as requiring education. This position occurred within participants’ middle narratives, suggesting a link with the trainer role:

“I’ve been asked to work at the hospital to help teach and train medical staff how to talk to people with physical and learning disabilities, not only the nurses, doctors, medical students, the paramedics as well” (Charlie).

John positioned himself in this role in relation to the researcher:

John: *Have you heard about the White Paper?*

Researcher: *I know a bit but tell me your experience of it*

John: *Well the white paper is, it comes from PLD....*

Wise. Five participants positioned themselves as sensible, knowledgeable about life, and with good judgement. This role was strongly linked to participants' middle narratives but not always to the trainer role:

"Keep yourself to yourself you know. Don't hang around with people that are not good for you. Just keep yourself really focused and strong".

(Tom).

"You may as well go out somewhere, somewhere new, learn about it and see where you can go from here. That's the difference between coming from here (points to ground) here to here (points to ceiling)"

(Justin).

Acceptance-based roles.

Valued individual. Five participants positioned themselves as feeling worthy and admired by others. This role occurred in relation to self-other interactions with fellow trainers, staff, professionals and the public. It was strongly related to being a trainer given its occurrence within participants' middle narratives:

“They applaud us for all the things that all of the trainers have done....you know it’s worth doing when you get those sort of comments” (Oliver).

“Everybody was interested in me where before I had never thought anyone would be interested in me, not me as a person but my lifestyle and like I say, it just made me feel so important” (Mary)

Moralistic. Five participants positioned themselves as holding strong opinions about how people with physical/learning disabilities should be treated, and positioned others as ignorant. This role solely occurred within participants’ middle narratives in relation to being a trainer:

“The white paper is, it comes from PLD because they, half the people never read it or they can’t be bothered or they chuck it away in the bin and I think it’s totally wrong. I mean people with learning difficulties should be treated like anybody else in the community” (John).

“People are looking down on us all the time thinking ‘oh she got a disability, we won’t talk to her’ and that was wrong because it’s not all right. This is what we do all the time and it’s hard and we just put a stop to it” (Sarah).

Belonging to something/group. Five participants positioned themselves as having a place in a group and feeling part of something. This

occurred within participants' beginning, and middle narratives in relation to training:

"I know that it [training] makes me feel like I'm part of something"
(Justin).

"Joining the [training company] is the best thing of all because I kind of feel like I'm, not home, but, what I mean by home, everyone is in the same boat, no one's different, no one's better than anybody else"
(Peter)

Support roles. These roles involved both supporting others and being the recipient of support.

Advocate. Six participants positioned themselves as standing up for the rights and fair treatment of other PLD, and held strong beliefs about PLD being heard, particularly those less able. This role occurred within participants' middle narratives and was related to being a trainer:

"You have to get people to stand up and be counted and to speak up and speak up for yourself but also for, stand up for other people as well" (Oliver).

"I always try and raise awareness of people who have a LD, not only a LD, a physical learning disability as well" (Charlie).

Supporter/helper. Six participants positioned themselves as someone to turn to, as helpful towards others, and positioned others as needing support/rescuing. This role was linked to the trainer role within participants' middle narratives:

"To be a trainer is really interesting for me to help people". (Erica)

"I don't like seeing anyone hurt so I try and help people as much as I know how to. If there's anything that they want to talk to me about quietly, I try, if I can, make time for them to do that" (Oliver).

Enabled. This role related to participants' positioning of staff, family and professionals as supportive and encouraging. All nine participants adopted this role at some point within their narratives but it was not strongly related to being a trainer:

"One of my teachers, actually that was quite nice, she support me and said don't worry about it, you know you can do it just get yourself focused that kind of thing" (Tom)

"When I go to hospital appointments and doctors or nurses or whoever is seeing me start using medical jargon or medical language what I don't understand [mother] will say to them we don't understand" (Charlie)

Dependent. Seven participants positioned themselves as reliant on services (social services, counselling), and family to manage everyday life. For most, this role was strongly linked to participants' personal lives rather than their trainer role, and occurred most often within participants' beginning narratives. However, some were reliant on their trainer role to maintain wellbeing (i.e. John):

"If I wasn't working for [company]...I'll lose it again because I couldn't, I couldn't do anything else" (John)

"If mum and dad wasn't around today I couldn't cope" (John).

"My mum is also my full-time carer....she always makes sure I'm alright, I'm going out safely" (Charlie).

Disempowered roles.

Victim. Eight participants positioned themselves as recipients of bullying, abuse and discrimination within their beginning narratives. Sarah also adopted this role within her middle narrative, independent of being a trainer. This role conveyed isolation, fear and paralysis, and positioned others as unkind, hurtful, and deceitful:

"This guy bullied me and chucked all my stuff all over the place....I was scared to tell anybody....I didn't know who to tell" (John).

"I tend to have been getting a bit of beating at home....I had no one to turn to" (Mary)

"When I wasn't in my room, some of the staff would go in my room and go through my stuff and take things" (Peter).

"I went into a place one day... she said 'oh come on, I'm not waiting all day for you'...I said you haven't got a disability have you, I'm not rushing for my signature" (Sarah)

Rejected. Five participants talked about being segregated and cast aside by others (i.e. children, professionals, public) predominantly within their beginning narratives:

"Some of them [teachers] were nasty....if you had learning problems you were put to the back of the room so they didn't want to know" (Mary)

However, John alluded to feeling rejected as a trainer:

"We trained one doctor, 'Do you read the white paper?', "Yes, it's a waste of space, we don't see anybody with learning disabilities" (John)

Disabled. Seven participants positioned themselves as disabled by their physical/learning disability, and metaphorically by others who were

restrictive, controlling or discouraging. This predominantly occurred within participants beginning narratives, but also within some participants' middle narratives, independent of being a trainer:

"Everyone kept telling me...no you can't do that because your epilepsy"

(Peter)

Two participants positioned themselves as disabled within their middle narratives as a trainer:

"We didn't realise there were steps were so high and I've got a disability so trying to get up on that was a nightmare...to get up on the stage to accept the award" (Sarah).

"Sometimes they're talking over my head a lot and I'm sitting there thinking well I don't understand a word you are talking about" (Mary)

Synthesis

How do people with a learning disability who are trainers tell their story about being a trainer in the context of their lives?

In line with Gergen and Gergen (1983), participants' stories about being a trainer reflected stability, progression and regression.

Stability. Positive stability was evident in some participant's beginning narratives in that life followed an unwavering positive path that was fulfilling and enjoyable:

"When I was young and went to school in [location]....I saw my friends and I had teachers too....I went to the gym. I went everything (Erica)

Conversely, consistent with negative stability, many participants' beginning narratives portrayed life as following an unwavering negative path due to bullying, health problems, and discrimination, linked to hopelessness, isolation and frustration:

"I used to be down, I used to be lonely, I used to be that kind of person, thinking I'm not going to get anywhere in life" (Justin).

"There were people not very nice and other students that were not understanding me being a disability...I used to get very angry" (Tom)

Stability was evident in some participants' middle narratives in that they spoke about their lives and about being a trainer in a matter-of-fact way:

"I moved down here...from there I went into the community and I finally got my own flat about 12, 14 years ago" (Sarah)

Stability was also linked to participant's end narratives in terms of a desire to continue training in its current guise, or a sense that life would continue in the same vein even without the trainer role:

"I'd go on with seeing some of the friends that I normally see on Sundays when I go to church" (Oliver)

Progression. Some participants spoke about progression within their beginning narratives in relation to school, moving out, and securing employment:

"We could go out and play football and do all sorts of things there so that kind of kept me on my feet" (Peter)

Participants' middle narratives also conveyed progression, which for most was strongly related to being a trainer:

"My life's changed. I've done a hell of a lot here and my career's going on but where I am now is better" (John)

"After college there wasn't a lot out there for me until I met Phil...he was the man who introduced me to here" (Peter).

Progression was strongly linked to personal development and wellbeing resulting from the trainer role:

“I found that from the beginning with [training organisation] it’s built my [confidence] up” (John)

“If I weren’t a trainer I think I’d still have it [abuse] bottled up inside” (Mary)

Progression was also evident in participants’ end narratives in terms of an ambition to expand their role, or try something new:

“I’d love it as a full-time job you know...I only volunteer but I wouldn’t mind doing it even as a volunteer everyday” (Mary)

“I just see myself in the next couple of years of either continue doing a trainer or maybe trying something out new” (Justin).

Regression. Some participants’ beginning narratives conveyed experiences of regression related to physical health problems and losing one’s job:

“At one stage I wanted to kill myself because when my fits were bad, I used to have really bad ones and I wasn’t allowed to go out and I kind of felt I was going to be stuck indoors for the rest of my life” (Peter).

However, apart from Erica's bereavement, participants' narrated little by way of regression within their middle narratives. Similarly, with the exception of John's anxieties about future care, regression was not present within participants' end narratives.

How do participants position themselves within their narratives and what does this reveal about the way they see themselves and others?

Participants adopted multiple roles suggesting they viewed themselves in different ways. Many roles were positively associated with being a trainer (e.g. go-getter, new me, educator/expert). However, some positive roles were independent of the trainer role. For example, the fighter role emerged in relation to early experiences, whilst the able and independent roles related to finding work, living independently and attending college prior to becoming a trainer.

Implicit in some roles were ways participants viewed others. The supporter/helper and advocate roles often positioned other PLD as more disabled than themselves and in need of support. The supported and acceptance-based roles positioned family, professionals and staff as enabling and encouraging, whilst the disempowered roles positioned the general public, professionals, and staff as unkind, discriminatory and unjust towards themselves and PLD in general. Given the disempowered roles were almost exclusively linked to life before being a trainer, this suggests a significant change in participants' sense of self and their perception of others. Becoming

a trainer may have enhanced participants' sense of their own resilience, and in turn, diminished the saliency of previously disempowering experiences. The emergence of the ambivalent roles also suggested that the learning disability identity was not necessarily internalised and that participants privileged preferred identities linked to their trainer role.

Discussion

Summary of results

Participants adopted empowered, ambivalent, knowledge and acceptance-based, supporter/supported and disempowered roles within their narratives. The progression and positive roles within participants' middle narratives conveyed improvement, development and success related to the trainer role. For some participants, being a trainer contributed to stability, and there was evidence of positive roles prior to becoming a trainer. Progression was also linked to experiences within the broader context of participants' lives (i.e. moving out, employment) that were unrelated to being a trainer.

The limited regression within participants' middle and end narratives suggested that being a trainer contributed to a positive perspective on their current lives and future. Many roles elucidated participants' views of others and their responses to negative experiences of being positioned as disabled, which also varied as a function of their trainer role. Therefore, in terms of the overarching research question, being a trainer contributed to positive changes

in most participants' lives, and promoted a positive self-identity and perception of others.

Theoretical and research implications

The fact that participants positioned themselves as trainers in positive roles suggests this identity positively impacted their self-esteem, in line with social identity theory (Tajfel & Turner, 1978). Additionally, within the defensive role participants made downward social comparisons with PLD with more severe disabilities, and described themselves as 'better off' than other disabled individuals (Craig, Craig, Withers, Hatton, & Limb, 2002). This may have reflected an attempt to cope with the stigma attached to the learning disabled identity (Jahoda, Markova, & Cattermole, 1988). However, the extent to which participants integrated the LD label into their self-concepts was unclear given the emergence of ambivalent roles.

Like PLD in other valued social roles closely aligned with the LD identity (e.g. self-advocacy), trainers did not necessarily identify with the LD label (Simons, 1992; Beart, Hardy, & Buchan, 2004). The occurrence of disempowered roles within participants' beginning narratives, compared to the emergence of empowered roles within their middle narratives also suggested that becoming a trainer diminished their stigmatised identity (i.e. learning disabled) or created a positive social identity for it (Brown, 2000; Rapley, Kiernan, & Antaki, 1998). Participants may also have been using denial as defence against the damaging effects of the LD identity (Stokes & Sinason, 1992).

The emergence of a positive identity as a trainer is consistent with previous literature (i.e. Black & Roberts, 2009; Borisov & Reid, 2010), Normalisation/SRV, and outcomes for PLD in other valued social roles. For example, PLD as students evidenced increased independence, confidence and communication skills (O'Brien et al., 2009), consistent with the new role. The emergence of empowered and acceptance-based roles supports evidence of increased empowerment and social belonging for PLD in open employment (Kober & Eggleton, 2005). The advocate role is consistent with the finding that PLD as researchers (i.e. co-facilitating focus groups, data entry) felt more confident in supporting others to speak up (Conder, Milner, & Mirfin-Veitch, 2011).

However, being a trainer was not solely associated with positive outcomes. Participants spoke about practical challenges (e.g. managing steps) and narrated challenging past experiences resulting in the emergence of disempowered roles. In line with Beart, Hardy, & Buchan (2004) who found that being a self-advocate led to a reflection on past painful experiences (e.g. bullying), being a trainer may present a similar challenge. Furthermore, some participants positioned themselves as rejected and disabled by others as a trainer, highlighting an additional challenge of being an expert in something that is de-valued. Therefore, being a trainer does not necessarily result in a unitarily positive identity, and there are different challenges associated with it that Normalisation/SRV do not address.

Like self-advocates, trainers did not necessarily identify with the LD label (Simons, 1992; Beart, Hardy, & Buchan, 2004). Instead they had multiple social identities beyond being learning disabled (Fine & Asch, 1988) or being a trainer that were often reciprocal and contingent on social context. For example, some participants positioned themselves as empowered as trainers and dependent in other areas of life, and were reluctant to reveal their learning disability outside of their trainer role. This is consistent with social constructionist ideas of learning disability whereby “people have multiple social identities that emerge within their socio-cultural contexts” (Dudley-Marling, 2004, p. 483), and the notion that the “boundaries between identity and context are not clear-cut and static but ambiguous and dynamic” (Cole, 1996). Therefore, this study extends previous literature by highlighting the role of context in the relationship between social identity and valued social roles.

Additionally, this study illustrates how altering traditional power relations can positively affect the psychosocial well-being of PLD, in line with Albee’s (1986) assertion that the increased incidence of emotional disorders in minority groups results from powerlessness arising from exploitation. In support of his incidence formula, whereby distress can be ameliorated/managed by decreasing organic factors, stress, and exploitation, and increasing coping skills, self-esteem and social support (Albee, 1986), the emergence of empowered/strength-based roles suggests that being a trainer decreased participants’ perception of powerlessness. The trainer role also contributed to positive changes in self-perception (e.g. increased confidence, decreased anger), belonging and support that may have reflected increased

self-esteem, social support, and coping skills. Therefore, in line with Albee's formula, being a trainer may have enhanced participants' psychosocial well-being.

Lastly, the emergence of the moralistic role has not been found in previous literature on the impact of training or valued social roles generally. Constructing stories can facilitate resolution, decrease rumination and alter the intensity of distressing experiences (Pennebaker, 2000). Therefore, the trainer role may facilitate the expression of strong feelings (e.g. anger, outrage) in a way that is therapeutic and redemptive. In support, people with mental health difficulties involved in teaching reported therapeutic benefits as a result of telling their story (Walters, Buszewicz, Russell, & Humphrey, 2003).

Practical and clinical implications

The positive impact of being a trainer highlights the potential usefulness of partnership working between statutory services and training organisations to support and encourage this role (e.g. increased involvement of PLD in staff training). Given financial constraints resulting from the current economic climate may threaten the future of such organisations, clinical psychologists may be well placed to contribute to their sustainability using their skills in service evaluation, audit and research (e.g. has involvement in training impacted participants' engagement with other services)? Their therapeutic, consultation, supervision skills, and training in group dynamics and systemic approaches may also be useful in supporting trainers and staff generally, and in helping trainers and staff to acknowledge, talk about and

work with the challenges associated with the role. Given positive outcomes have been found for recipients of user-led training (Biswas, Raju, & Gravestock, 2009), it also seems vital that clinical doctorate courses involve trainers in teaching.

The ambivalent roles suggest that professionals should not assume the LD label is salient to all PLD, or that PLD have the same understanding of the label. This may translate into strong feelings about attending services aligned with the LD identity, or a lack of understanding about why they are being seen within LD services. Therefore, it seems important for professionals to talk to PLD about what the label means to them, particularly during initial assessments.

Strengths and limitations

Employing a narrative approach invited participants to tell stories of their lives, in line with the emphasis on listening to the voices and experiences of PLD (DH, 2001). The structural and performance approach facilitated a rich insight into participants' identities and their temporality in relation to becoming a trainer, and wider life experiences. Given trainers are a niche group, it was positive that the sample comprised participants from multiple organisations, mixed ethnic backgrounds and gender. The results were consistent with previous literature, contributed to the paucity of empirical research, and highlighted the influence of social context and power on social identity in PLD.

In line with Booth and Booth's (1996) assertion that excluding 'inarticulate' participants feeds into the deficit model of learning disability, participants' level of learning disability was not an inclusion/exclusion criteria. However, the responsibilities associated with being a trainer, and reliance on verbal communication in interviews may have weighted the sample towards individuals with mild to moderate learning disability. Whilst this limits generalisability, this is not a goal in NA (Riessman, 1993). Interviews with PLD can also result in acquiescence or social desirability bias, and one cannot assume causality, or ascertain the extent to which the trainer role positively impacted participants' lives based on this study's design.

Future research and conclusions

Becoming a trainer positively contributed to changes in participants' lives and sense of self. Longitudinal studies may be useful in elucidating these outcomes over time, whilst comparative studies may isolate the effect of the trainer role. The use of LD-specific quality of life measures or generic self-esteem measures (e.g. Comprehensive Quality of Life Scale-Intellectual disability, Rosenberg self-esteem scale) may help identify specific outcomes. Informant data could extend an understanding of the wider context and impact of being a trainer given participants implicated family members, professionals and the general public in various roles. Testing aspects of social identity theory may also contribute a greater understanding of the relationship between social identity and being a trainer for PLD.

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Emma Taylor

Section C: Critical appraisal

Word count: 1934

What research skills have you learned and what research abilities have you developed from undertaking this project and what do you think you need to learn further?

Undertaking this project was both rewarding and challenging. My decision to adopt narrative analysis (NA) was borne out of a perceived similarity between the ethos of the method as empowering for PLD (Booth & Booth, 1996), and my own motivations for conducting the project as a way of empowering participants to tell their stories and be heard. Therefore, I was happy with my decision to adopt NA for this reason.

However, unlike other qualitative methodologies NA does not follow a single agreed method (Andrews, Squire, & Tamboukou, 2008). Whilst a part of me found the range of approaches within NA liberating, another part felt overwhelmed and anxious about which approach to use and how. Initially, I considered using McAdams' (1995) life story approach whereby interviews are analysed using a specific protocol focusing on different aspects of the narrative (e.g. life chapters, significant characters, themes, metaphors). However, following some initial analysis this approach felt restrictive given it seemingly relied on participants' capacity to reflect on their lives, which can be a challenge for PLD (Booth & Booth, 1996). In choosing this method I also slightly lost sight of my motivation for conducting the project and my research questions, given my anxiety about using NA for the first time. My research diary was crucial in helping me reflect on this process and to formulate an

alternative approach. Therefore, I feel that conducting this study has enhanced my reflexivity skills.

As I was still in the early stages of training when I chose my NA approach, I also think my anxiety related to the fact that I had greater control over this project compared to being on placement where decisions were often made for me. However, having relished opportunities for greater autonomy as I have progressed through training, I anticipate that I will feel more capable and comfortable about making decisions about appropriate research methodology in the future.

Conducting interviews was also something I looked forward to given my desire to give voice to the experiences of PLD. In line with Booth and Booth's (1996) recommendations, I also enjoyed getting to know participants outside of the research interview by staying for informal breaks between interviews (e.g. coffee, lunch). However, this occasionally resulted in some participants and other trainers approaching me to talk about current difficulties in their lives. This also occurred during some interviews where participants disclosed current difficulties (e.g. mental health difficulties, historical abuse) that they seemed keen to talk about. Given the boundaries of my researcher role, this initially caused me considerable anxiety, and resulted in a perceived pressure to adopt a clinical role. However, by setting out the remit of my role to participants and by reminding myself of this, I felt increasingly comfortable to manage this as interviews progressed. Therefore, this experience has taught me about the challenges of conducting research as a dual-role clinician,

enhanced my understanding of the importance of clear boundaries regarding the research role, and allowed me to develop skills in sensitively conveying these boundaries to participants without impeding the research relationship.

The data analysis skills I developed in using NA will be highly transferable to other qualitative approaches given some of their similarities (i.e. identifying themes). The process of weighing up the usefulness of NA against other qualitative approaches also increased my knowledge of other qualitative methodologies. However, given the breadth of approaches in NA, I feel my experience in this study was merely the 'tip of the iceberg'. Therefore, I am keen to expand my repertoire of skills by undertaking further NA research using a different approach.

If you were to do this project again, what would you do differently and why?

Given PLD as trainers are a relatively 'niche' group, I was pleased with the number of participants and their diversity of gender and ethnicity. However, the sample appeared to comprise individuals generally at the more able end of the learning disability spectrum. Whilst this is likely to reflect the roles and responsibilities of the majority of trainers, I was aware of other individuals within the organisations I visited with more significant disabilities who did not participate. Although I cannot assume they wanted to participate, the use of interviews and the reliance on participants' literacy skills to understand the information sheets may have triggered assumptions in others

(i.e. managers) and themselves about their capacity to engage. On reflection, I too held an anxiety about my capacity to engage individuals with more limited verbal communication skills, which supports the idea that 'the problems of interviewing inarticulate subjects are merely a function of their own limitations' (Oliver, 1992, p. 110). Therefore, I would make more of an effort to involve individuals with more severe disabilities given that 'those who most need to have their stories heard may be least able to tell them' (Baron, 1991; cited in Booth & Booth, 1996). Placing less emphasis on verbal communication by introducing talking mats (Murphy, 1997) or relying on visual methods, such as photos or Photovoice, whereby PLD are given cameras in order to capture aspects of their lives (Booth & Booth, 2003), may have been useful. However, having gained further LD experience on placement, I feel increasingly confident in my capacity to engage individuals with a range of ability.

My initial experience of trying to contact and gain consent from one of the organisations' managers to distribute information sheets and consent forms was challenging. As someone who considers themselves a 'go-getter', it felt frustrating to rely on someone else to move things forward. However, my supervisor's suggestion about asking for an alternative contact, and setting a deadline for a response moved the process along. Therefore, I would endeavour to do this from the outset in future research.

I was also aware that some of my interview questions were not always considerate of the difficulties that some PLD can experience. For example, at

times I was overly focused on establishing a timeline of events, which can be challenging for PLD who often have difficulty with dates and numbers (Booth & Booth, 1996). Having transcribed an interview whereby I did this often, I noticed this resulted in shorter answers and greater involvement on my part, which seemed at odds with the ethos of the method as liberating the voices of those who are typically silenced (Owens, 2007). Therefore, as suggested by Flynn (1986), I would avoid questions about time and frequency, and I would be more aware of my questioning style throughout the interviews.

Given more time, I would also give greater consideration to conducting interviews over multiple sessions given that this can enhance the research relationship with PLD (Booth & Booth, 1996). However, this would require careful planning and preparation with participants, given that 'entering into a research relationship contributes to the succession of different faces drifting in/out of their [PLD's] lives' (Stalker, 1998; p.10).

As a consequence of doing the study, would you do anything differently in regard to making clinical recommendations or changing clinical practice, and why?

Given that I hope to work with people with learning disabilities when I qualify, this project will impact my clinical practice in multiple ways. The process of reading about and gaining informed consent with/from participants in line with Nind's (2008) recommendations (e.g. clear information about the purpose of the relationship, attention to body language etc.) has made me

more aware of how I approach this in my clinical work with PLD, and other related populations, such as older adults. It would also be useful to disseminate these guidelines to staff in future clinical settings.

Hearing participants talk about challenging experiences and their resilience in overcoming these has also reminded me about the importance of considering participants' strengths within formulations, and generally in clinical practice. The finding that some participants were ambivalent about the applicability of the LD label to themselves and/or its impact on their lives has also made me aware of the assumptions I hold about the saliency of the LD label. Therefore, I will endeavour to be more curious about the meaning of the label for individuals and the way it impacts their lives, if at all. The emergence of victim roles that were strongly related to experiences of bullying also highlights the importance of asking PLD about these experiences in assessments. The development of positive working relationships with support staff would also be crucial to early identification and the provision of appropriate support.

Bearing witness to the positive relationships and collaboration between staff and trainers in the organisations involved in this project has also strengthened my desire to employ more collaborative ways of working with PLD in clinical settings (e.g. joint training, greater involvement in staff interviews, joint research).

Similarly, given that positive outcomes arose for trainers, it also seems useful as a clinician to be aware of relevant organisations and charities that PLD can become involved in. Establishing a positive working relationship with these organisations would be vital to this process, (i.e. by visiting), and may have the added benefit of raising the profile of LD services, and the role of psychologists within them, such that non-statutory services are better equipped to refer individuals where necessary.

If you were to undertake further research in this area what would that research seek to answer and how would you go about doing it?

Participants' narratives often implicated family members as crucial to their role as trainers and their capacity to manage their daily lives. Mothers in particular were strong influences in many participants' narratives, suggesting a possible impact of the attachment relationship on participants' motivation to engage in the role, and their continued success within it. This suggests that the impact of the trainer role expands beyond the trainer themselves to their wider system. Employing a systemic perspective integrating the views of significant others in future research may enhance our understanding of the impact of the trainer role on participants' lives. Therefore, future research could explore how being a trainer impacts the lives of significant others, or how the parent-child relationship impacts participants' desire to be a trainer. Interviewing mothers, other family members/carers, and trainers using IPA may be appropriate given it focuses on the meaning individuals make of

specific experiences (i.e. becoming a trainer) (Smith, Flowers, & Osborn, 1999).

Secondly, the emergence of the belonging role whereby participants spoke about having more friends and of being part of a group as a result of being a trainer, suggested that the role impacted participants' social lives/networks. Jahoda, Kemp, Ridell, and Banks (2008) found that PLD as supported employees reported greater integration with non-disabled colleagues and enhanced social networks compared to non-supported employees. In relation to being a trainer, this could be explored by asking: Does becoming a trainer increase participants' social networks and lead to enhanced social integration? Using a repeated measures design, participants could complete measures, such as the Social functioning-Social Network Index (SNI; Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997), at the time of attending an induction day at the training organisation, and then at different time points during their role (e.g. 3, 6, 9 months). Descriptive data (e.g. level of learning disability, co-morbid neurodevelopmental disorders, social competence) could highlight correlations between the trainer role, social ability and social outcomes. This would be useful in expanding our understanding of the impact of valued social roles on PLD, and may support the sustainability of other organisations supporting PLD in similar roles given the outcomes might be of interest to funding bodies and commissioners.

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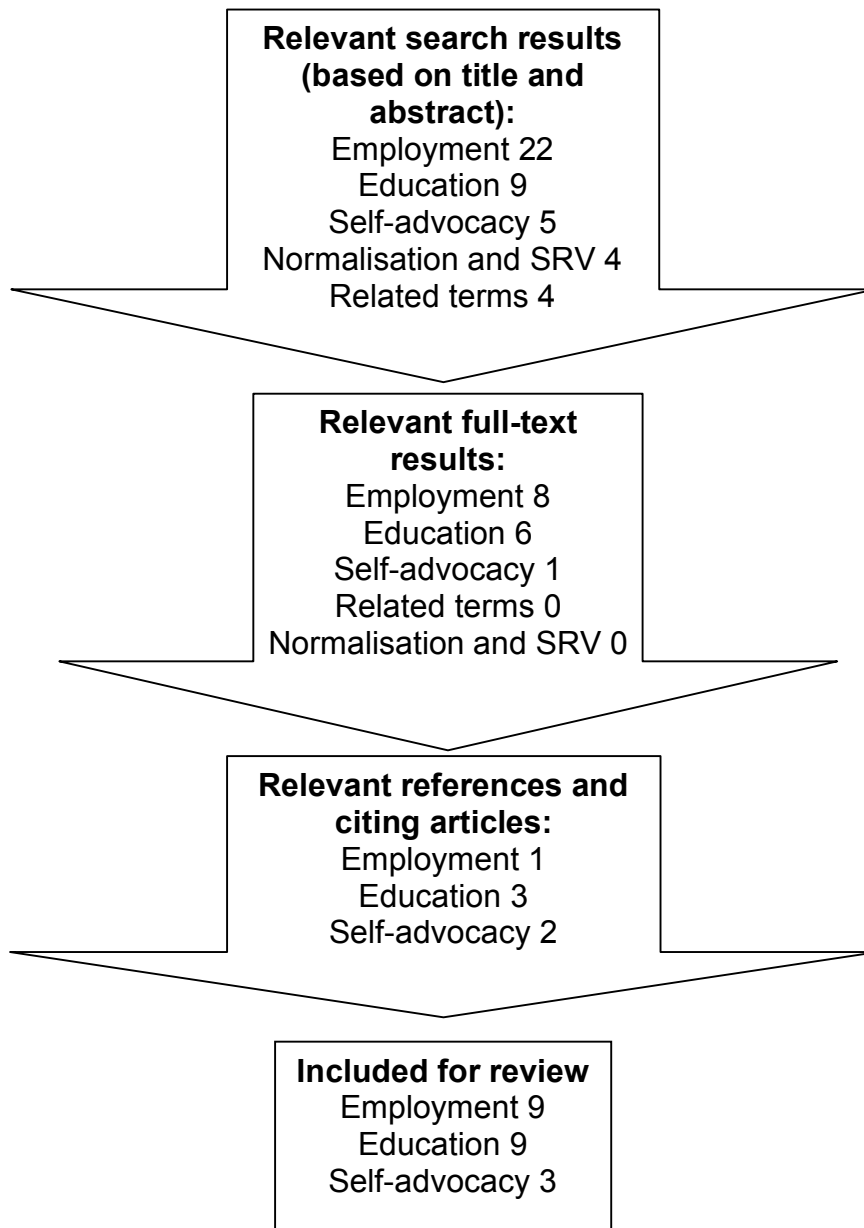
Section D: Appendices

Appendix 1: Search strategy

Population search terms		Domain Search terms
Intellectual disability OR Intellectual disabilities OR Intellectually disabled OR Intellectually impaired OR Intellectually handicapped OR Mentally disabled persons OR Mentally handicapped OR Mentally disabled OR Mentally retarded OR Mentally impaired OR Mental retardation OR Learning disabled* OR learning disability* OR Downs syndrome OR Autism	AND	Employee OR Personnel OR Employment OR employment status OR Volunteers OR Apprenticeships OR Work (Attitudes Towards) OR Supported Employment or Employment Status
		Vocational Rehabilitation OR Education
		Self-advocacy OR Advocacy OR Speaking out
		Social role valorisation OR valued social role OR normalisation
		Researcher OR Research OR Experimentation OR Emancipatory research OR Participatory research OR Co-researcher OR Participatory action research OR training OR Training OR trainer

*not used in PsychINFO as this refers to learning difficulties (e.g. dyslexia)

Appendix 2: Search procedure and results



Appendix 3: Summary of reviewed studies

Study	Aim(s)	Participants	Design	Main findings	Critique
Sinnott-Oswald, Gliner, and Spencer (1991)	Compared perceived quality of life (QOL) for PLD in supported employment (SE), sheltered workshops, and non-disabled employees	N=29; 10 in SE, 10 sheltered workshops, 9 non-disabled	Quasi-experimental	<ul style="list-style-type: none"> The number of leisure activities, use of leisure time, self-esteem, involvement in activities, mobility, job skill perceptions, and perceptions regarding changes in income were positively related to supported employment 	<ul style="list-style-type: none"> Results may have been attributed to the part-time status of SE participants Self-report QOL measure
Jahoda, Kemp, Ridell, and Banks (2008)	Systematic review of SE outcomes for PLD	N/A	Systematic review of 15 quantitative studies	<ul style="list-style-type: none"> SE related to greater QOL compared to sheltered workshops and unemployment Some PLD reported greater integration with non-disabled colleagues and enhanced social networks compared to non-SE individuals Quality of social relationships (i.e. reciprocity, supportiveness) did not 	<ul style="list-style-type: none"> Inclusion of peer-review studies enhanced credibility of results Workplace or participant variables may have impacted QOL Observational methods prevented insight into subjective quality or meaning of social interactions Negated direct

				differ	experiences of PLD given exclusion of qualitative studies
Verdugo, de Urries, Jenaro, Caballo, and Crespo (2006)	Compared QOL outcomes for supported employees with sheltered employees in Spain	N=232; 160 in SE, 71.3% male, 72 in SECs, 86.1% male, age range 16->50 Severe LD=SE 0.6%, SEC 0, Moderate=SE 10.1%, SEC=17.1%; Mild=SE 57.6%, SEC 58.6%, Borderline=SE 31.6%, SEC 24.3%	Quasi-experimental	<ul style="list-style-type: none"> No differences for QOL between supported and sheltered employees Higher job 'typicalness' correlated with higher total QOL Participants with higher levels of direct support, women, and workers with lower training demonstrated lower QOL 	<ul style="list-style-type: none"> Participants were not randomly selected Sample biased towards mild and borderline LD Majority of participants lived in family home
Beyer, Brown, Akandi, and Rapley (2010)	Compared QOL, and quality of work environment in SE, employment enterprises and day services with non-disabled workers	N=54; 17 SE, 76% male; mean percentile ranks ABS 85; 10 employment enterprise workers, 40% male, ABS 77.8; 10 day service attendees, 90% male, ABS 74.1; 17 non-disabled colleagues, 41% male	Quasi-experimental	<ul style="list-style-type: none"> Supported employment related to greater objective QOL compared to enterprise workers and day service attendees Non-disabled co-workers scored higher on total objective QOL compared to PLD 	<ul style="list-style-type: none"> High proportion of males in SE and day services Small samples
Banks, Jahoda, Dagnan, Kemp, and	Explored psychological impact of supported	N=49 supported employees; age range 16-53, mean 31.2; 61.2% male; mean	Mixed methods (interviews and self-	<ul style="list-style-type: none"> Within nine to 12 months of starting a job, 27% of participants experienced job breakdown unrelated 	<ul style="list-style-type: none"> Use of interviews to access the direct experiences of PLD Mean IQ score of 69

Williams (2010)	employment	WASI 69, five scored lower than 75	report measures)	<p>to age, gender, living arrangements, type of school attended or IQ</p> <ul style="list-style-type: none"> • No differences for QOL and psychological well-being for PLD who lost their jobs compared to those who retained employment • Job loss related to boredom, laziness and uncertainty about finding another job 	<p>meant that samples was biased towards participants with mild learning disability</p> <ul style="list-style-type: none"> • Limited number of participants scored below LD range on WASI
Stephens, Collins, and Dodder (2005)	Assessed longitudinal outcomes of employment	N = 2760; male 55.8%; age range 16-65; Mild LD 26.1%, Moderate LD 16.3%; Severe 15.4%, Severe 15.4%;	Longitudinal	<ul style="list-style-type: none"> • PLD who moved from unemployment to sheltered, supported and/or competitive employment showed increased adaptive behaviour skills • Those who moved from employment to unemployment evidenced decreased adaptive skills 	<ul style="list-style-type: none"> • Generalisability enhanced by the inclusion of people with moderate and severe LD • Large sample • Maturation effects may have confounded results given longitudinal design
Jahoda, Banks, Dagnan, Kemp, Kerr, and	Explored relationship between employment and adaptive	N=35 employees; 24 male, 11 female; age range 16-53; IQ range 55-84	Longitudinal, qualitative	<ul style="list-style-type: none"> • SE provided purposeful activity, financial reward, increased choice, independence, social activities, status, and self- 	<ul style="list-style-type: none"> • One of few studies to address challenges of employment for PLD • Some participants scored above the cut-

Williams (2009)	skills in supported employees			worth <ul style="list-style-type: none"> Challenges pertained to anxiety about starting a new job, job retention, learning and retaining new skills and meeting new people 	off for a learning disability limiting generalisability to LD population
Kober and Eggleton (2005)	Explored effect of sheltered and open employment on QOL	N=117; 62% male; mean age 31; 55% in open employment, 45% sheltered employment;	Quasi-experimental	<ul style="list-style-type: none"> Open employment linked to higher total quality of life and individual empowerment/independence, social belonging/community integration compared to sheltered employees High functional work ability employees in open employment had higher empowerment/independence, social belonging/community integration, and total quality of life scores 	<ul style="list-style-type: none"> Results limited by the recruitment of participants from a specific geographical location Lack of matched samples Level of LD unclear
Petrovski and Gleeson (1997)	Explored relationship between job satisfaction and psychological	N=31; 52% males, 100% mild intellectual disability, age range 18-41, mean 24 years	Mixed methods	<ul style="list-style-type: none"> High job satisfaction linked to low perceived stigma and loneliness at work Few participants saw work 'friends' outside of work 	<ul style="list-style-type: none"> Lack of control group Unclear whether measures were validated for use with PLD

	health in open employment			<ul style="list-style-type: none"> Females reported higher loneliness than males at work 	
Knox, Mock, and Parmenter (2000)	Reflections of a wider research project about community relationships for PLD	N=6, aged 19-54, living and working in community settings	Exploratory	<ul style="list-style-type: none"> Researcher role helped participants feel heard, legitimised, able to talk about experiences that had not been asked about or heard before Increased knowledge of research process 	<ul style="list-style-type: none"> Predominantly descriptive and reflective Limited focus on challenges of the role Self-selection bias Level of LD unclear
Conder, Milner, and Mirfin-Veitch (2011)	Reflections of participatory action research project	Unreported	Exploratory	<ul style="list-style-type: none"> Researcher role related to increased confidence and in supporting others to speak up Improved reading skills Challenges included difficulty reading and lack of time to memorise material 	<ul style="list-style-type: none"> Predominantly descriptive and reflective Highlighted both positive outcomes and challenges Number of participants unclear
Borisov and Reid (2010)	Explored benefits of PLD as physical education teaching assistants	N=5, 3 male, 2 female, age range 18-21; 3 with moderate to severe LD, 2 with mild LD	Qualitative	<ul style="list-style-type: none"> Role related to positive affect, connectedness, pride and accomplishment, career aspirations, self-identity as helper, responsibility towards others, being a role model, modification of behaviour (e.g. increased 	<ul style="list-style-type: none"> Multiple methods of data collection (i.e. observation, semi-structured interviews) Small sample with limited age range Focus on the benefits of role negated an understanding of likely

				focus, attitudes towards school) and altruism	challenges
Black and Roberts (2009)	Explored outcomes for PLD as trainers of a staff value-based pilot training program	N=7 trainers, age range 24-41, mean 37.6; three had Down's, one had ASD, three had undifferentiated LD; N=8 course participants	Exploratory	<ul style="list-style-type: none"> • Participants felt positive about “telling people what matters”, felt listened to, made friends, and felt the role enhanced their personal development (e.g. memory, confidence). • Practical challenges included difficulties with reading and mobility • Perceived increased confidence and competence, and decreased anxiety with experience at follow-up • Positive changes in staff attitudes and increased awareness of the perspectives of PLD post-training 	<ul style="list-style-type: none"> • Inclusion of trainer and recipient perspectives strengthened results • Largely descriptive • Lacked formal measures (e.g. attitude scales) to back-up results • Small sample
Weeks, Shane, MacDonald, Hart and Smith (2006)	Explored outcomes of two-day training event delivered by PLD to PLD	Unreported	Exploratory	<ul style="list-style-type: none"> • Trainers developed new skills in teaching and running training (e.g. role plays) • Increased confidence as a result of involvement 	<ul style="list-style-type: none"> • Largely descriptive • Lacked formal measures (e.g. attitude scales) to back-up results • Number of participants

					unclear
Paiewonsky (2011)	Explored the experiences of college students with LD	N=9, age range 19-21, gender and LD not reported	Qualitative	<p>Themes relevant to impact of the student role were:</p> <ul style="list-style-type: none"> • 'Having a new identity and feeling different' pertained to increased independence and integration with other students. • 'Adjusting to new expectations' meant being treated like an adult and taking responsibility for oneself. • 'Campus life' referred to increased social opportunities and access to practical resources. • Challenges pertained to a lack of access to classes of interest, and desire for support in making new friendships 	<ul style="list-style-type: none"> • Generalisability limited by participants' ages, lack of gender and LD level data • Participants recruited from one specific geographical location • Small sample
O'Brien et al. (2009)	Explored the experiences of PLD at university	N=19, six male, 19 female, age range 19-48 years	Qualitative	<p>Student role led PLD to adopt multiple novel roles:</p> <ul style="list-style-type: none"> • 'Learner', with increased independence, confidence and communication skills • 'Friend, with an increased 	<ul style="list-style-type: none"> • Limited generalisability given participants were from one Irish University

				<p>social network and access to activities</p> <ul style="list-style-type: none"> • 'Different person', who felt happier, more included and who non-disabled students perceived as 'ordinary' 	
Hamill (2003)	Explored outcome of student role for Megan	N=1, 26 years old with Down syndrome; 7 students, 3 members of staff	Case study	<p>Student role led to:</p> <ul style="list-style-type: none"> • Increased independence, self-esteem and pride • Fellow students reported learning more about the experiences of people with disabilities • Difficulties developing meaningful friendships, leading to feelings of exclusion were reported • Challenge to understand coursework and college life procedures 	<ul style="list-style-type: none"> • Inclusion of multiple viewpoints (i.e. Megan, her parents, teachers, students) • Case study data limits generalisability • Level of LD unclear
Casale-Giannola and Kamens (2006)	Explored outcome of student role for Jacqueline	N=1 with Down syndrome, aged 21 years; and her mother	Case study	<ul style="list-style-type: none"> • Student role resulted in perception of 'sameness' with fellow students • Fostered a positive relationship with non-disabled mentor • Fellow students cited increased positive 	<ul style="list-style-type: none"> • Inclusion of multiple viewpoints enhanced credibility of results • Case study data limits generalisability • Level of LD unclear

				<p>attitudes towards people with disabilities</p> <ul style="list-style-type: none"> • Jacqueline experienced a lack of meaningful relationships with peers. 	
Caldwell (2010)	Explored leadership development in self-advocates	N=13, age range 21-61, 6 female, 7 male, level of LD not reported	Qualitative	<p>Self-advocacy encouraged:</p> <ul style="list-style-type: none"> • Resistance towards oppression resulting from disability • Fostered connections with a disability community • Increased self-confidence and self-determination • Provided safe and trusting environment within which to be heard • Facilitated positive self-identity by developing a personal concept of disability independent of societal beliefs 	<ul style="list-style-type: none"> • Snowball sampling subject to bias • Small sample and level of LD not reported
Beart, Hardy, and Buchan (2004)	Explored experience of belonging to a self-advocacy group	N=8, 24-44 years	Qualitative	<ul style="list-style-type: none"> • Self-advocacy resulted in change in self-concept (increased confidence, autonomy, status, skills) • Being in a group provided a positive social environment, new friendships, support and 	<ul style="list-style-type: none"> • Inclusion of the voices of PLD given use of semi-structured interviews • All participants were White British • Level of LD not reported

				<p>help</p> <ul style="list-style-type: none"> • Changes in self-concept lead to reflection on past painful experiences (e.g. bullying) • Participants cited positive reactions from others, including family, friends and professionals arising from role 	
Gilmartin and Slevin (2010)	Explored experiences of self-advocates in Ireland	N=13, age range 32-60	Qualitative	<p>Self-advocacy led to:</p> <ul style="list-style-type: none"> • Participants feeling safe to speak out • Enhanced self-determination, confidence and self-esteem • Increased individual and collective empowerment • Changes in personal identity • Expanded social networks • Challenges included not feeling listened to, feeling unable to effect change, and nervousness and tension within group 	<ul style="list-style-type: none"> • Level of LD not reported

Participant information sheet



Salomons Campus at Tunbridge Wells
Department of Applied Psychology
Faculty of Social & Applied Sciences

Who I am and what I am doing

- My name is Emma Taylor.
- I am a trainee clinical psychologist studying at Canterbury Christ Church University.
- I am doing a project about people with learning disabilities who are trainers.
- A trainer is anyone with a learning disability who is part of a group of people who talk to/teach people about having a learning disability.



Why is this project happening and why have I been chosen?

- There are not many people with learning disabilities who are trainers
- I would like to find out about you and why you decided to become a trainer.
- You have been chosen because you are part of a group of people with learning disabilities who are trainers.



Do I have to take part?

- It is your choice whether you take part or not.
- Some people find it helpful to talk to someone they know to help them decide.
- If you agree to take part, I will ask you to sign a form called a consent form to show me that you agree.
- If you do not wish to take part, that is ok too.
- Saying no to taking part will not affect your role as a trainer or any support you receive.



What would I be doing if I want to take part?

- We would meet for an interview where I ask you some questions and we talk about your experiences.
- We would talk for as long as you feel comfortable but no more than two hours in total.
- We might meet more than once.
- To help me remember what you say I would record our interview on a voice recorder.



Will anyone else know what we have talked about?

- Some of what you say may be written word for word in the final project.
- I will also discuss what people say with my supervisors.
- BUT no one except me will know it was you who said it.
- Your name will not be appear anywhere in the project, unless you want it to.



What happens to my recorded interview when it is done?

- I will delete the interview from the voice recorder and put it on a computer that is private.
- I will then listen to the interview, write down what we talked (called a 'words sheet') and delete the interview from the computer.
- Your 'words sheet' will be kept in a secure place.
- Once the project is finished the 'word sheet' will be stored securely for 10 years.
- You will not be recognised from your 'words sheet'.



What would be good about taking part?

- This project might help us understand more about the experiences of people with learning disabilities.



Are there any risks to taking part?

- Talking about your life and your experiences might be difficult.
- If this happens we can take a break or stop at any time.
- If you feel distressed at the end of the interview we can talk about it.
- If you tell me anything that I think puts you or someone you know at risk, I will have to tell someone about it but we would talk about this first.



Will I get anything for taking part?

- You will receive:
 - a £10 gift voucher
 - Up to £10 towards travel expenses.
 - Anything over £10 will not be paid for by the researcher.
- This will be less if you stop taking part in the project before it is finished.



What happens if I want to take part but then change my mind?

- You can change your mind without giving a reason at any time.
- If we have already met for an interview, I will delete it and it will not be used in the project.
- Changing your mind will not affect your role as a trainer or any other support you get.
- After July 2013 it will not be possible to change your mind because the project will be finished.



Who has approved this project?

- My project has been allowed to happen by a group of people called an Ethics Panel.
- This means they think the project is safe to go ahead



How can I find out about the results of the study?

- When the project is finished I will share the results with everyone who took part.
- Sometimes projects like this are written about in a science journal.
- If this happens, I will let you know.
- You and your organisation will not be named.



Questions?

- You will be given a copy of this sheet to keep.
- You can phone and leave me (Emma Taylor) a message at my university on 01892 507673 and I will get back to you.
- You can email me:
et104@canterbury.ac.uk



Who is supervising the project?

- Dr Jennifer Jackson, Clinical Psychologist
jennifer.jackson@oxleas.nhs.uk
- Dr Louise Goodbody, Clinical Psychologist
louise.goodbody@canterbury.ac.uk
- Celia Heneage, Clinical Psychologist
celia.heneage@canterbury.ac.uk

Appendix 5: Consent form



Salomons Campus at Tunbridge Wells
Department of Applied Psychology
Faculty of Social & Applied Sciences

PARTICIPANT AGREEMENT FORM

Project title: A project about people with a learning disability who are trainers

Name of Researcher: Emma Taylor

Please initial EACH box

1. I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that it is my choice whether to take part or not. I am free to change my mind about being part of the project at any time and I do not have to give a reason. This will not affect my involvement as a trainer or with any other services or support I receive.

3. I agree that anonymous quotes from my interview may be used in the final reports of the project. This means that what I have said may appear word for word but no one, other than the researcher, will know it was me who said it.

4. I agree to the results of the project being written about in a science journal. My name and the company/group I work with will not appear in the journal.

5. I agree to take part in the above study.

Name of Participant _____ Date _____

Signature _____

Name of Person taking agreement _____ Date _____

Signature _____

Appendix 6: Aide-memoire

Introductions: Explain the purpose of the study and outline of interview

Questions:

1. To get us going a bit could you please tell me a bit about you and yourself?
2. Could you please tell me the story of how you became a trainer?

Possible topics of investigation:

- Positive and negative things about being a trainer
- What participants get out of being a trainer
- Being a trainer and a person with a learning disability at the same time

Appendix 7: Ethics

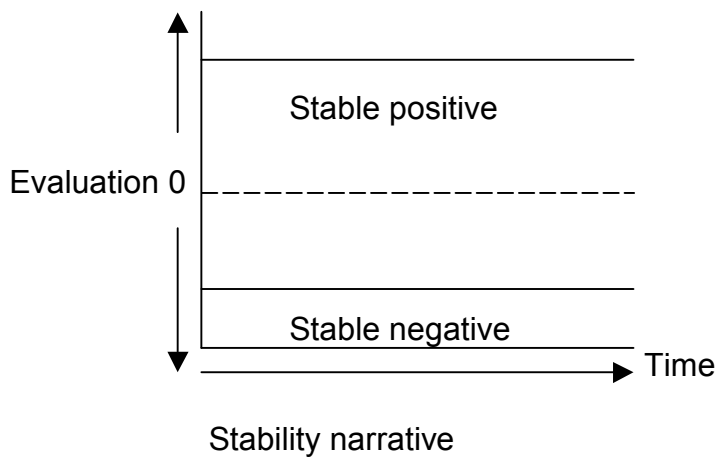
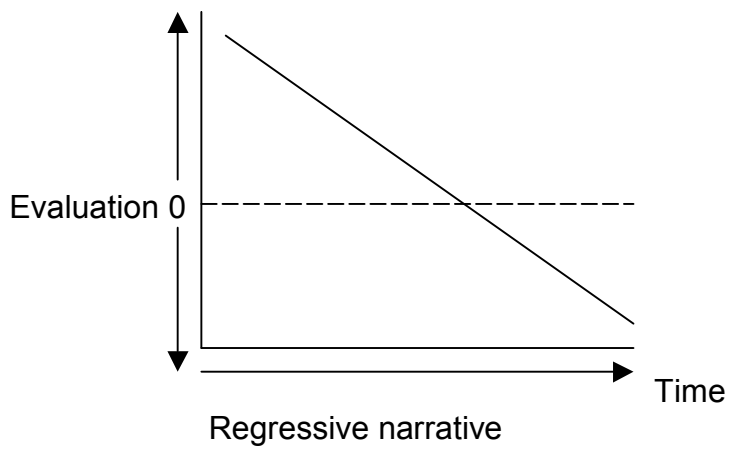
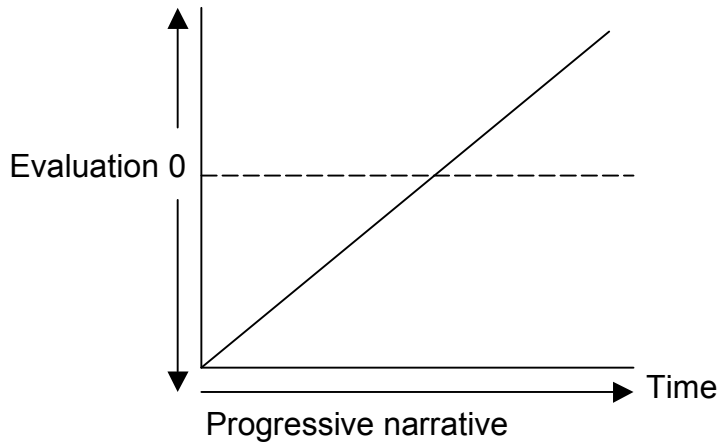
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Appendix 8: Example Murray summary

Sarah		
Murray summary		Gergen and Gergen
		Structure
Key features: Beginning-childhood and early adulthood events	As a child, Sarah attended a 'special school' and was bullied by her peers. At home, Sarah described not being allowed to go out by her parents, whilst her siblings, without a disability, could. Her father was a key figure in this section of her narrative and was positioned as being restrictive and controlling by not letting her go out. Sarah then speaks about the fighting back against her father and eventually moving out of home to live independently. Sarah then talks about her early experiences of employment and how she was let go from two previous roles, which she attributes to her physical disability. Sarah also went to college and worked in various others roles.	Negative stability followed by progression
Middle-current life	Sarah talks in detail about the process of becoming a trainer in terms of the interview process, training and pay. She became involved through a friend of hers who convinced her to join. She talks about wanting to go out there and train people about how PLD should be treated, and to get the voice of PLD across. She has trained different groups of people including professionals, students, staff, carers etc. Some of the challenges of the role include the travel and remembering what she has to say. She talks about the experience of accepting two awards on behalf of her training organisation. Outside of her role as a trainer, Sarah talks about her reluctance to let people know she has a learning disability for fear of what they might say. She talks about a friend who was in hospital who received poor treatment because they had a learning disability. This seems linked to her motivation to become a trainer, and a sense of morality.	Stable
End-Future hopes	Sarah wants to continue training people and specifically mentions carers. She finds the role very satisfactory and says it helps her talk to people about how PLD feel.	Stable

*related to being a trainer

Appendix 9: Illustration of Gergen and Gergen's (1983) three basic structures of narrative



Appendix 10: Analysed transcript

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Appendix 11: Stages of positioning analysis

Excerpt from master list of roles across participants

Transcript roles (all participants)	Role	Role category
Robust Robust* Robust* Strong willed	Robust	Resilient roles
Self-belief* Confident* Trainer role as facilitating confidence Trainer role as confidence boosting	Self-confident	Empowering roles
Active* Active Active/go getter* Go-getter* Go getter/adventurer* Positive risk taker Risk-taker* Determined (in the face of challenges)	Go getter/active	
Agent/advocate of change Agent of own destiny* Agent of own destiny Agent of own destiny Agent of change* Agent of change* Decision-maker Agent of own life Agent of own destiny* Agent of own destiny Assertive* Self-advocate Self-advocate Standing up for oneself	Agent of own life/destiny	
Self as changed person* (due to role) Trainer role as leading to changed man* New person* Trainer role as life changing* Improved self Self as more in control* Bettering oneself Trainer role as bringing positive changes in self-perception	Changed person	

<p>Trainer role as promoting positive behaviour change</p> <p>Trainer role as facilitating positive changes</p> <p>Trainer role as life changing</p> <p>Trainer role as offering perspective on life</p>		
<p>Independent</p> <p>Independent*</p> <p>Independent</p> <p>Independent</p> <p>Trainer role as freeing/empowering</p> <p>Trainer role as liberating</p>	<p>Independent</p>	
<p>Accepted*</p> <p>Accepted in role*</p> <p>Accepted in role of trainer*</p> <p>Trainer role as facilitating acceptance</p>	<p>Accepted</p>	<p>Acceptance-based roles</p>
<p>Worthy*</p> <p>Worthy*</p> <p>Worthy/respected*</p> <p>Worthy of fair treatment/equality</p> <p>Worthy*</p> <p>Deserving of respect</p> <p>Credible*</p> <p>Credible</p> <p>Wanting/worthy of being heard</p> <p>Valued/worthy*</p> <p>Valued*</p> <p>Needed by others*</p> <p>Invaluable*</p> <p>Valued by profs*</p> <p>Asset</p> <p>Respected by others/credible*</p> <p>Worthy (of recognition)</p> <p>Others as admiring*</p> <p>Admired*</p> <p>Others as admiring*</p> <p>Others as admiring</p> <p>Needed by others</p> <p>Students as accepting</p> <p>Validated*</p> <p>Validated by others*</p> <p>Trainer role as valued</p>	<p>Valued individual</p>	

Initial roles framework

Resilient roles: Able to cope with and overcome adversities and challenges in one's life		Fighter (taking an active stance/fighting against something)		Coping (managing in the face of adversity)		Survivor (facing adversities and coming out the other side)		Robust (demonstrating strength in the face of adversity/challenges)	
Empowered roles: Having control over own life	Self-advocate (speaking up for oneself)	Go-getter (seeking out opportunities and facing challenges head on; adventurous)	Independent (able to cope on own)	Able (disability as enabling, viewing oneself as having skills and resources)	Agent of change (direct one's life in the desired direction)	New me (trainer role as facilitating a change in self-perception)	Self-confident (being confident in oneself)		
Acceptance/Equality-based roles: Accepted by and equal to others		Moralistic (feeling strongly about how others should be treated)		Accepted/Understood (feeling accepted for who you are and feeling understood rather than judged)		Worthy/Valued (deserving of fair/good/equal treatment to/by others and feeling equal to others)			
Support/knowledge-based roles: helping others, imparting knowledge	Advocate (speaking up on behalf of others)	Confidant/Mentor (someone to turn to)	Saviour (rescues others from negative experiences)	Educator/teacher (imparting knowledge onto others)	Expert/Wise (has significant knowledge and skills)				

Supported roles: being in receipt of support		Dependent/needing support (relying on others for support)		Others as supportive/encouraging (family in general, mothers, and professionals)		Part of a team/group (feeling part of something, feeling a sense of inclusion and belonging)		
Disempowering/vulnerable roles: at the mercy of others, feeling unable to effect change	Victim (being the recipient of abuse, stigma, bullying)	Rejected/abandoned (unwanted by others)	Disabled/Restricted (by disability and others, unable to do what you want)	Isolated/segregated (Alone without support, separated from others)	Un-supported (by others)	Taken advantage of: others as untrustworthy	Unfulfilled/ Hopeless (Feeling life is not worth living, feeling dissatisfied with life)	Weak/vulnerable (lacking strength to change)
Defensive/ambivalent roles		Defensive/Ambivalent about LD (using it in some circumstances but not others)		Self as not disabled (denying disability)		Above/better than others (carrying a value judgement about others)		

Final roles framework

Empowered/strength-based roles	Fighter (demonstrating strength and resilience in face of adversity/challenges)	Go getter (seeking out opportunities/challenges in life; directing life according to own agenda)	Able (capable, in relation to a capacity to learn and one's disability)	Independent (self-sufficient)	New me (changes in self-perception)
Ambivalent roles	Ambivalent about self as learning disabled (having mixed feelings about their learning disability)		Defensive (defensive about learning disability and use of label)		
Knowledge-based roles	Educator/expert (imparting knowledge to others; others as requiring education)		Wise (knowledgeable about life, and with good judgement)		
Acceptance-based roles	Valued individual (feeling worthy and admired by others)	Moralistic (strong opinions about how people with physical/learning disabilities should be treated; others as ignorant)	Belonging to something/group (having a place in a group and feeling part of something)		
Support roles (supporting others and being recipient of support)	Advocate (standing up for the rights and fair treatment of other PLD)	Supporter/helper (someone to turn to; helpful towards others; others as needing support/rescuing)	Enabled (positioning of others as supportive and encouraging)	Dependent (reliant on services and family to manage everyday life)	
Disempowered roles	Victim (recipients of bullying, abuse and discrimination)	Rejected (segregated and cast aside by others (i.e. children, professionals, general public)	Disabled (disabled by their physical/learning disability, and metaphorically by others)		

Changes to roles framework

Initial roles framework	Final roles framework	Changes
Resilient roles Fighter Coping Survivor Robust	Empowered/strength-based roles Fighter Go-getter Able Independent New me	<ul style="list-style-type: none"> The resilient and empowered roles were merged and re-named given they both related to having strength and being empowered Empowered was used instead of resilient to reflect the active positioning that participants adopted in relation to challenges and life as a whole The coping, survivor and robust roles were collapsed into the fighter role given they seemed to describe qualities associated with being a fighter rather than roles in and of themselves The self-advocate and agent of change roles were collapsed into the go-getter role given they both conveyed agency in terms of how participants approached life and their own destiny Self-confident was considered an aspect of the 'new me' role rather than a role per say
Empowered roles Self-advocate Go-getter Independent Able Agent of change New me Self-confident		
Acceptance/Equality-based roles Moralistic Accepted/Understood Worthy/valued	Acceptance-based roles Valued individual Moralistic Belonging to something/group	<ul style="list-style-type: none"> The valued individual role was created to encompass a sense of participants feeling accepted/understood and worthy/valued The belonging role was created to capture participants' positioning of themselves in relation to others (e.g. fellow trainers, staff) and the impact this had on them. This also encompassed the 'part of a team' role previously in the supported roles category.
Support/knowledge-based roles Advocate Confidant/mentor Saviour Educator Expert/Wise	Knowledge-based roles Educator/expert Wise	<ul style="list-style-type: none"> Support and knowledge based roles were split into separate categories given they seemed to relate to different aspects of participants' identities The advocate role was deemed more relevant to a support role as participants spoke about supporting other PLD to speak up The confidant and saviour roles were collapsed into the supporter/helper role

		<ul style="list-style-type: none"> The support role was expanded to encompass being supportive and supported
Supported roles Dependent/needing support Others as supportive/encouraging Part of a team/group	Support roles Advocate Supporter/helper Enabled Dependent	<ul style="list-style-type: none"> The enabled role was created to reflect participants' sense of being encouraged/supported by others The saviour and confidant/mentor role were subsumed under the supporter/helper role The part of a team/group role was moved to the acceptance-based roles and re-named belonging to something/group
Disempowering/vulnerable roles Victim Rejected/abandoned Disabled/restricted Isolated/segregated Unsupported by others Taken advantage of Unfulfilled/hopeless Weak/vulnerable	Disempowered roles Victim Rejected Disabled	<ul style="list-style-type: none"> The isolated/segregated role was subsumed under the rejected role The disabled role was used to capture participants' sense of being unsupported by others and of being taken advantage of The weak/vulnerable and unfulfilled/hopeless roles were deemed relevant to the victim role as they seemed to convey the meaning behind participants' experiences of being a victim, rather than roles in and of themselves
Defensive/ambivalent roles Defensive/ambivalent about LD Self as not disabled Above/better than others	Ambivalent roles Ambivalent (about self as disabled) Defensive	<ul style="list-style-type: none"> The defensive/ambivalent role was split as there seemed to be a distinction between participants defending against their LD identity by denying it, versus having mixed feelings about it The self as not disabled and the above/better than others roles were subsumed into the defensive role

Appendix 12: Example of stage two positioning analysis

Sarah				
Murray summary		Gergen and Gergen	Positioning analysis	
		Structure	Transcript roles	Final roles framework
Key features: Beginning-childhood and early adulthood events	As a child, Sarah attended a 'special school' and was bullied by her peers. At home, Sarah described not being allowed to go out by her parents, whilst her siblings, without a disability, could. Her father was a key figure in this section of her narrative and was positioned as being restrictive and controlling by not letting her go out. Sarah then speaks about the fighting back against her father and eventually moving out of home to live independently. Sarah then talks about her early experiences of employment and how she was let go from two previous roles, which she attributes to her physical disability. Sarah also went to college and worked in various others roles.	Negative stability followed by progression	Father as restrictive Siblings as better off Restricted/controlled by parents Victim Others as unkind Segregated Unfulfilled Independent Agent of own destiny Resilient/fighter Supported by professionals	Fighter Go-getter Able Independent Enabled Dependent Victim Rejected Disabled
Middle-current life	Sarah talks in detail about the process of becoming a trainer in terms of the interview process, training and pay.	Stable	Knowledgeable/educator* Skilled* Learner*	Go-getter* Able* Independent

	<p>She became involved through a friend of hers who convinced her to join. She talks about wanting to go out there and train people about how PLD should be treated, and to get the voice of PLD across. She has trained different groups of people including professionals, students, staff, carers etc. Some of the challenges of the role include the travel and remembering what she has to say. She talks about the experience of accepting two awards on behalf of her training organisation. Outside of her role as a trainer, Sarah talks about her reluctance to let people know she has a learning disability for fear of what they might say. She talks about a friend who was in hospital who received poor treatment because they had a learning disability. This seems linked to her motivation to become a trainer, and a sense of morality.</p>	<p>Educator* Sociable* Advocate (for PLD)* Identifying self as distinct group (them and us)* Valued/worthy* Proud* Physically disabled* Coping* Respected by others/credible* Successful* Disabled yet equal* Part of a team* Belonging to something* Multi-talented* Deserving of respect* Moralistic* Worthy of fair treatment/equality* Fulfilled (as trainer)* Agent/advocate of change* Wanting to be heard* Brave (in the face of anxiety)* Learner Active Equal to others Second best* Anxious* Victim De-valued Misunderstood</p>	<p>Ambivalent about self as disabled Educator/expert* Valued* Moralistic* Belonging* Advocate* Victim Disabled*</p>
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			Labelled PLD as devalued/unequal Outcast/different Needing support (financially dependent) Ambivalent	
End-Future hopes	Sarah wants to continue training people and specifically mentions carers. She finds the role very satisfactory and says it helps her talk to people about how PLD feel.	Stable	Ambitious*	Go-getter*

Appendix 13: Abridged research diary

January 2011

We had the research fair today. I was disappointed by the lack of learning disability representation. However, there is one project with Celia that sounded interesting about people with learning disabilities being involved in doctoral training, and how this impacts learners. This made me think about my experience of working with trainees as an assistant psychologist in learning disabilities. It seemed like trainees were often quite anxious about doing a learning disabilities placement, whilst others seemed quite resistant and would try and take as much leave as they could in order to get through it. As a result, I'm really interested in researching something about the attitudes of trainees towards people with learning disabilities. I've written to Celia with my idea so I'll wait to see what happens.

February 2011

Celia came back to me about my research idea and sounded very enthusiastic, which is exciting. We're going to meet in a few weeks time once I've had more of a think about possible areas to look into. I've also contacted a clinician in CAMHS about a project on models of consultation with looked after children (LAC) social workers. Although I don't have any experience of working with LAC, it sounds interesting, and thinking pragmatically, is local to me, which would be really helpful. We've arranged a meeting in March to discuss it further.

March 2011

I went to meet two CAMHS clinicians about the LAC project and it turned out to be almost like an interview, which I wasn't expecting at all. They have also had interest from another trainee so they have chosen to meet us both before making a decision. It feels strange being in competition with a colleague. I really liked the sound of the project and it seems to fit with my QIP in terms of models of supervision. They are going to let me know within the next week who they would like to work with. I also met with Celia who told me more about some research she has already done with an assistant psychologist looking at outcomes of user-lead training for IAPT trainees. It sounds like there is some existing data that could be used, but also room for a more qualitative analysis of the feedback that IAPT trainees give following the teaching. I think it would be really interesting to extend this to trainee psychologists as well. Celia was also telling me they have good links with the Surrey course, which also involves people with learning disabilities in their teaching, so it sounds like there could be a relatively large pool of participants. I also wondered about interviewing trainees about their attitudes towards people with learning disabilities generally, or perhaps pre and post LD placement. Celia is going to speak to some of the research staff to get their feedback on these ideas and then get back to me. She also told me about a previous MRP looking at attitudes towards people with learning disabilities following teaching, that I'll look in to.

March 2011

I had another meeting with Celia and Louise about my MRP ideas. The feedback from the research staff was that they did not feel it would be possible to interview trainees because they are unlikely to speak openly about their opinions of people with learning disabilities to a colleague. We also spoke about my reading of the other MRP on attitudes of recipients of training by people with learning disabilities. One of the studies that was mentioned looked at the impact of people with learning disabilities being involved in training, which seems to be an under-researched area. This was also something that Celia had put down as an initial idea on her research fair proposal. This seems more interesting to me as I think I'm keen to do something empowering, which focuses on people with learning disabilities themselves rather than recipients. It made me think about the reading I did as an assistant psychologist in learning disabilities about social role valorisation and normalisation and how there are assumptions about how roles like this are positive for people with learning disabilities. Therefore, we decided to go along with something about the impact on trainers of delivering training. I also let Celia know that I was chosen to do the LAC project and that I am going to think more over the next week about which project I want to do.

April 2011

I submitted my supervisor selection form for my MRP today. It's been a difficult decision about which project to choose and I've been weighing up the pros and cons of both. It feels difficult because a part of me wants to do something relatively straightforward in terms of being local, whilst the other part wants to do something I'm passionate about but that may not necessarily be straightforward. However, I've chosen to go with the LD project given that I feel quite strongly about doing something that will privilege the voices and experiences of people with learning disabilities themselves. Celia is also confident that we can get participants from two organisations for people with learning disabilities involved in training that she has regular contact with. I've also been reflecting on my clinical experiences of working in learning disabilities and my encounters with people with learning disabilities who were living in residential accommodation. It often felt like they had so little choice in their lives and that there was little room for them to be heard, which doesn't sit comfortably with me. Perhaps this is why I feel so strongly about doing something that will allow the voices of some PLD to be heard.

May 2011

I've been doing some more reading around the idea of researching the impact of being involved in training on trainers themselves and there is very little research out there. In some way this is positive in that it means that my project will be hopefully filling a gap in the literature, but in another way it means that there is very little to go on in terms of focusing the project further. I did come across a study about people with learning disabilities who have lived in long-stay hospitals and how this experience has impacted their social identity, which was interesting. It seems plausible that being involved in training may have some impact on the way people with learning disabilities see themselves. Having done some more reading around normalisation and

social role valorisation this also seems to support the underlying assumptions of positive outcomes in these theories.

June 2011

I've been reading more about identity for people with learning disabilities and feel really excited and interested in this as a potential avenue for my research project. It's been really interesting to read the literature on the use of the LD label by people with learning disabilities and I've been surprised at what seems to be a significant feeling of ambivalence towards the learning disabled identity. On reflection, this is definitely something I took for granted in my clinical experience of working with people with learning disabilities and never really thought about whether this identity was relevant to people or not. Reading this literature has really challenged my assumptions about how people with learning disabilities see themselves and made me more interested in researching this in relation to being involved in training.

July 2011

Celia thinks it would be a good idea to have another supervisor on the project so I've asked Jennifer, my previous supervisor from my learning disabilities assistant post, if she would be interested, which she agreed to. I think it will be really useful to have both a research and clinical perspective on the project and having another person in the mix allows for greater idea sharing. Celia has also mentioned my project to the two organisations that she is involved with and they have agreed for me to contact them with more information about the project once my proposal is completed.

August 2011

I met with Celia and Louise today to provide a summary of the literature I've been reading on identity and people with learning disabilities. We're all really excited about the idea of integrating social identity theory into my project. This also seems like an under-researched area in terms of there being very little about people with learning disabilities involved in training and the impact of this role on how they see themselves. We also spoke about potential research methods that might be useful. I had in mind narrative analysis, in line with the study about social identity for people with learning disabilities who lived in log-stay hospitals. Having done some more reading around this, it also seems to fit with my motivation to do something empowering with people with learning disabilities given it is considered a way of giving voice to those who do not traditionally have much power and influence in this way. I also had in mind the potential for grounded theory given the lack of literature in the area. However, having spoken with Celia and Louise we have decided that narrative seems like a good fit. I'm also pleased that Louise has prior experience of using this given it will be new to me. We've agreed that I will send round a draft of my proposal by mid September so that I can get feedback on it in time for submission in early October.

September 2011

I've been writing my MRP proposal, which has been useful in helping me consolidate the reading I've done and to develop some specific aims for the project. I came across another study about the impact of self-advocacy on

identity of people with learning disabilities, which is really useful as it talks about this process being a challenge for self-advocates. This seems more realistic than what feels like an overly simplistic assumption within normalisation and social role valorisation about roles like self-advocacy and trainer being positive. I also think this reflects my stance on life in terms of there being both positive and challenging aspects to everything. Having found this study also makes me feel more confident that social identity as the theoretical underpinning of my project is the way to go at this stage.

Trying to decide on which narrative analysis method to use has felt quite stressful given the breadth of approaches and the vast literature about the epistemological position that I'm not sure I'm able to get my head round yet. I've made an initial decision to go with a structural approach that was used in the identity study I found, and an approach that draws on a life story interview protocol which seems like a useful way of organising and analysing the data given that it offers more of a framework for how to go about it.

October 2011

I had positive feedback on my MRP proposal, which is really encouraging, and I've submitted it for review. Our LD teaching has also started, which I've been really looking forward to. I was really impressed by the teaching from the Baked Bean Theatre company and how confident the trainers appeared in their roles and during our lunch break where we were able to talk with them further. Talking to participants about their experiences was really useful in helping me reflect on my motivations and aims for doing my project. I was particularly struck by the trainers' passion about their role and how much they seemed to have internalised a desire to change the lives of people with learning disabilities for the better by raising awareness of their experiences. It felt really empowering as someone being trained to see people who traditionally have had so little power in their lives do something that they have created themselves, and that offers them the opportunity to do something valuable in their lives. In a way it makes me think about what is possible in life and what you can achieve if you set your mind to it. This has been really useful given things on the course are getting more demanding and there is more work on the way given the increased focus on starting the MRP.

November 2011

I had my MRP panel meeting today, which was nerve-racking but also enjoyable. The panel seemed interested and excited about my project and made some suggestions of things I could consider to improve/alter it. The primary one related to using discourse analysis instead of narrative analysis, which was not something I had considered. Having done some more reading on it, I'm not sure it fits with my ethos of wanting to empower participants to tell others about their experiences and do something collaborative in the same way that narrative does. Furthermore, although I'm sure it has been used successfully with people with learning disabilities in past research, I worry about the emphasis it places on the use of language given this is often challenging for people with learning disabilities. Having spoken to Louise and Celia, they are also in agreement, so we are going to stick with narrative

analysis. I also need to change my consent form and participant information sheet to provide more detail about the project.

December 2011

I'm desperately trying to get my ethics form done before Christmas as I'm really keen to get started on recruitment just in case it proves challenging. I definitely underestimated how much work an ethics application involves. However, like my proposal, it has been a useful process in terms of ironing out some of the areas that I was unsure about (e.g. research questions, informed consent etc). Jennifer has also been really helpful in offering feedback and looking at things from the perspective of someone who has gone through the process, particularly in relation to safety plans and informed consent. Trying to ensure that the information sheet and consent forms are accessible has been challenging given I don't know the abilities of the participants I potentially want to recruit. However, I met with a trainer who gave me some useful feedback about the wording of some of my questions on my aide-memoire and the language used in my information sheet and consent form, which has made me feel more confident about them.

January 2012

My ethics has been approved, which is really exciting. I had to make minor amendments to my managing risk section but other than that it went smoothly. The project is feeling more real now. I've spoken to Celia about contacting the training organisations and she has provided their contact details. I'm hoping to hear back from them in the coming weeks.

February 2012

I had a response from one organisation who are keen for me to interview their trainers. Hooray! I spoke to the manager to explain more about the project and helped answer their questions about it. Having not had anyone do research within their setting before, they were understandably a bit unsure about what it would involve. I sent them my information sheet and consent forms and they have come back saying that three trainers would be interested in being interviewed. I asked them whether they wanted me to do a presentation about the project but they said they had gone through the forms with participants and that they were keen to be involved. Therefore, we arranged for me to come and interview them in March. I also had an initial response from the other organisation saying they were interested but haven't heard anything since I sent them the information sheets and consent forms, which is worrying. Celia says that she often has trouble contacting the manager there though too so I'll leave it a while longer before following it up. Recruitment feels really challenging because I don't want to pester people but I also feel I have to chase them in order to keep their interest alive.

I conducted a bracketing interview today with a fellow trainee. It was really interesting to reflect on my motivations for doing the project and for focusing on identity given my dual-citizenship and experience of living in two different countries. This was not something I had considered relevant until today. It also made me more aware of the impact of attending school where children with learning disabilities were integrated into mainstream settings and how I

had internalised a sense of this being disempowering for them, whereas perhaps it might not have been.

March 2012

I conducted three interviews today and feel exhausted. I was amazed at the kindness and enthusiasm of the staff and participants about me coming to talk to them. I was also relieved that participants were familiar with the information sheet and consent forms and that I felt they were making an informed decision to participate. With the consent of the participant, the first interview was conducted in the presence of a staff member. This felt really nerve-wracking and I felt a pressure to keep her talking, particularly given that some of her answers were very short and not at all how I had expected in terms of eliciting a story about participants' lives. She also seemed to struggle with my question about telling her story about becoming a trainer, which made me aware of the need to change the wording of this in future interviews. She brought along photos of herself collecting an award on behalf of her training organisation and I was struck by how proud she seemed as a result of her role. However, on the other hand, it felt difficult to elicit any emotion about the significance of the role for her, which was also surprising. It made me consider my assumptions about the role being significant in everyone's lives.

The second interview was also challenging but in a different way. This participant was very keen to tell me his life story but seemed to become stuck when narrating times of distress in his life. As a researcher and a clinician, I was torn between wanting to move him on in order to progress the interview without making him feel dismissed, and wanting to explore this with him further in the way I might do if I were in therapy. He was also very keen to educate me at times about people with learning disabilities, which felt somewhat frustrating and belittling of my experience. However, thinking about this psychologically, this may have been a projection of his experiences of not feeling heard in his life. This participant also seemed ambivalent about his learning disability as on the one hand he said he had one, but on the other hand said it did not impact him at all. This seems to fit with the literature about the use of the LD label by people with learning disabilities.

The third interview was closer to the first in terms of a limited sense of how the role of trainer impacted the participants' life. Nonetheless, I was struck by how much this participant seemed to internalise a view of himself as a helper, and as someone who could do something in their role as a trainer that might improve the lives of people with learning disabilities, which felt incredibly empowering to listen to.

From these three interviews it does seem that the trainer role impacts the way participants see themselves but is perhaps not as life changing for everyone as I may have initially thought.

April 2012

I'm still trying to recruit from the other organisation. I heard back from them asking me to re-send my information sheets and consent forms but have not heard anything since, despite chasing them, which feels frustrating. I spoke to

Jennifer about this and she suggested that I should put a deadline in place for the manager to reply by, or ask whether there is another contact I should liaise with in case this is not something the manager can give their attention to at the moment. I also arranged another interview with an independent trainer who was keen to be involved. Unlike my other interviews, this participant narrated very little in terms of her life before being a trainer, but spoke much more about the positive impact it had on her life. There was a strong sense from her that the role had changed her life. I noticed she narrated very little in terms of the challenging aspects of the role, which felt disappointing given I had hoped to be able to gain a balanced perspective on the role. Perhaps this is where my assumptions need to be challenged and perhaps the role is wholly positive for participants?

May 2012

I had a meeting with another trainee doing narrative analysis and Louise today. Although it felt interesting to hear about their project, I left feeling as though I didn't have a clue what I was talking about in relation to my knowledge of narrative. I think the difficulty was that the other trainee was taking a different narrative approach and seemed to have a different agenda in terms of their aims for the meeting than I did, which made it challenging to focus on one thing. Given I have conducted some interviews, we also agreed that I would circulate a transcript with some initial thoughts regarding my analysis. On a positive, I heard back almost immediately from the manager of the organisation I was chasing and they have given me another contact, who has invited me to give a presentation to trainers in May. Things are progressing well now!

May 2012

I went to do my presentation at the training organisation today. I was really anxious and unsure what to expect but they were very friendly and welcomed me in to watch them practice a training session they were preparing before I spoke about my project. At the end of the presentation five trainers volunteered to take part and I have arranged interviews with all of them in the coming weeks. I have also been reading some previous MRPs that have used narrative and got really excited about one project I read which used a positioning approach as this seems to compliment my interest in identity. Perhaps there is a way that will allow me to integrate this with the methods I've already chosen? It just feels so tricky because none of the other methods give you any guidance about how to go about doing them, which feels incredibly anxiety provoking!

June 2012

I met with Louise and Celia today to start thinking about my section A and to talk more about the narrative method I've chosen. Choosing a method that allows me to stay true to my initial reasons for wanting to do the project, whilst balancing this with my anxiety about using a new approach has been difficult. I'm also feeling anxious about the expectations for section A and how to make it a stand-alone piece that also relates to section B. Nevertheless, we came up with some initial ideas about looking at the literature on valued social roles that emerged from normalisation and social role valorisation. Hearing that my

supervisors are feeling excited about the project and about working with me, has helped my confidence. Nevertheless, the pressure is definitely on at the moment, which feels hard, particularly when other trainees don't seem to be too worried about the same things I am because they are at a different stage. A trainee friend raised a good point though by saying that eventually the pressure will be on for everyone, so whether it's now or later, everyone will probably be feeling what I'm feeling at some point.

I've done three more interviews so far. One was with a trainer who came across as very experienced given the amount of training they have been involved in. It was also interesting that on the one hand they seemed keen for me to know how able they were, yet on the other spoke about having their mother as their carer and how they cannot manage health appointments without her. This felt somewhat confusing to me but perhaps it reflects the literature about ambivalence towards the LD label? The second interview was brief but I felt completely in awe of the participant during the interview and at the end. They spoke positively about their life and how they have sought out experiences in life in order to direct it according to their own agenda, which I admired. The third interview was similar to the second in that this participant also seemed to have internalised a very positive sense of self that they were keen to convey in the interview. However, I had a sense that they were keen to talk regardless of the questions I asked them, which felt challenging to manage given I wanted to give them space to talk, whilst also ensuring I covered the areas I was interested in. My different reactions to these interviews made me reflect on what it is about them that I warmed to and found more challenging. As someone who values independence I think I warm to people who adhere to that value, which both interview two and three seemed to be doing in comparison to the other one. This will be something to bear in mind when I begin my initial analysis.

July 2012

I've done my final two interviews. The first was challenging as the participant was less verbally able than any of my other participants. I found myself repeating my questions several times and I wondered about the impact of this on the participant. I also noticed that I became overly focused on trying to establish a timeline of events with her, which on hindsight, seemed to slow the interview down and was particularly challenging for her. Nevertheless, there was a strong sense of pride for this participant as a result of their role and it seemed to help them feel more confident about themselves. My final interview was also really interesting. Like other participants, he spoke about negative experiences of bullying as a young person, but also spoke fondly about his childhood, which few participants have done. I was particularly interested in a section of his interview where he was comparing himself to other people with learning disabilities who were more 'severe' than he was, or had physical disabilities that meant they were less independent. In line with the literature, this may be an example of a downward social comparison.

August 2012

I've started transcribing my interviews and I'm worried that some of them are not detailed enough to analyse according to McAdams' approach given that

some are relatively short, or lack detail about different parts of their lives (e.g. childhood). This has made me question whether this approach is the most useful one in terms of data analysis. I'm also trying to balance this with feeling understandably anxious about doing narrative analysis for the first time and whether any method is going to feel containing enough as a result? I've also started writing a draft of my section A and I've decided that I am going to look at the impact of valued social roles. The problem is that the term 'valued social role' encompasses a range of roles, making the area too vast to cover without narrowing it down to specific domains or roles. This also feels difficult in terms of justifying why I have chosen specific roles over others.

October 2012

I'm glad that the deadline is out of the way and I can begin to focus on my MRP again. As I've been transcribing my interviews I've noticed that my initial interviewees seemed to have internalised a strong moralistic tone to their interviews and in their role as a trainer, in terms of how people with learning disabilities have been poorly treated in the past and how this is wrong. This is an interesting finding that I had not anticipated. Other participants spoke broadly about their interests and current lives in terms of other activities besides training that they were involved in, which was interesting. Perhaps this reflects the fact that being a trainer changes the lives of some participants, whilst others would be doing other things if they weren't a trainer. It has also made me wonder whether this has led to participants adopting multiple identities, whereby the trainer role is not the only one they have adopted. I'm also finding it really useful to transcribe the interviews myself as this helps me become familiar with the data. It has also been useful in thinking about my style of questioning and spotting times when I could have phrased something differently such that it was more accessible to participants. I think this will be useful for my upcoming LD placement.

November 2012

Still feel as though I'm floundering a bit with section A. I'm finding it really hard to word my question properly and have done so many literature searches that I'm losing track of it all. I'm feeling an immense pressure to get the draft done by the end of November! I met with Jennifer who has helped me put things into perspective. It was also really good to get an outsider's views on the potential areas to review and explain my rationale for choosing these over other areas. I also had a meeting with Louise about my initial analysis. It was really interesting talking through one of the transcripts and be challenged about what had led me to come to certain conclusions. Louise challenged me about my hope that participants would present a balanced view of life as a trainer rather than something that has been wholly positive given my assumption that this does not reflect a realistic view on life, which also came up in my bracketing interview. It was also interesting to talk about how to go about analysing the data such that it is aligned with the narrative method rather than thematic analysis. This meeting also made me realise that I was trying to fit the interviews into what I thought was significant (e.g. a life phase about being a trainer) and losing sight of what the narrative was actually telling me. However, talking about this has helped me feel back on track now.

December 2012

Somehow I managed to get a draft of section A done by the beginning of this month. After much deliberation, I decided to review the impact of self-advocacy, employment and education-based roles for people with learning disabilities. Although my draft could have been better, I'm happy that those three areas feel relatively aligned such that they make for an interesting and informative review. I've also revisited my previous analysis and I'm still feeling a bit confused about how to go about using the McAdams approach. It seems quite formulaic, which at first glance was containing but now I just feel as though it's too restrictive. I'm also not sure how well it answers my research questions or speaks to what my data is trying to say. It feels like there will be significant gaps in terms of what does not get discussed, which is a shame given my whole interest in the project was driven by a desire to give voice to a group of people who typically haven't had one.

I've had a look at my research questions and tightened them up. I have also decided to change my analysis method to something that feels like it explicitly maps onto the research questions. I've decided to use a positioning approach given it is well aligned with the study of identity, and go back to my idea about using Gergen and Gergen given this seems to fit better with the way participants are narrating their stories (i.e. in sections, with an emphasis on temporality). Choosing a narrative method has definitely been one of the most challenging aspects of this project so far! I've analysed one transcript with a positioning approach in mind and it's been surprisingly interesting. It's reminded me of reciprocal roles on cognitive analytic therapy and I've started drawing out the roles that the participant takes in his narrative as a way of illustrating the data. I've got a meeting with Louise to go over my initial analysis in January, so it would be good to discuss this with her to see what she thinks.

January 2013

I've had feedback on my section A from Celia and Jennifer and they both feel that it only requires minor changes! I'm really shocked. I had resided myself to having to write a whole new one, or something similarly catastrophic! It just goes to show that I can be really hard on myself. I also had a meeting with Louise today to go over some more analysis and review my research questions. The meeting confirmed to me that the new narrative method I have chosen sits well with my overall ideas about identity of the participants, and also my interest in terms of how PLD are positioned. Talking about the interviews was also interesting and I was struck by how many thoughts I had regarding the transcript that I had not really articulated to anyone as yet. Specifically, we spoke about my reflection that it seemed difficult for participants to narrate the challenges of the role and wondered whether there was something about the role being a position of power that makes it difficult for people to talk about difficulties they may within it. Perhaps this parallels another struggle in terms of reconciling themselves as a person with a learning disability and a trainer at the same time given the differences in power that come with these different identities. This made up think about whether participants are sitting in a paranoid schizoid position. It was really

interesting how a conversation can help spark ideas about things. I'm feeling much more motivated now and it's re-ignited my interest in the project!

February 2013

I've been doing some analysis for a few weeks now and it seems to be going well. However, the upcoming deadlines mean that I'm probably going to have to put it on the back burner for a bit, which is disappointing as I feel like I'm getting into it. I'm beginning to draw similarities between the roles adopted by participants across the interviews, which is exciting. It has also been useful to meet with Jennifer to do some initial analysis together. Interestingly, we seem to be on the same page when it comes to thinking about roles that are relevant for participants.

April 2013

I've been taking a much needed break from work after the last deadline and my initial analysis, which has helped me regain my motivation to carry on. I sent my second draft of section A to Jennifer and there were only minor changes to make. Now I can move onto section B, which I hope to have a draft of by the end of May. In terms of my initial analysis, it has been really interesting to reflect on my reactions to different interviews and how this is informing my analysis. It almost feels as though there may be a parallel process going on for me whereby I am struggling to assign both positive and negative roles to some participants, and they are struggling to talk about the positive and negative aspects of the role of trainer. Whereas for participants who I experienced as more balanced in their perspective, this feels easier.

May 2013

I've finished analysing my interviews from a positioning approach and I'm at the stage of having to narrow things down and look for commonalities in roles across interviews. I think I've come up with a few overarching categories of roles. It has also been interesting to see the emergence of what I'm calling empowering roles for participants given my initial motivation for doing this project in this first place, and I'm really pleased that participants have positioned themselves in this way. It has also been interesting to see the different reactions participants have had to the learning disability label in terms of whether they admit they have a learning disability, or the extent to which they feel it applies to them. This has really challenged my initial views about this group of people having internalised this identity given it is a requirement for them to have a learning disability in order to be a trainer. However, it is exciting that it fits with previous research. The extent to which trainers had internalised a sense of themselves as helpers was also a surprise. Although on hindsight it seems an obvious motivation to engage in the trainer role, I guess I hadn't thought it would be as strong as it is for some participants. There also seems to be a split for most participants in terms of their life prior to being a trainer as challenging, versus their lives as a trainer now as being much more positive. My sceptical side questions this and wonders whether this relates back to there being something about the role that makes it hard for participants to acknowledge challenges given it could be viewed as weakness, which goes against the role as being powerful. I also met with Louise who suggested linking my positing analysis to my participant

summaries and my structural analysis as this may help further elucidate the link between participants' roles across the temporal duration of their narrative. This means more work but I think it will add another layer to the study.

June 2013

I've emailed everyone a draft of my section B and I have started writing section C. This has been really useful in terms of reflecting on some of the pragmatic and personal challenges that I have encountered in doing this project, and provides a sense of closure. Thinking about areas for future research also makes me think that an LD job with scope for research would be something I would be interested in.

I've had feedback on my section B from my supervisors who felt it was good. I've tweaked my introduction slightly and added some things to my discussion. It was really interesting that everyone seemed to pick up on the challenge of getting everything in that we have talked about over the last few months. There was a sense of loss around the fact that it is not possible to include everything. Part of me also feels this too given the amount of work that has gone into the project, whilst another part of me just feels relieved that it's nearly over! Overall, I'm pleased with how it has turned out.

July 2013

Just the final formatting and proof reading to go! Really hoping to hand it in on our last day of teaching! What a great way to celebrate the end of the third year!

Appendix 14: Ethics end of study report

Professor M Callanan
North Lodge
David Salomons Estate
Tunbridge Wells, Kent
TN3 0TG

11/7/13

Dear Professor Callanan,

Study Title: A narrative account of the impact of being a trainer on the lives and identities of people with learning disabilities

I am writing to inform you that the above study that commenced in January 2011 was completed on 19th July 2013. This letter is to inform you of the outcome of this study.

This study aimed to explore the impact of being a trainer on the lives and identities of people with learning disabilities (PLD) using social identity as a theoretical framework. Training providers are increasingly being encouraged to involve PLD in training, and research suggests that being involved in training impacts the identities of people with learning disabilities, and other disadvantaged groups (e.g. people with mental health difficulties). However, the existing literature about PLD is limited by small sample sizes and the majority of the data emerged from reflective accounts rather than empirical research. Furthermore, no studies have explicitly explored identity in learning disabled trainers. Therefore, it seemed pertinent to further explore the experiences of PLD in this role.

Open-ended interviews were conducted with nine trainers with a learning disability from three training organisations. Given narratives are central to how we conceive identity (Ricoeur, 1984), this study employed an integrative narrative analysis (NA) approach drawing on a structural and performance-based methods. This enabled the researcher to elicit key roles within participants' narratives that can be indicative of identity, and to explore the temporality of these roles within the wider context of participants' lives.

The results indicated that participants adopted multiple positive roles in relation to being a trainer (e.g. new me, go-getter), suggesting the role had a positive impact on their sense of self and identity. Being a trainer contributed to positive changes in most participants' lives in comparison to their lives before training. Interestingly, many participants were ambivalent about their learning disability identity despite needing a learning disability diagnosis to become a trainer. Being a trainer was also associated with practical challenges (i.e. travel, long days) and potentially resulted in a reflection on past painful experiences given the focus on talking to others about their experiences.

Clinical implications included the potential for partnership working between statutory services and training organisations to support and encourage this role (e.g. increased involvement of PLD in staff training). Additionally, clinical psychologists may be well placed to contribute to the sustainability of training organisations given their skills in service evaluation, audit and research (e.g. has participants' involvement in training impacted their engagement with other services)? Their therapeutic, consultation, supervision skills, and training in group dynamics and systemic approaches

may also be useful in supporting trainers and staff generally, and in helping trainers and staff to acknowledge, talk about and work with the challenges associated with the role. Professionals should also be wary of assuming that the LD label is salient to all PLD.

Employing NA facilitated a rich insight into participants' identities in relation to becoming a trainer, and their wider life experiences. It was positive that the sample comprised participants from multiple organisations, and different ethnic backgrounds. However, the responsibilities associated with being a trainer, and reliance on verbal communication in interviews may have weighted the sample towards individuals with mild to moderate learning disability. Whilst this limits generalisability, this is not a goal in NA (Riessman, 1993).

Longitudinal studies may be useful in further elucidating the relationship between being a trainer and positive changes in participants' lives. Employing quality of life or self-esteem measures may help identify more specific outcomes, whilst testing aspects of social identity theory may contribute a greater understanding of the relationship between social identity and the trainer role.

If you require further information please do not hesitate to contact me at the above address or via email at et104@canterbury.ac.uk.

Sincerely,

Emma Taylor
Trainee Clinical Psychologist

A project about people with learning disabilities who are trainers

By Emma Taylor
Trainee Clinical Psychologist
Canterbury Christ Church University
Email: et104@canterbury.ac.uk

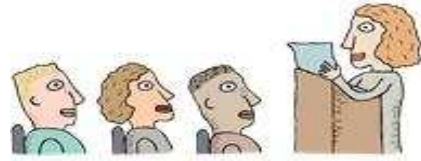
What was the project about?

- This project asked people with learning disabilities what it is like to be a trainer
- Trainers were asked about what is good and challenging about being a trainer



Why was this project done?

- People with learning disabilities are the best people to teach others about their needs
- But we do not know how being a trainer impacts the lives of people with learning disabilities



What did the project involve?

- Nine people with learning disabilities who are trainers were interviewed
- This involved talking about being a trainer
- The interviews were looked at to see what they said about being a trainer



What did the project find out?

- Being a trainer affected the lives of people with learning disabilities in different ways
- Some participants said that being a trainer improved their lives
- Other participants said their life before being a trainer was positive
- Being a trainer made participants see themselves and others differently

What do these results mean?

- Being a trainer is a valuable role for people with learning disabilities
- This project suggests that people with learning disabilities should be supported to become trainers if they want to
- More research is needed to find out more about what it is like to be a trainer



What happens next?

- Thank you to all of you who talked to me about being a trainer
- Thank you to the staff who made me feel welcome
- This project finished in July 2013
- I hope to write about it in a science journal
- I will let you know about this so you can read more about it

The text "thank you!" is written in a playful, multi-colored font. The word "thank" is on the top line and "you!" is on the bottom line. The letters are in various colors: 't' is yellow, 'h' is green, 'a' is light blue, 'n' is red, 'k' is yellow, 'y' is orange, 'o' is light blue, and '!' is red.

Appendix 16: British Journal of Learning Disabilities instructions for authors

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Edited By: Professor Duncan Mitchell

INSTRUCTIONS FOR AUTHORS

4. MANUSCRIPT FORMAT AND STRUCTURE

All manuscripts submitted to The *British Journal of Learning Disabilities* should include: Accessible Summary, Summary, Keywords, Main Text (divided by appropriate sub headings) and References. Articles should be no more than 5,000 words in length including references.

Title Page: This should include: a short title to indicate content with a sub-title if necessary; the full names of all the authors; the name(s) and address(es) of the institution(s) at which the work was carried out (the present addresses of the authors, if different from the above, should appear in a footnote); the name, address, telephone and fax numbers, and email addresses of the author to whom all correspondence and proofs should be sent; a suggested running title of not more than 50 characters, including spaces; and up to six key words to aid indexing.

Accessible Summary: Authors must now include an easy-to-read summary of their papers. This innovation was effective from 2005 and is in the spirit of making research findings more accessible to people with learning disabilities. It should also make scanning the Journal contents easier for all readers. From now on, therefore, authors are asked to:

- Use bullet points (3 or 4 at most) to help summarise the content
- Express ideas in straightforward language
- Say why the research matters to people with learning disabilities.

Summary: should be a comprehensive summary of the contents of the manuscript, of approximately 150 words.

Keywords: these are words which have relevance to the type of paper being submitted, this is for reviewing and citing purposes. You are asked by Manuscript Central to input keywords when submitting a paper, but up to 6 keywords must also be included within the 'main document' underneath the Accessible Summary.

Style

Abbreviations and symbols:

All symbols and abbreviations should be clearly explained. Abbreviations should not be used when they refer to people (e.g. learning disabilities, not LD; developmental disabilities, not DD; intellectual disabilities, not ID). Please also use “people with learning disabilities” wherever possible, not “learning disabled people”.

References

The Journal follows the Harvard reference style. For full details, please see the Journal website

<http://www.wiley.com/bw/journal.asp?ref=1354-4187>.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here:

www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here:

www.refman.com/support/rmstyles.asp

Tables, Figures and Figure Legends

Tables should only be used to clarify important points. Tables must, as far as possible, be self-explanatory and should be numbered consecutively with Arabic numerals, e.g. Table 1, Table 2, etc, in order of their appearance in the text.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. Each figure should have a legend and all legends should be typed together on a separate page at the end of the manuscript and numbered correspondingly. All symbols and abbreviations should be clearly explained.

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

All figures and artwork must be provided in electronic format. Please save vector graphics (e.g. line artwork) in Encapsulated Postscript Format (EPS) and bitmap files (e.g. halftones) or clinical or in vitro pictures in Tagged Image Format (TIFF). Further information can be obtained at the Journal website <http://www.wiley.com/bw/journal.asp?ref=1354-4187> and at Wiley-Blackwell's guidelines for illustrations: <http://authorservices.wiley.com/bauthor/illustration.asp>

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Supporting Information: Supporting Information, such as data sets or additional figures or tables, that will not be published in the print edition of the Journal, but which will be viewable via the online edition, can be submitted. Please contact the Production Editor (bld@wiley.com) for further details.