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EXPLORING RECOVERY IN PEOPLE WITH LEARNING DISABILITIES

Section A:
How can we understand the mental health of people with learning disabilities (PwLD) and what helps them to feel better?
A review of the literature

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Summary of MRP portfolio

Section A is a review of the literature which examines how mental health difficulties may differ for people with learning disabilities (PwLD) and the general population; with respect to their vulnerability to mental ill-health and the definition, presentation and treatment of mental health problems. Factors which have been found to positively impact on the mental health of PwLD are then explored. The review considers methodological limitations and gaps in our understanding, highlighting a need for further research focusing on mental health recovery for individuals with learning disabilities.

Section B presents a study exploring what recovery means for people with learning disabilities and mental health difficulties. Interviews were conducted with nine individuals and Interpretative Phenomenological Analysis used. A model was developed which described participants' entry to the therapeutic service and also their progression towards recovery. Clinical implications include: highlighting the features specific to PwLD which are instrumental in encouraging recovery and the need for acknowledging LD and non-LD identity. Social integration was explored as a way of enabling ongoing recovery.

Section C offers critical reflections on the qualitative study in four main areas: research skills acquired, retrospective evaluation of the study, implications for clinical practice, and ideas for further research in the area.

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Section A:

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Abstract

The review asks, how can we understand the mental health difficulties of people with learning disabilities (PwLD), and what helps them to feel better? The literature discusses factors contributing to the vulnerability of mental health problems in PwLD, exploring cognitive, emotional, developmental and social influences. It then examines how severe and enduring mental health definitions, presentations and subsequent interventions may differ between PwLD and the general population.

Relevant literature focussing on factors which have been found to positively impact on the mental health of PwLD and include perceptions of beneficial change was reviewed and critically evaluated. The resulting studies explored: cognitive ability; process of psychodynamic therapy; psycho-education/advice; positive sense of self; feelings of empowerment; assertiveness and problem-solving training; coping; therapeutic alliance; emotional, practical and systemic support; the conflicting nature of support versus control; groups; and the relative influence of each on the mental health of PwLD. Additionally a summary of factors within this research pertaining to negative mental health influences was also included.

The results from the review were then discussed in light of what is known about the recovery literature and the research focussing on adjustment to chronic health conditions. Further research is warranted which will explore what factors may improve mental health, and contribute to the 'recovery' of PwLD.

Introduction

It is generally considered that people with learning disabilities (PwLD) are at higher risk of mental health problems (Valuing People Now, Department of Health, (DoH) 2009, No Health Without Mental Health, DoH, 2011). Studies have reported higher prevalence rates, most notably a Scottish survey of the learning disability (LD) population by Cooper, Smiley, Morrison, Williamson and Allan (2007), which accounting for past methodological limitations in estimating rates, reported 40.9% of PwLD with a clinical diagnosis. Little is known of the factors associated with this increased prevalence (Smiley, 2005) or equally what alleviates this distress. This critical review of the literature will discuss factors contributing to PwLDs' vulnerability to mental health problems, and how severe and enduring mental health presentations and subsequent interventions may differ between PwLD and the general population. The discussion will then focus on the factors researched as positively impacting on the mental health of PwLD.

Factors contributing to increased vulnerability of mental health problems

Biological. LD inevitably affects all early psychological processes and emotional development. Individuals with LD experience poorer cognitive abilities, which may affect memory, abstract thinking, skills in planning, problem-solving and capacity to adopt appropriate and effective coping mechanisms (van den Hout, Arntz & Merckelbach, 2000; Stalker, Jahoda, Wilson & Cairney, 2011). Difficulties with communication, focussing attention and recognising emotional states (Sturmey, 2004) are also common. These difficulties can be further complicated by associated sensory and neurological impairments, (e.g. epilepsy) that can exacerbate individuals' dependency on others.

A number of genetic syndromes are furthermore associated with increased vulnerability to various mental health problems, for example, Fragile X, Prader-Willi and Downs Syndromes (Charlot & Beasley, 2013). Co-morbidity with Autistic Spectrum Disorders, and its concomitant effect on social and emotional functioning, may compound anxiety related disorders (Greig & Mackay, 2005).

Growing evidence supports the notion that low cognitive ability increases risk of developing mental health problems (Gale, Hatch, Batty & Deary, 2009; Koenen at el., 2009; Benson, 2004) and that in the absence of the necessary cognitive skills required to understand and benefit from psychotherapy, potential gains are considered unlikely (Taylor, Lindsay & Willner, 2008). There is some evidence to suggest that vulnerability to mental ill-health increases with the severity of the individual's LD (Whitaker & Read, 2006), and several of the deficits by which individuals are defined as having a LD (i.e. limitations in social skills, communication, and independent living skills) are compounded when psychopathology is present (Matson & Shoemaker, 2011).

Emotional/Developmental. Hollins and Sinason (2000) discussed the mental health of PwLD from a psychoanalytic perspective. Issues highlighted in this paper were conscious and unconscious fantasies that accompanied the disability and awareness of being part of a stigmatized group (Jahoda, Markova & Cattermole, 1988), namely a fear of annihilation, feelings of loss over the "normal self" and the impact of dependency. In addition, they discussed difficulties associated with sexual development and understanding the concept of mortality. Some of these emotional issues have also been emphasised by Arthur (2003) along with loss, sadness, rejection, abandonment, anger and low self-esteem (Cooper, 2003).

The ability to tackle mental health difficulties when it coexists with LD is further compounded by potentially fragile emotional attachments with caregivers, which impacts on individuals reaching developmental maturity. Families may also continue to grieve for the loss of a 'normal development' throughout the life stages (Bicknell, 1983; Blackman, 2003), and sometimes also experience a sense of heightened stress and learned helplessness (Nezu, Nezu & Gill-Weiss, 1992).

Social. PwLD are likely to experience a range of negative life events associated with an increased risk of developing mental health difficulties (Brown, 2000). These include: unemployment, poverty/social disadvantage (Emerson & Hatton, 2007), a lack of meaningful relationships and/or social support networks, social isolation, (McVilly, Stancliffe, & Parmenter, 2006), low levels of activity and stimulation (Mansell, Beadle-Brown, Macdonald & Ashman, 2003), stressful family circumstances, traumatizing abuse (Deb, Thomas & Bright, 2001; Emerson, Hatton, Felce & Murphy, 2001; Hastings, Hatton, Taylor & Maddison, 2004), and multiple experiences of loss (Sinason, 1992; Turk & Brown, 1993).

Such situations increase susceptibility to mental ill-health (Tsakanikos, Bouras, Costello & Holt, 2007) and have clear associations with psychological problems (Hulbert-Williams & Hastings, 2008).

How do mental health difficulties differ for PwLD?

Research suggests that rates of mental health problems in PwLD are underestimated, particularly anxiety disorders (Richards et al., 2001) and depressed mood (Nezu et al., 1995). Furthermore there is increasing recognition that this population may be more likely to experience prolonged and atypical grief (Bonell-Pascual, et al., 1999; Dowling, Hubert, White & Hollins, 2006).

Underestimating mental health diagnoses has been attributed to the distinct cultures of specialist LD and mainstream mental health services which leads to gaps in provision (Hatton & Taylor, 2005), and a lack of experienced professionals trained in both (Hatton, 2002). Furthermore the reliability and validity of diagnostic assessments are questionable (Deb et al., 2001); distress is often presented or expressed in different ways amongst PwLD (Hollins & Sinason, 2000; Whitaker & Read, 2006) which instead becomes labelled as 'challenging behaviour', and is viewed in services as separate to a mental health issue (Hatton & Taylor, 2005). Alternatively, mental health difficulties are subject to 'diagnostic overshadowing', whereby symptoms are misattributed to aspects of the LD (Reiss, Levitan & Szyszko, 1982).

Defining mental ill-health is particularly complex in relation to LD. Severe and enduring mental health difficulties is defined by the Department of Health (DoH) document, National Service Framework for Mental Health (1999) as,

> People with recurrent or severe and enduring mental illness (…) have complex needs which may require the continuing care of specialist mental health services working effectively with other agencies (p. 43).

In the general population, this usually pertains to psychosis, bipolar affective and personality disorders, and concomitant chronic physical health. However when considering an integrative diagnosis of biological, psychological, social and developmental factors (Cooper, 2003; Dosen, 2007) and the inherent difficulties this presents, the definition of severe and enduring mental health for PwLD expands and becomes far more inclusive. Research supports this notion, showing the composition of referrals meeting secondary care criteria to be of a broad range of presenting

problems (Jackson, 2009). This is reflected also in the samples amongst the many studies exploring mental health in this client population.

In light of the above discussion, the mental health of PwLD can be best understood by integrating the medical and social model (Williams & Heslop, 2005) and considers all biological, psychological, social and developmental factors together.

Therapeutic Interventions for PwLD

Recent research has contended the suggestion that mature and complete cognitive capacity is a prerequisite for good therapeutic outcomes (Taylor, 2010). Other additional factors have been acknowledged; for instance, the influence of confidence and motivation on outcomes (Willner, 2006). More importantly, research has focussed on making interventions more accessible for PwLD and the necessary adaptations required.

Adaptations

The strongest evidence suggests that interventions which have been modified appropriately for the needs of PwLD and focus on 'cognitive deficits' rather than 'cognitive distortions' will be the most successful (Willner, 2005). This would entail self-management, self-monitoring, and self-instructional training approaches in order to address cognitive impairments and process information (Willner & Goodey, 2006). Effective adaptation needs to take account of the content and also the process of therapy. Research has focussed on modifying CBT (Whitehouse, Tudway, Look & Kroese, 2006). Examples include: reinforcement of learning, reducing pace/length of sessions, more sessions dedicated to engagement, using visual aids, simplifying language, and emphasising in-vivo exercises.

Effectiveness of Interventions

There is a growing evidence-base indicating that with appropriate modification psychodynamic psychotherapy and CBT can have positive effects for PwLD (Beail, 2003; Beail, Warden, Morsley & Newman, 2005; Willner, 2006; Nicoll, Beail & Saxon, 2013).   However less is known about the factors that determine the effectiveness of therapy, or what helps people with mental health difficulties improve. In the absence of any literature which focuses on the recovery process of PwLD, factors which positively influence mental health from the client's experience and includes some perception of benefit/change will be examined. More details on the inclusion criteria and selection strategy can be found in Appendix A.

The literature[1] reviewed falls into categories of:

1) Research into the effectiveness of particular therapies for PwLD, describing factors integral to the content of the therapy or studies which investigate the process of therapy.

2) Service-user views on the experience of therapy; some of which also include results from outcome measures or clients' subjective perception of change, whilst others simply explore service users' opinions or levels of satisfaction.

3) Studies which have looked at coping strategies used by PwLD.

Ability

Research by Rose, Loftus, Flint and Carey (2005) (n=86) which compared a 16 session Cognitive Behavioural Therapy (CBT) group intervention for aggression with a waiting list control group found that a higher receptive vocabulary improved outcomes. However this result did not apply at follow-up, and there remained a large amount of variance unaccounted for, suggesting that there were numerous influential factors other than ability. A smaller treatment-control study (n=16) by Willner, Jones,

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[1] A summary table of the studies included can be found in Appendix B.

Tams and Green (2002) reported a strong correlation between progress in a similar treatment (but of shorter duration) and verbal IQ. They also observed clients' struggling with cognitive restructuring. The generalizabilty of this study was limited by poor participant attendance. Conversely, in a mixed methodology evaluation of an anxiety group (n=8), participants were reported to struggle with aspects of the intervention that relied on written materials, literacy and verbal fluency (Marwood & Hewitt, 2012), although this was based on author observation only. These studies suggest there is some limited evidence that cognitive ability may positively influence outcomes of therapy and improvements to mental health difficulties.

Process of Psychodynamic Therapy

Three studies have looked more closely at the process of change in psychodynamic therapy with PwLD. A small quantitative study (n=8) by Newman and Beail (2005) and a case study by Salvadori and Jackson (2009) each focussed on a brief psychodynamic intervention to examine how PwLD assimilate their problematic experiences, ultimately develop mastery over them and by implication 'feel better'. Both studies used the Assimilation of Problematic Experiences Scale and found evidence for PwLD having increased understanding of their problems, moving from the lowest level 'warded off', defined by avoidance and a lack of awareness, to 'attaining a degree of insight' characterised by recognising and reconciling positive and negative emotions. This indicates that PwLD tend to enter therapy at a lower level of assimilating problematic experiences (Newman & Beail, 2005) and progress at a pace which is more helpful to their mental health, possibly reflecting difference in cognitive ability.

A case study by Alim (2010) studied therapy progression through stages of the Malan model and evaluated therapy outcomes using qualitative analysis of therapeutic

sessions. Results suggest that by adopting different parental phases the therapist made reparation for early parental rejection and encouraged the psychological growth of the client from childhood through adolescence and onto adulthood, thereby improving levels of pre-therapy anger, psychiatric symptoms and self-esteem.

Part of this development involved recognising ambivalence, likened to that of a younger child who comes to realise the merging of object relations so that the world and therapist is experienced realistically as good and bad. Ambivalence also featured as part of assimilating problems and was evidenced within the description of the model (Newman & Beail, 2005), and in comments made by the client (Salvadori & Jackson, 2009).

Repetition and rehearsal is required to achieve the third stage of 'adolescence' in Alim's (2010) study. This stage is defined as developing more independence and autonomy and deeper and more equal relationships, suggesting additional time is required for PwLD to master these aspects. In the same way, Newman and Beail (2005) identified it may be necessary to repeat and rework lower stages in order to consolidate learning and lay foundations for the acquisition of more sophisticated levels. Neither study specifically tested to see if rehearsal led to automation of previous levels. Alim (2010) as a research-practitioner introduced the possibility of bias; there are also gaps in the information provided about the significance of clinical change measured and by whom. Service-user opinion on improvement in mental health was only sought by Salvadori and Jackson (2009), whereas improvement was assumed via the progression of therapy (Newman & Beail, 2005). Both studies focussed on short durations of therapy only, limiting potential results. All studies limited measuring progression to within the therapy session, and only Alim (2010) validated raters' measurements.

Results imply that PwLD require more time and rehearsal in acknowledging, addressing and assimilating problems, as well as regarding their overall psychological growth, both of which may be integral to tackling mental health difficulties. The common experiences of stigma, social rejection and attachment difficulties contextualises the importance of filling gaps in psychological development, as well as the length of time required to build a trusting therapeutic alliance. Furthermore the recognition of and the working with ambivalence appears key in the progression of mental health.

Psycho-education/Advice

Studies have suggested that participants valued educational components of therapy, for instance, those aimed at understanding and managing anger, anxiety and depression and receiving advice and guidance around these aspects. Qualitative research has looked at the 'lived experience' of individuals receiving counselling which utilised various clinical modalities (Fitzgerald, 2012) and evaluated experiences of a group intervention for anxiety (Marwood & Hewitt, 2012); whereas a quantitative research study focused on the effectiveness of a group intervention for depression (McCabe, McGillivray & Newton, 2006). More specifically, service-user evaluation studies which studied the effectiveness of individual counselling sessions (Dowling et al., 2006) and group interventions (Read & Papakosta-Harvey, 2004) found the educational element of bereavement workshops of great benefit often through normalising experiences. This is especially so given that PwLD are frequently protected from the subject of death and facts about grief and loss.

In a case study examining Cognitive Adaptive Training used with a PwLD and psychosis, teaching coping strategies was reported as beneficial (Allot, Francey & Velligan, 2013) and showed improved outcomes in anxiety, depression and self-

concept in the research by Marwood and Hewitt (2012). Similarly, a large

quantitative treatment-control study (n=179) purporting the effectiveness of a group

CBT intervention for anger and showing fidelity to the model, focussed on teaching

behavioural strategies more than addressing participants' emotions and cognitions

(Willner et al., 2013). Whereas, the qualitative study by Fitzgerald (2012) and a

quantitative study (n=44) by Rose, West and Clifford (2000) both investigating

factors associated with the efficacy of an intervention for anger, attributed

improvements in mental health to being taught to regulate emotion.

These studies differ in whether they capture views on what participants found

helpful in the intervention (Dowling et al., 2006; Fitzgerald, 2012; Marwood &

Hewitt, 2012; McCabe et al. 2006; Read & Papakosta-Harvey, 2004), or whether

beneficial aspects are indirectly assumed through studies demonstrating positive

effects for therapeutic interventions (mode and content) rather than specifically testing

the particular variable independently (Rose et al, 2000; Willner et al., 2013).

Furthermore these differing studies may also feature corroborating outcome

measurement (Allot et al., 2013; Dowling et al., 2006; Marwood & Hewitt, 2012;

McCabe et al., 2006; Rose et al., 2000; Willner et al., 2013) albeit with limited

clinically significant change reported, the positive exception being McCabe et al.

(2006).

Fitzgerald (2012) and Read and Papakosta-Harvey (2004) did not measure

service-user' perception of change per se, but captured a more general post-treatment

evaluative opinion. It is frequently unclear in the latter study whether comments

discussed came from the participants or whether they reflect the subjective views of

the authors; positive evaluation may also be influenced by the promise of a social

event post-study. Lastly, not all participants had a clinically significant mental health

diagnosis, (McCabe et al., 2006; Marwood & Hewitt, 2012). These comparative differences with the other studies reviewed may influence findings.

These results show that the mental health of PwLD may benefit from directly acquiring information through advice or education. This knowledge may not previously have been taught due to others being over-protective, not deeming it appropriate, or underestimating individuals' ability to understand; or it may have been poorly taught or not retained due to cognitive limitations. Willner et al. (2013) highlighted the difficulties inherent in working with the 'cognitive distortion' model as opposed to focussing on addressing 'cognitive deficits'.

Empowerment

Gaining insight and understanding can empower individuals which may in turn benefit mental health. Research has shown that group interventions with a focus on psycho-education for bereavement have promoted confidence within individuals enabling them to confront or talk to their families (Read & Papakosta-Harvey, 2004; Dowling et al., 2006).

A small (n=10) quantitative evaluation of Solution-Focused Brief Therapy (SFBT) for PwLD, by Roeden, Maaskant, Bannink and Curfs (2011) showed that by giving the client ownership of their goals and giving them expert status in the accomplishment of these goals increased a sense of empowerment. SFBT by definition focuses on an individual's ability to solve problems, and is designed to develop self-efficacy. In this study positive change in mental health was psychometrically measured, using reliable and valid instruments, albeit improvement was arbitrarily deemed significant. Fidelity to the model was not tested, nor did this study have a control group and the small sample size limits statistical power of this study. Moreover SFBT seeks to address only concrete and immediate issues and so

more likely caters to the cognitive abilities of PwLD, which may have led to more positive results.

Positive Sense of Self

Another gain to learning, which like empowerment may amplify any therapeutic effect, was identified by Willner et al. (2013) as a positive sense of self. This finding was echoed by Pert et al. (2013) in a qualitative study using Interpretative Phenomenological Analysis to investigate clients' perspectives of CBT. Willner et al. (2013) found that participants frequently expressed pride in their achievements and the praise received for them, both in and outside of the CBT group. Service-users, evaluating their treatment reported having more confidence and feeling better able to express themselves (Pert et al., 2013). Caution with interpretation is needed as some of the participants in this study had an IQ which exceeded the confidence intervals of a score of 70. As IQ is one of the three component parts of a LD diagnosis, if levels of ability measured in IQ does impact on the therapeutic process, or clients' perceptions of this, the validity of these results as specific to PwLD is questionable.

None of these studies established a direct link between improved mental health and feeling empowered or feeling better about oneself. There are no independent or psychometric measures of these constructs; instead they focus on service-user views within treatment effectiveness studies, or were deemed to be a component part of the therapy model.

Assertiveness and Problem Solving-Training

In line with evidence that acquiring knowledge and feeling empowered may positively affect mental health, input on assertiveness in a CBT programme for depression has also been well-received by participants (McCabe et al., 2006). Furthermore, a cross-sectional study (n=28) by Nezu, Nezu and Arean (1991) found

both assertiveness-training and problem-solving to show sustained improvements

(after 3 months) for self-reported psychological symptoms and distress. Similarly the

study by Rose et al. (2000) incorporating these two elements into a group CBT

treatment, attributed its success to both. This intervention also emphasised client

involvement within its delivery, therefore it is not distinct from the possible benefit of

feeling empowered and having increased self-esteem.

Coping

Possible benefits of empowerment or autonomy have been evidenced by Hartley

and MacLean (2005), who reported that having perceived control moderated the

ability to cope with distress (as evaluated by measures of anxiety and depression). In

conjunction with perceived high levels of control this correlational study and a later

one (Hartley & MacLean, 2008) found active coping to offer effective strategies.

Exploring types of active coping, Hartley and MacLean (2008) found although

problem-focussed coping was used more often, when controlling for other factors

emotion-focussed coping (EFC) was the only strategy to negatively predict distress.

The beneficial nature of EFC is supported by service-users' views on therapeutic

experiences expressed in Pert et al. (2013). It seems that feeling good about oneself;

feeling empowered and in control of situations and able to resolve problems

contributes to feelings of improved mental health. Regulating emotions is also

considered to be effective although used less frequently which may reflect the

teaching required to do so (Fitzgerald, 2012; Rose et al., 2000).

Both Hartley and MacLean studies (2005; 2008) found a weak association

between avoidant coping and psychological distress. Given that PwLD are often

unable to exert any control over their lives, they argue this to be a relatively proactive

stance rather than a maladaptive coping strategy. These studies have focussed on

coping with social situations which PwLD experience as distressing. Little is known

about how these results would generalise to other situations. Less than half the

sample had a clinical mental health diagnosis, and these studies may be more

applicable to what helps in cases of less severe levels of distress.

Therapeutic Alliance

Qualitative research examining subjective experiences of individual therapy has

shown clients to report the value of the relationship with their therapist and having a

collaborative working alliance (Khan & Beail, 2009; Merriman & Beail, 2009;

Raffensberger, 2010; O'Brien & Rose, 2010; Gifford, Evers & Walden, 2013; Allot et

al., 2013). Equally this finding has been psychometrically measured (Roeden et al.,

2011) and is represented as integral to the validated model in the Willner et al. (2013)

study. In particular, qualitative evaluations of varied therapy modalities have reported

the appreciation of person-centred characteristics of warmth, empathy and validation,

unconditional regard and being non-judgemental (Macdonald, Sinason, & Hollins,

2003; Gifford et al., 2013; Pert et al., 2013). In the latter study the importance of

being treated like an adult was also noted, when this was not always apparent

elsewhere.

Considering key aspects in the development of the therapeutic alliance, the

importance of boundaries is reflected in the studies previously described that focussed

on psychodynamic therapeutic process but also in the value placed by participants on

privacy (Merriman & Beail, 2009), safety and confidentiality (Dowling et al., 2006;

Gifford et al., 2012), and trust (Fitzgerald, 2012).

Aforementioned studies relied on subjective opinion in measuring therapeutic

alliance, apart from the Roeden et al. (2001) study. Participants gave concrete

examples of positive change in mental health (Gifford et al., 2012; Merriman & Beail,

2009), whereas others did not consider themselves to have improved, or worried about the sustainability of changes (Macdonald et al., 2003; Pert et al., 2013). The remaining qualitative studies captured participants' views on the helpfulness of the intervention and Dowling et al. (2006) and Marwood and Hewitt (2012) also included outcome measurement to demonstrate improvement.

Views on therapeutic alliance may have been skewed by the authors' vested interest in the type of therapy (group analytical) delivered (MacDonald et al., 2003) or the presence of support workers/carers when PwLD were asked for their views regarding improving mental health services (O'Brien & Rose, 2010).

There is strong evidence of a therapeutic relationship having a positive impact on the mental health of PwLD, which is similar to research within the general population. However it could be argued that PwLD are less likely to experience close relationships generally; thus an alliance will be highly valued, fulfilling a long-standing need. It may well be that a good therapeutic alliance underpins the successful imparting of information enabling feelings of empowerment and other positive factors.

Support - Emotional

The correlational study by Hartley and Maclean (2008) found support-seeking ameliorated distress, whereas qualitative studies exploring service-user views (Khan & Beail, 2013; Raffensberger, 2010) have discussed the importance of consistent support received from counselling in achieving positive outcomes. In the latter study, this led to recommendations for careful planning in the termination of the counsellor/client relationship and the organisation of sufficient support beyond counselling to ensure that changes made are maintained. Multiple research interviews in the Raffensberger (2010) study took place over a period of several months, which

may have influenced PwLD's perspectives on support and provided more opportunities for reflection on their experiences, which not all studies may have afforded.

Support from family, friendships and having a social life is also valued by service-users (McCabe et al., 2006; Pert et al, 2013) and in a study by Taggart, McMillan and Larson (2009) which interviewed women with LD and mental health problems, these have been identified as protective/resilience factors regarding mental health.

Support - Practical & Systemic

Service-user views have shown the potential benefit in establishing a well functioning support network, and that practical support is as important in facilitating positive outcomes as emotional support (Taggart et al., 2009; Raffensberger, 2010). Carer involvement has been found to enhance treatment effects. Willner et al. (2002) in an intervention study for group CBT observed that clients who did best overall (post-treatment and at follow-up) were those who were accompanied by carers. In addition, SFBT (Roeden et al., 2011) and Cognitive Adaptation Training (Allot et al., 2013) include family and/or carers in the treatment. Both studies showed positive outcomes but fidelity to the model was not tested, nor were these aspects assessed as independent variables.

Support vs. Control

In hypothesising possible correlational findings, Hartley and Maclean (2008) proposed that support which was more descriptive (e.g. offering advice) rather than constructive (e.g. implementing practical guidance) may not be helpful in the long-term if it obstructed growing independence by fostering reliance on others. However, there were no significant findings to corroborate this. Also, consideration of how an

individual copes is limited to one time point only, which discounts the possibility that individuals could learn from advice offered and later implement this. Seeking advice is viewed negatively as a position of dependency. However, the effective use of strategies will vary according to each unique situation; the key to success in coping is likely to be having the flexibility to apply these appropriately.

Merriman and Beail (2009) found that clients developed a dependent alliance with their therapist, assuming a subservient position. Service-users' views on their experiences of various modes of therapy have also demonstrated an external locus of control, believing that the responsibility of progress and maintaining any positive changes made rested with their psychologist (Kilbane & Jahoda, 2011; Pert et al., 2013; Gifford et al., 2013); a sense of self-agency was not thought to affect therapeutic engagement and improvement. However, service-users have also commented on a need for help and support and how this sometimes conflicted with their desire for autonomy over their lives (O'Brien & Rose, 2010). It could therefore be argued that some degree of independence and autonomy is beneficial for mental health; however this has not been independently tested. What is more certain is that support is an important factor in ameliorating the distress and symptoms of mental health difficulties (Lakey & Orehek, 2011); also that support can encourage dependency, although the impact of this is questionable.

Groups

Research has shown the value of group process as indicated in the validation of the manualised group CBT intervention of which this was an integral part (Willner et al, 2013). Additionally, service-user comments have highlighted positive gains attributed to being part of a group; as well as feeling able to talk and feel listened to, the group offers both a sense of belonging and reciprocal support with others who are

experienced as 'similar' (MacDonald et al., 2003; Read & Papakosta-Harvey, 2004; McCabe et al., 2006; Marwood & Hewitt, 2012). Group cohesion promotes mutual sharing, personal knowledge and understanding (Read & Papakosta-Harvey, 2004).

The evidence suggests that being part of a group is of value. Additionally, documented benefits of psycho-education, empowerment and positive sense of self, were predominantly evidenced within group interventions and positive effects of group process are echoed in the general population (Yalom, 1995). However the LD literature shows a tendency towards living with social isolation/stigmatisation, a situation potentially impacting on access and inclusion to groups.

Negative Mental Health

The review of service-user experiences also revealed factors perceived as negative to mental health. Although not pivotal to reviewing the factors which help ameliorate the mental health difficulties of PwLD, by implication, these issues may prove relevant and beneficial, and therefore worthy of mention. Examples of these negative influences include obstacles to engaging in services and knowing what to expect, the identity ascribed to PwLD and associated feelings of stigma, marginalisation and a sense of injustice. That PwLD experience difficulty accessing services reflects PwLD lacking (and therefore seeking) knowledge which is salient to their lives, as well as failure of their expectations being managed. It could also be that PwLD are not treated autonomously by significant others and that their communication needs are not catered for on a societal level. It is the ramifications of the social construction of LD identity compounded with mental health needs which may well result in marginalising experiences. Perceptions of unfair treatment comparable to non-LD others and awareness that their needs have failed to be accommodated will inevitably result in a sense of injustice for PwLD.

General Critique

Most of these results were based on qualitative methodology, which whilst enriching our understanding, is subject to problems of representativeness and generalisability. Findings are frequently inferred from service-user views or from the content of the intervention model, the fidelity of which is only tested in one study. Few quantitative studies look directly at independent effects on mental health. Studies vary in whether positive change is measured, and whether follow-up measurements exist.

There is the unavoidable problem inherent in comparing different clinical diagnoses or severity as well as the variety of measures used. Unless otherwise stated, studies considered the needs of individuals in the design of their research. However, problems remain for all measurements which rely on memory and understanding abstract concepts. Samples sizes are frequently small and purposive selection strategies adopted which may incur bias. Participants may have been chosen on the basis of compliance with desired findings or this may have been encouraged within the individual as a consequence of selection.

Conclusion

The contributing factors to the mental health of PwLD are likely to be complex, full of many possible interactions untested for in this population. This review gives some indication of what factors may improve mental health, and contribute to the 'recovery' of PwLD.

The literature suggests that cognitive ability may impact on the effectiveness of interventions, though arguably less so given necessary modifications. PwLD take longer to assimilate problem experiences and progress through stages of

psychological development and growth, possibly due to reasons of cognitive

limitations and/or societal influences. Accepting ambivalence has also been shown as

pivotal to better mental health.

More certain is that PwLD perceive seeking information and acquiring

knowledge as helpful to their mental health (which supports the 'cognitive deficit'

model). Viewed as particularly helpful are coping strategies, and problem-solving

techniques.

Feelings of self-efficacy, empowerment and most importantly feeling in control

of one's situation may contribute to coping with mental health difficulties. Self-

efficacy and self-development, (both emotionally and in terms of acquiring

knowledge) and establishing supportive relationships can all be seen as attempts to

improve ones' self-identity. The importance of self-concept in mental health is

reflected by the negative experiences reported as associated with a 'learning disabled'

identity.

Key influential factors seem likely to be the therapeutic relationship, and

support which involves carers and families. Support can lead to dependency although

it is not clear whether this would have a positive or negative effect on individuals'

mental health. It may be that dependency is internalised through the therapeutic

alliance to achieve independence. The value of group processes is highlighted as

particularly beneficial for this population, and may be the active ingredient to other

positive influences, such as positive self-concept and learning.

Gaps in emotional understanding, development and knowledge acquisition may

be explained by the body of research which describes the experience of PwLD as one

of stigma, social isolation and possible relationship/attachment difficulties, coinciding

with cognitive impairments. The studies vary in evidence and rigour in measuring

positive changes to mental health and very few direct positive effects have been

observed.

How these findings relate to the recovery literature

Many of the factors identified in this review as potentially improving the mental

health of PwLD are reflected in the recovery literature within the general population

(Leamy, Bird, Le Boutillier, Williams & Slade, 2011; Schrank & Slade, 2007) with

older people (Cheffey, Bagwell, Marlow & Barnes, 2010; Daley, Newton, Slade,

Murray & Banerjee, 2013) and within specialist settings in forensic, substance misuse

and eating disorders (Turton et al., 2011). They are prevalent too in the literature on

psychological adjustment of chronic health conditions (de Ridder, Geenen, Kuijer, &

van Middendorp, 2008; Dennison, Moss-Morris & Chalder 2009; Stanton, Revenson

& Tennen, 2007).

Support is featured throughout the recovery literature, described as a feeling of

connectedness, experienced through relationships or as part of a community.

Similarly, specialist populations experience social inclusion, which draws

comparisons with the benefits experienced as being part of a group and valuing a

support network. From a chronic health standpoint, supportive others can help

individuals better understand problems, use more effective coping strategies and

increase their motivation. The acknowledgement and expression of emotions on its

own has been found to positively affect mental health. Furthermore, a review by

Martire (2005) supported the inclusion of family members in psychosocial

interventions.

The conflict between receiving support and the resulting feelings of

dependency, and personal autonomy is reflected within research on older people with

cognitive impairment. Specialist groups were found to experience ambivalence between the safety of treatment and recovery.

Resuming responsibility and regaining control over one's life dominates the mainstream literature and specialist population research as does the promotion of re-establishing 'normal life.' Similarly empowerment features heavily as an element of recovery. Self-efficacy and appraisal of own capabilities and perceived control over outcomes is also seen within the chronic ill-health literature. Self-management benefits psychological adjustment and problem-solving is valued regarding chronic health conditions.

Coping skills are described within the recovery literature as "symptom management". Active coping strategies are promoted within chronic health reviews, especially more adaptive emotion-focussed coping and to a lesser extent problem-focussed coping. Coping strategies specified in older adult studies include seeking information and understanding about their physical illness, and promoting a sense of identity.

Rebuilding and redefining a positive sense of identity and overcoming stigma is a significant element within the general recovery literature and there is strong emphasis on the maintenance and continuation of identity in Daley et al.'s (2013) study on older adults. This is in contrast to the above review of the literature which considers a 'learning disability' identity as problematic to mental health.

Aspects in the recovery and psychological adjustment to chronic health literature not reflected within the review are: hope and optimism about the future, belief in recovery, finding meaning and purpose in life which may lead to personal growth and enrichment, spirituality, acceptance of the illness, and finding benefits within the mental ill-health experience.

Recovery has been regarded to a lesser extent as a lifelong process, or as living with uncertainty which is described as deficiencies in information and unpredictability regarding symptoms, diagnosis, treatment, relationships and future plans. Achieving a full recovery and perceiving getting back to normal as unrealistic has also been expressed by those with mild cognitive impairment (Cheffey et al., 2010). The positive influences of emotional development and therapeutic alliance on mental health are specified only within the published LD literature. Numerous treatment effectiveness studies suggest group processes are an integral feature of successful interventions for individuals with borderline personality disorder (e.g. Bateman & Fonagy, 2008) and psychosis (e.g. Dannahy et al., 2011).

To date, factors which may enable the improvement of mental health for PwLD can only be inferred from other related research. There has not been a direct examination of the experience of individuals with learning disabilities who feel better and their mental health progression retrospectively from the position of 'recovery'. Adopting a qualitative inductive approach will best address this gap in the recovery literature, whilst simultaneously respecting the heterogeneity within the client group.

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EMMA TRUSTAM

Section B:
What does recovery mean for people with learning disabilities (PwLD) who have mental health difficulties?

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Abstract

Recovery as an approach has gained momentum over the past 20 years. There has been a proliferation of research exploring the definition of recovery within adult mental health populations, but no research to date which has focussed on recovery in PwLD. The aim of this study was to explore the experiences of recovery for individuals with learning disabilities and mental health difficulties and see how they compare to those findings within the existing recovery literature. A qualitative design using Interpretative Phenomenological Analysis was applied and nine interviews were conducted. A model was developed to depict the recovery experience. The model firstly describes how participants felt entering the service, their Mental Health/Therapy Experience, and explains how these experiences were validated and the recovery process enabled through the therapeutic alliance. Once enabled, the second dimension of the model is detailed, that of the Client Recovery Experience which extends across three phases of recovery. The first phase, Feeling Better describes elements perceived as integral to improved mental health. The second phase, Recovery Ongoing identifies that more input is required. Thirdly, Attainability?: Reality, Ideals and Fantasy, reveals PwLD's perceptions of recovery and the techniques used in striving to achieve this. Salient features of recovery specific to PwLD are recognised as important to clinical practice, and results suggest there is a need to openly discuss LD identity, and address idealisations surrounding a non-LD one. This would involve setting realistic goals and managing expectations accordingly and focussing on social integration as a way of enabling ongoing recovery.

Keywords

Background

The prevalence of the recovery approach has gained momentum over the past

two decades and has flourished most notably within the field of adult mental health.

Most recently governmental policy has promoted and driven the recovery movement

within the Mental Health Plan 2009-2019[2] (DoH, 2009a) which states that all mental

health services should include a recovery focus. Despite the global commitment for

services to deliver recovery-orientated practice (Davidson & Roe, 2007); recovery is

as yet an ill-defined term; however, it is generally used to describe the process of

improving or coping with mental health difficulties and associated adversities, as

defined by service-users themselves.

Defining Recovery

Definitions of recovery populate the adult mental health literature, focussing

on severe and enduring mental ill-health of psychosis, depression and bi-polar

disorders. Very little research exists for other groups in specialist settings and there

has been no research to date which has looked at recovery for people with learning

disabilities (PwLD), as highlighted by Handley, Southwell and Steel (2012).

'Clinical recovery' is a term developed by mental health professionals that

refers to symptom relief, the restoration of functioning in all areas and 'getting back

to normal'. This differs from 'social recovery' which involves living a meaningful

and satisfying life, regardless of ongoing or recurring symptoms or problems. This

definition pertains to the 'normalisation movement' (Wolfensberger, 1972) and

'social role valorisation' (Wolfensberger, 1983). It emphasises PwLD integrating into

and being accepted into society in light of the social challenges faced as a result of

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[2] New Horizons: A shared vision for mental health

mental health problems. Of significance here is that recovery is not synonymous with cure; it is a way of living in order to make the most out of life (Rethink, 2005).

The most widely accepted definition of recovery comes from Anthony (1993),

"A deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in life as one grows beyond the *catastrophic effects of mental illness"* (p. 13).

Recovery is a highly individual process, what is personally meaningful and satisfying will vary across people and for the same person at different times in their lives. These multiple perspectives may explain the lack of consensus around the definition of recovery (Slade, 2010). However, personal efforts to conceptualise recovery in adult mental health (mainstream) literature have revealed several common themes.

Research in Adult Mental Health

A recent review of all recovery literature has developed a conceptual framework which includes: connectedness, hope and optimism about the future, identity, meaning in life, and empowerment (Leamy, Bird, Boutillier, Williams & Slade, 2011). This review adds the extra dimension of 'connectedness' to the personal recovery framework developed by Slade (2009), and Schrank and Slade (2007) provided a more detailed examination which also included spirituality, responsibility and control, and symptom management. Support for these themes can also be found in a review of British literature by Bonney and Stickley (2008), which included 'risk and responsibility' and made reference to the current ethos of 'risk-reduction' as inhibiting choice, independence and hampering potential for change.

Research in Specialist Settings

The noticeable dearth of literature on PwLD recovering from mental health difficulties goes against recommendations made by Royal College of Psychiatrists (2008) who reported that recovery should be better understood with regards to all mental health specialisms and the founding principles of the recovery approach, which argues the meaning of recovery, should be defined by service-users. Within a society where mental health difficulties for PwLD are most prevalent (Deb, Thomas & Bright, 2001), it begs the question as to whether the existing recovery model is useful for PwLD, or does it need re-conceptualising to meet their needs?

A pilot study by Turton et al. (2011) focussed on the notion of recovery for patients with eating disorders, dual diagnosis, and forensic mental health. Many of the results were comparable to the mainstream literature; the process of recovery was seen as lifelong and focussed on alleviating clinical symptoms. Of importance was establishing a positive sense of self, having a sense of purpose and valued social roles within society and autonomy in their treatment. Hope and a sense of future were also paramount. Ambivalence was however, an unusual theme, apparent in participants weighing up the benefits and losses of recovery.

Research by Cheffey, Bagwell, Marlow and Barnes (2010) and Daley, Newton, Slade, Murray and Banerjee (2013) on accounts of recovery for older adults identified other differences. These included living with uncertainty and difficulty in negotiating a balance between empowerment and dependence.

Where the results stood apart for all three specialist population studies is in adopting a realistic notion, one which considered full recovery as not easily attainable or recovery not necessarily satisfying.

What do we know about PwLD and mental health recovery?

In the absence of research exploring recovery for PwLD, Handley et al. (2012) draw significant comparisons between the recovery movement and existing policy within the field of learning disabilities (LD). They point to Valuing People (DoH, 2001), Valuing People Now (DoH, 2009b), A Life Like Any Other? Human Rights of Adults with Intellectual Disabilities (House of Lords, 2008) whose aims were to empower and include PwLD within society by promoting social inclusion, independence, choice and rights. Furthermore, the authors describe the tension in services between these aims, and the duty to care and protect PwLD within the current culture focussed on "risk management".

Considering what is known about learning disabilities: the recognition of impaired cognitive abilities, emotional/psychological development and social challenges may help elucidate their experience of recovery, and what the impact these factors may have on a number of areas, including self-confidence and the ability to understand, relate to others, and implement actions.

Also, in view of the many social challenges faced by PwLD in society, the notion of 'social recovery' is of particular relevance. This relates to living with stigma; discrimination (for instance, loss of rights regarding employment and housing); and lack of opportunities for self-determination, or socially valued roles: all these factors may negatively affect mental health and inhibit recovery.

For PwLD these challenges are not something that they incur due to their mental health difficulties alone; these are issues that they face in everyday life because of the challenges LD presents. Also where recovery differs for PwLD, compared to the general population is in the emphasis placed on returning to a former positive state, for example, re-joining the social world and rediscovering self-identity.

However, what if PwLD were not previously integrated members of society or felt happy in their lives, and what if they did not feel a strong sense of self to return to?

Handley et al. (2012) illustrated this point, arguing that PwLD face 'double jeopardy' in that mental health difficulties are not so easy to disentangle from one's LD; both lead to limited social opportunities (e.g. employment), and in turn are associated with poor mental health. Given that a learning disability is a lifelong condition and given that PwLD are the most excluded in society (DoH, 2009b) the chances of 'double jeopardy' are high.

In order to examine these hypotheses relating to the definition of recovery for PwLD, the next step is to explore the experiences of mental health recovery from the perspective of PwLD (Handley et al., 2012) and seek to understand whether these are unique to this client group, and if so how.

Research Aims

The aim of this research is to investigate how the recovery literature is relevant to PwLD and specifically, what is the unique experience of recovery for PwLD.

Method

Research Methodology

Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) aims to capture the essence of individuals' experience through a process of interpretative engagement with the data. The nature of recovery naturally lends itself to qualitative methodology, in particular IPA, as the underlying concept of recovery is described as an individual developing a meaningful understanding of a "deeply human experience" (Anthony, 1993). Furthermore, IPA has been successfully

employed with people with learning disabilities where communication needs are fully

accounted for (Perry, 2004).

Participants

Participants had received therapeutic services across three neighbouring urban

areas, and had been discharged within the past three months (or were in the final

sessions of treatment). Clinicians initially approached potential participants in order

to gauge their interest in the study; the following criteria were used to identify

participants:

- Demonstration of the capacity to consent.

- Over the age of 18

- A learning disability and a significant mental health difficulty as assessed by

  the referral criteria to the service which included a formal measurement of

  LD and the Health of the Nation Outcome Scale –Learning Disabilities

  (HoNOS-LD).

- Perception of a mental health improvement by both the client and clinician.

For more details on the recruitment procedure please refer to Appendices C and

D. Capacity to consent was assessed by the individual's clinician using the Mental

Capacity Act (2005[3])

There were nine participants in total, consisting of six males with ages ranging

from 20-54 years (mean age =33.2). Five participants had been discharged from

services and four had only a few sessions left. Whilst seven participants lived in the

community, two resided in a forensic inpatient setting (Appendix E).

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[3] British Psychological Society (n.d.). Mental Capacity Act (2005) Short reference guide for
psychologists and psychiatrists. Royal College Psychiatrists, London: Department of Health.

Procedure

Clinicians sought verbal consent from interested participants to be telephoned to discuss the study further and to ask any questions. On agreement an accessible information sheet and consent form (Appendices F and G) were sent and individuals given at least 48 hours to consider. This was then followed up with another phone-call to check consent and that the information had been understood, after which an interview was arranged at a location convenient for each participant. Information for carers/ family members was also made available, if agreed by the participant (Appendix H).

Capacity to consent was checked again before and after each interview and further confirmation sought that information regarding the study had been understood, and any questions addressed. Written consent was then obtained. Interviews were audio-taped and conducted following the guidelines set out by Smith et al. (2009) and lasted between 41 -59 minutes.

Ethical Considerations

Ethical approval for this study was obtained by the NHS Research Ethics Committee (Appendix I) and the Research and Development department of the host NHS organisation (Appendix J).

The possibility that the interview may prove distressing for participants was recognised (Cameron and Murphy, 2006) and the following precautions put in place:

- Each participant was reminded that they could withdraw from the study at any time, and the researcher would terminate the interview in the event of undue distress.

- Participants were debriefed after the interview and arrangements put in place to talk to someone of their choosing who was independent from the study.

- Details of relevant support organisations and the Complaints Procedure were
  outlined.

A brief summary of the results will be sent to all the research participants in a clearly communicated and accessible format. Data was not personally identifiable at any stage, and data protection guidelines and policies were followed to ensure confidentiality.

Design

The study's design followed guidelines developed by Smith et al. (2009). Service-users were consulted in the development and piloting of the interview schedule (Appendix K); this was also reviewed by practitioners with experience and expertise in the field of learning disabilities.

Methodological considerations for PwLD were followed (MENCAP, 2000; Perry, 2004); visual information was included in the form of photographs (Swain, Heyman & Gilman, 1998) and a large 'time-map' was used to represent and explain the abstract concept of time (Appendix L). The delivery of the interview considered issues of acquiescence and power dynamics.

Data Analysis

Each interview was transcribed in line with guidance on data analysis for IPA (Smith & Osborn, 2003). Firstly, a key transcript was identified and read repeatedly noting initial conceptual ideas and reactions to the data. On subsequent reading initial interpretations were made and themes identified. The same procedure was then carried out on all subsequent transcripts. Using an iterative process, themes were then examined and categorised to develop 'super-ordinate' themes, whilst making continuous reference to the original texts.

Quality Assurance

In order to support researcher reflexivity a journal was kept (Appendix M) to manage and evidence any assumptions and reactions influencing data collection and interpretation (Fischer, 2009). A sample transcript was also independently analysed, and themes cross-checked by supervisors (Turpin et al., 1997). Participant demographics (Appendix E) contextualise each individual within the sample.

Established IPA recommendations (Smith et al., 2009) were followed and accounts of methodology and data analysis (Mays & Pope, 2000) were clear, transparent and replicable. Appendix N is an example transcript detailing all codes and themes, and Appendices O and P outline how the initial themes correspond to the model of recovery developed.

Results

The aim of this study was to use Interpretative Phenomenological Analysis (IPA: Smith, 1996) to privilege people with learning disabilities' personal experiences of recovery from mental health difficulties, and understand these in relation to their learning disability.

The analysis revealed that the recovery experience for PwLD can be conceptualised as the Mental Health/Therapy Experience and the Client Recovery Experience (Figure 1). The first dimension depicts the early experiences of mental health as participants enter the service, and describes what is perceived as helpful in terms of what the therapy/service provides. Four distinct themes elaborate on this experience: Expressing Unfair Treatment, Seeking Understanding, Valuing Information, and Managing Expectations.

Secondly, the Client Recovery Experience includes three phases of recovery that describe participants Feeling Better, but require or are perceived to require additional input and continuing support (Recovery as Ongoing). The phase Attainability questions the realism of attaining some of the goals expressed and the role that fantasy played in accomplishing these. It includes presentations of idealised versions of oneself or one's life, and a desire to deny ones learning disability or consider that it is possible to recover from this condition thus aspiring to a perception of a "normal" life. Seven themes define the Client Recovery Experience: Self-Management of Mental Health, Emotional Development, Autonomy, Connectedness, Positive/Empowered Identity, and Belief in Recovery; lastly Process of Recovery represents the abstract experience of what it is like to feel better and recognises multiple interactions amongst themes from both dimensions of experience (Mental Health/Therapy and Client Recovery).

Aspects of the mental health and therapeutic experience are all facilitated by the Therapeutic Alliance. The relationship with the therapist, especially the feeling of being understood enables all elements within the Client Recovery Experience.

Themes within each phase of recovery are described and supported by illustrative quotes. The focus of interpretation considers aspects of the recovery experience in light of the client population and seeks to understand why they are unique to PwLD.

Figure 1 – Model describing recovery of mental health difficulties for people with learning disabilities

DIMENSION	MENTAL HEALTH/THERAPY EXPERIENCE		CLIENT'S RECOVERY EXPERIENCE		
Phases	*Entry to service*		*Feeling Better*	*Recovery as Ongoing (/More support needed)*	*Attainability: Reality, ideals and fantasy*
Themes	**Seeking Understanding** about life questions and confusions	**Talking and Therapeutic Alliance** – "It's just good to talk about things" (building trust, feeling understood)	**Self-management of Mental Health – "Learn how not to get injured from stuff"**		
			Using coping strategies, techniques i.e. finding support network, talking to others, adapting speech Monitoring feelings	Reinforcement of coping strategies required-	Learning from "wrestling moves". Escapism, catharsis, as coping strategies
	Expressing Unfair Treatment in Life		**Emotional Development- "She has her moments, bit like everybody else"**		
			Being treated like an adult, Tolerating ambivalence, Self-understanding/ Understanding "the other"	More opportunities wanted: Being treated like an adult Continued needs identified in all areas Understanding/normalising fear	Displacement of anger through metaphor of wrestling
	Valuing Information Advice, learning coping strategies		**Autonomy vs. Support – "I _can_ do things for myself" vs. "She's always there for me"**		
			(Balance between autonomy and support) Independence/Dependence Personal responsibility for recovery Strengths/Resourcefulness	More independence, personal responsibility wanted Continued support/information - needed	Analogy of "devil trapped in a box"- taking control of recovery. Fantasy of independence, (boat, maps, driving)
	Management of Expectations Clarity of, Ability to recall without reinforcement		**Positive/Empowered Identity – "Remember how people make me feel good about myself"**		
				Recovery from LD:	
			Non LD Identity Self Efficacy, Sense of purpose Knowing rights (asserting self)	Better Me	New & Different Me
			Connectedness – "Meeting other people has helped"		
			Improved relationships Feeling accepted, getting involved	Desire for (more) friends, Relationships, marriage, family	Influence of cultural norms, social convention
			Belief in Recovery- "You're getting nearer and nearer and better and better"		
			Recovery is possible	Looking to the future	Recovery from what though?
			Process of Recovery – "Except for I had a bit of a wobble yesterday"		
			Difficulty in overcoming difficulties. Gradual, developmental. Variable Relatedness- (themes overlap) Ongoing…		

Themes

Mental Health/Therapy Experience

Expressing Unfair Treatment in Life. Most participants were troubled by situations that they felt to be unfair. Their main concerns included bullying and losing emotional or practical support; at the very least these contributed to, and at times were pivotal to their mental health difficulties. Luke's experience was centred on his perceptions of power dynamics as experienced at home and shows how such feelings of injustice may be compounded by mental ill-health and low self-esteem.

*"Probably felt nervou*s*… with all my behaviour problems going on when I first [sought] help, I wasn't sure if the psychiatrist was going to moan at me, blame* me, and I t*hought sometimes that they weren't going to help me. (…), like it's all* my fault, how I brought it on – *I thought they'd be on mum and dad's side…"* (3-4)

Seeking Understanding. Participants had questions or queries about life which they struggled to make sense of. Understanding was often sought regarding situations perceived as unfair. Not feeling treated as an adult, was an important issue for most participants.

*Yvonne: "*Yeah, I want to be an adult, *not a child no more."* (72) Yvonne later spoke about her experience of professionals,

*"No, they haven't bee*n *truthful, cos nobody tells me nothing."* (78)

Participants revealed having been protected from knowledge that may be construed as harmful or beyond their comprehension; certain topics may elicit in professionals feelings of guilt and discomfort. Interestingly diagnoses were not mentioned by participants, instead mental health symptoms were described using feelings, for example, "upset". Withholding such information is likely to compound feelings of frustration at not being treated like an adult.

Public perception may underestimate the cognitive limitations of PwLD's ability to understand. James' depiction of what has been referred to as the 'handicapped smile' highlights this:

*"It's good to always wa*lk around with a smile on your face and not look *miserable."* (658)

Valuing Information. Understanding can be assisted by acquiring information which may have been lacking or delivered ineffectively; of particular value was learning coping strategies and talking about relationships.

Seeking advice was highly sought after, the benefits of which may relate to a supportive relationship that empowers, and helps bolster self-identity and autonomy, which the literature suggests for PwLD can be in short supply,

Luke: "It's better to get this from talking to people one to one, then you can talk about how you're feeling, what your problems are and how you *can sort them out without having to talk about them in front of your parents."* (94)

However, it was also possible to become dependent on advice,

Yvonne: "She knows what I must do about it." (427) especially if coupled with low self-esteem and awareness of an identity defined by "disability".

Management of Expectations. Participants were often not aware of how to access the service, what to expect from the service or the reason for referral.

James: *"Well, I'd been before, well I didn't, the first time I came I didn't know what it was like, I didn't, no."* (198)

Hesitancy over referring may be due to information not being accessible, both on a cognitive and practical level.

Therapeutic alliance. Building a relationship based on trust, respect, and feeling understood, enabled the issues participants brought to the service to be listened to, creating a space where interventions could be most effective.

Jenny: "Cos I look at them and I think well can we trust this person? Can, I?

Cos I test them before I can trust them." (336)

Insights were revealed through participants' sense of unfair treatment, illustrating valid reasons for a general mistrust of society as well as evidencing a relative absence of significant close relationships to use as a reference point. This alliance is therefore especially important for PwLD; their views are validated, their strengths recognised and thus they feel empowered.

Building a therapeutic alliance is critical to achieve all the elements which the analysis revealed as characteristic of recovery. Without this quality of relationship, recovery would not be possible.

Client Recovery Experience

The following themes will be discussed in turn and as they relate to all three phases: Feeling Better, Recovery as Ongoing and Attainability.

Self-Management of Mental Health. Participants found it beneficial to use various kinds of coping strategies, which allowed them to monitor and manage their emotions. Talking about feelings was a popular way of managing distress enabling participants to seek clarification and understanding, as was engaging in activities designed to distract.

*Joe: "I shou*ld calm down a little bit, give myself some time out, then I come

down stairs and then I talk to [mum about] it…it helps me (187). You

understand more (…)

I go to gym sometimes when I get bored at home or watch an African

programme or play on the PS3 co*mputer…"* (355)

As Joe shows, techniques for coping promoted feelings of autonomy and

positive self-identity. Learning to remain calm and avoid confrontations with his

mother also improved their relationship.

There was an overriding sense being reassured held the key to the success of any

coping strategy; Mikey illustrates this when out shopping with his clinician, he

"wasn't scared." (134) However, additional support was needed in trouble-shooting

techniques and generalising strategies across contexts, difficulties likely incurred due

to one's LD.

Agnes: *"Um. I can't do those exercises, it's difficult you can't do them in front*

of people, so *it gets you stressed even more."* (480)

For the majority of participants this was not their first referral, further indicating the

need for some degree of building upon and reinforcing previous learning.

Less overt coping strategies incorporated fantasy and were expressed through

escapism, catharsis and displacement. Notable was many participants' interest in

wrestling, which served to represent difficulties and adversities faced regarding either

feelings of mental health or learning disabilities, or indeed the combination of both.

Learning from "the moves" enabled participants to think around the problem safely,

and begin to strategize thereby avoiding "injury", or additional distress.

Interviewer: *"OK, so what sort of things can you learn [from wrestling]?*

Cameron: *You can, you know when they get into a fight, everything's real but to*

try not to get injured from *it (…).* Watching all the moves, plus they get injured

as well, they get *hurt and then they, get blood on their, pouring out their face."*

(285-289)

These alternative ways were unconsciously devised to counter problems learning or retaining conventional coping strategies, whilst also enabling executive functioning skills.

      Emotional Development. Participants visibly benefited by addressing gaps in their emotional development (which is invariably an incomplete area for PwLD).

They valued occasions when they were treated like adults and not children, and were eager for more opportunities to increase autonomy, build a sense of self-worth and strengthen relationships,

> *Luke: "I think when I'm feeling better it's more that I can do more stuff with* him, I can t*ake him places (...) Cos at first they didn't really trust me, until they started trusting me I took him to the chip shop."* (178)

However, given that participants' emotional development is often not commensurate with their chronological age and may never be; it may not always be possible to accord individuals full adult responsibility.

Participants experienced an increased self-awareness, feeling more able to recognise and understand their behaviours and emotions. They were also able to better understand and appreciate this in others, gaining an insight into interpersonal dynamics, and to some extent a greater sense of empathy.

> *Joe: "Sometimes when she's tired, I push her a lot, I have to be honest, I don't want to (…) when she's tired she doesn't feel like talking."* (453-457)

However, self-understanding is an ongoing process, as Sean reveals,

> *"… the other day when I wanted to have the answers. I could ask Xxxx, why did* I get hurt? I wanted to know why it happened to <u>me</u>*?"* (419)

Attaining full understanding is universally elusive but may be further complicated by limited cognitive ability. Sean highlights that both cognitive and

social resources were required to reconcile individuals' need 'to know' may be

limited for PwLD. In this respect, Luke struggled to generalise his interpersonal

understanding achieved with his friends, to his family,

> *Interviewer: "What would help you argue less [with your mum]?*
>
> Luke: Doing stuff round the house without arguing, and then talking to them
>
> *politely."* (330-331)

Participants also seemed more equipped to recognise, tolerate and reconcile

ambivalent feelings, or polarised perspectives, within themselves and their

relationships.

> *Jenny: "Um, I think they would sometimes say that I can be good and*
>
> sometimes I will h*ave like these off days when I'm really bad…"* (317)

There was an understanding and acceptance that things could be both good and

bad, that it was possible to simultaneously feel better and recognise that difficulties

remain, to have "*ups and downs".*

Tolerating ambivalence is however, a work in progress; Luke is struggling to

understand that each family member may hold some but not all responsibility for his

home circumstances. Equally, reconciling feelings of anger is still difficult, and

feared by many participants. Whereas, anger may be a perfectly understandable even

healthy response for participants, it was viewed only as bad,

> *James: "Aww probably that erm they couldn't ta*lk to me, probably think that
>
> *I'm* a nasty man or [an] *angry man, yeah."* (454)

Common among male participants, was the use of wrestling as a metaphor.

Cameron's collection of wrestling figures allowed him a way of displacing his anger

without fear of recrimination, acting out an unconscious fear of annihilation (Sinason,

1992) attributed to his awareness of his LD and possibly also his unavoidable

dependence on others.

      Autonomy/Support. Recovery means navigating a personally satisfying

balance between independence and dependence, assuming personal responsibility for

recovery, whilst appropriately drawing on the resources of others. For instance, Luke

highlights his need for a sense of security, stability and reassurance along with his

need to live independently.

> *"More like get a place of my own round the corner and then keeping in* contact
>
> *with my parents and just go round there sometimes."* (407)

Participants demonstrated resourcefulness in managing their mental health. For

instance, Cameron observed others in order to work out how to get involved socially,

and learned to adopt specific strategies, *"taking time to talk slower",* to accommodate

his LD. Whereas, Agnes devised an effective system of budgeting in response to

criticism that she was mismanaging her money, and built a very effective support

network of professionals[4] around her. These examples demonstrate that PwLD have

strengths.

The balance between levels of autonomy and support was hard to maintain for

participants. There was an ongoing desire for autonomy yet this was dependent on

opportunities availed and determined in part by public and self-perceptions of ability,

and a continued need for emotional and practical support. More input was required

with regards to managing expectations of the service/treatment and accessing

information/knowledge. Also, despite good ideas, participants often did not know

how to action their goals. This was striking for Mikey, who was keen to establish

friendships yet struggled to leave the house without support.

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4 This included her local GP, police, the congregation and vicars at her church, the NHS walk-in centre
and her Case Manager at the MENCAP office)

Problems in forward planning may be explained by impairments in executive functioning; the mental processes involved in connecting past experience with present action which enables planning, organising, strategising, and remembering details are likely to be compromised to some degree in PwLD. Assuming a passive role may also act as a 'secondary handicap' as termed by Sinason (1992), and serve to exert power and control over a situation in which Mikey feels hopeless, due to the severity of his social anxiety.

Maintaining levels of emotional support was equally important to participants. PwLD who have less empowering experiences to draw on or who have an awareness of, or negative self-concept relating to, their "inability" may require more reassurance.

Jenny demonstrates the wish to take control of her life, again through use of an analogy,

"...there's a box that I want to get rid of in my head (...) It's not the box that's evil, it's the devil that's evil, he's the one that's trapping me. And I've got to unlock it and [put] him in there and not *me... [And say to the devil] You know* w*here you're going? You're going out that window and you're staying out that window!"* (166-168)

The box provides a coping strategy for expressing frustration and processing the need to take ownership of her recovery, and as such empowers Jenny. The devil allows her to express how difficult and frightening it is to take these first steps whilst exonerating her from the potential shame of not yet exerting control over her recovery. A shame possibly compounded by the stigma and feelings of incompetence associated with her LD identity.

Aspirations for independence and autonomy used in fantasy or idealisation of what is achievable, serves to minimise the risk of disappointment and recognition of

reality. Mikey's overriding goal was to go out by himself and despite his dependence on others, he had been learning to drive for the last two years and was determined to succeed. His bid for independence was also safely facilitated through a wish to *"go on a boat",* and his interest in maps.

Connectedness. Participants valued improvements in relationships with others and defined recovery as feeling more accepted and being more engaged in life, which in turn, improved self-concept. Cameron explained that he became *"happier"* by *"getting more involved in things"* which ultimately made him want to "do more *things and stuff" (…) "Cos maybe I like to do things now".* (67-78)

Raised self confidence may help to buffer the negative reactions and treatment from others, or mitigate perceptions of these. Self-acceptance, rather than acceptance offered by others, may be the more influential element in recovery.

It was common to want to secure an increased sense of connectedness, illustrated by a desire for more friends. Interestingly, despite descriptions of friendship most participants when asked denied having friends.

Joe: "No not friends, no I don't have friends, but I got colleagues every time I go to work but I don't treat like enemies likes some people, but I talk to who's friendly, understandable, some one that can have a la*ugh, yeah."* (389)

Joe highlighted participants' experiences of bullying which may explain why friendships feel unachievable, and are made more difficult due to fewer social opportunities. Equally, a lower level of cognitive and emotional development could create problems of communication and difficulties within interpersonal relationships if the recipient was not *"understandable."* Bullying may result in not feeling worthy of friendships, further exacerbating these problems.

Intimate relationships were idealised and having a family viewed as a mainstream societal goal.

> *Joe: "Yeah, getting married with kids and with my wife…e*rr, *probably might pay the rent. (…) I may get a house in Xxxx, and then might live together on holiday."* (717)

Happiness may be defined by how relationships and friendships are perceived or portrayed in society. It may be that having friends and a family were perceived by participants as a measure of success in life, which is characteristic of the general population. Being a parent also represents a role afforded full adult responsibility and meaningful purpose, both qualities valued in participants' recovery.

Positive/Empowered Identity. Recovery brought with it a feeling from participants that they had acquired a sense of purpose and felt more capable and competent, all of which was self-affirming, empowering their sense of identity.

> *Sean: "Yeah, I am more able to do stuff now.*
>
> *Interviewer: So you can do more things, like….*
>
> *Sean: Everything."* (351-353)

Presentations such as these were common and served to overcompensate for participants' hidden 'self' which was less confident and more aware of their LD identity; an identity which potentially involves internalised feelings resulting from unfair treatment and recognition of their limited cognitive ability and associated stigma. It could also be argued that self-affirming descriptions which deny any aspects associated with a LD, thereby promote a "normal" identity. Interestingly, despite the interviewer referring to "learning disabilities", none of the participants identified with this term; although having Autistic Spectrum Disorder and medical conditions were spoken of.

Many participants talked about their rights with regards to a variety of situations and discussed ways in which they have asserted these.

Jenny: "…and I won't allow it no more. The police have been involved quite a lot, we've been involved, sooo they've been in, in the police cells cos of accusations that (…) and she's not." (80-81)

There was a strong sense that participants wanted to improve in order to become "better" people. This was stated generally but also in reference to coping better with emotions, having better table manners, being able to read and write, and proficiency at using the computer.

As participants' mental health improved, so did their motivation to self-actualise; however there was a tension apparent between optimism and realism. For some aspects articulated, it was unknown how achievable they will be, or how much desire for these improvements was in pursuit of, conscious or otherwise, the identity of a non-learning disabled person. This may be further complicated by the effects that positive self-concept and improved mental health may have on alleviating feelings of "disability", making a more holistic recovery seem possible.

For those participants felt to be further on in their recovery, feeling better brought with it greater understanding and subsequently the realisation of shortcomings in many aspects of their lives, regarding: housing, relationships, social opportunities etc. Furthermore that despite best efforts to fulfil one's potential they will never recover from their LD, leading to further denial of this identity. Participants' aspired to be someone else, a "new and different" persona. This was shown through identifying with the strength and resilience of wrestlers, by *"watching all the superstars come out"* (Luke). In aspiring to be an actor, Sean revealed the best

part about this is, *"the performance"*; James similarly wished to be like *"George Clooney"* or *"David Beckham"*.

The identities aspired to were ambitious, carrying with them the illusion of optimal success, 'celebrity' and ability. Participants valued ultimate achievements as situated within the general population, thereby reflecting cultural norms. Recovery was experienced as more than issues relating to mental health, but also to learning disability.

Fantasy further enabled participants to adopt new identities using escapism, whether this was an interest in TV filming locations or travelling to different places. For Jenny, it was going to the seaside, which allowed her freedom from her difficulties and a sense of empowerment.

"Yeah straight on the beach….and win hundreds of pounds and I'd just throw it all back in the machines. I like doing that." (111)

Belief in Recovery. There was generally optimism and determination that "things would get better". This was again often conveyed indirectly, for instance, by talking about wrestling in a "ladder" tournament where each stage had to be conquered in order to win the trophy.

Joe: "When you get it, you've got it, the moment that you (…) can see that, you try and try and tears, and you succeeded and lost and succeeded in the end." (705)

This shows the close relationship between self-efficacy and a positive self-identity as defined by the ability to recover. Belief expressed through religious faith also offered protection and reassurance, often by providing support and understanding about one's mental health, and a way of coping.

Recovery was seen as continuing into the future. For Sean, he "just want(s) to *move on"* (451) and Agnes expressed the importance of having *"things to look forward to"* (757). There remains the question of what exactly participants hoped to recover from, their mental health difficulties or their learning disability.

Process of Recovery. Experiences depict recovery as an ongoing challenge, a very long and gradual process; difficulties still remain and progress is slow and variable.

Agnes: *"Erm, I think it's more backwards and forwards. It used to be bad back then and then it [became] good and then I'd go back to bad…"* (545)

Having a learning disability may make recovery a particularly difficult and lengthy process; most participants had been re-referred at least once. The process of recovery may be compounded by difficulties and obstacles present within the biological and social definitions of 'LD', and the ramifications of both. Themes across all phases of the recovery experience are inter-related, which has been illustrated throughout the results, with the therapeutic alliance as pivotal.

Discussion

Participants entered therapeutic services seeking understanding and wanting information and advice. They expressed feelings regarding perceptions of unfair treatment in their lives which were only now validated and listened to. Raising these issues was dependent on the therapeutic alliance; building trust and feeling understood allowed these issues to be explored and addressed in order for recovery to be initiated. This recovery phase for PwLD is defined by the self-management of mental health difficulties, whereby individuals advance their emotional development, develop and pursue a more positive and empowered identity, experience an improved

sense of connectedness within society, achieve an optimal balance between support

and autonomy, and lastly hold a belief in recovery.

In accordance with the literature, recovery for PwLD is an ongoing and gradual

process (e.g. Anthony, 1993, Sheehan, 2002); yet dissimilar is the question

concerning how fully recovery can be attained and thought about in relation to both

mental health difficulties and LD. Fantasy and idealisation are used frequently as a

way of achieving recovery and avoiding consideration of what it means to have a LD.

The findings are discussed in relation to the existing recovery literature[5] and

other relevant theoretical and empirical research.

Amongst the several commonalities is having 'hope and optimism' (e.g. Slade,

2009, Bonney & Stickley, 2008, Schrank & Slade, 2007), which was represented in

this study as having belief in recovery, both presently and in the future. This study

also showed that self-managed coping strategies helped ameliorate mental health

difficulties, reflecting learning from the cognitive deficit model for how best to meet

the needs of PwLD and the subsequent delivery of techniques in services. Equally

self-management features as a principle of recovery within the literature and within

LD policy, e.g. Valuing People Now (2009b).

The therapeutic alliance is only emphasised in the "grey"[6] recovery literature

(Stickley & Wright, 2011) but is widely recognised as essential to successful

therapeutic treatment (Bachelor & Horvath, 1999; Horvath & Bedi, 2002). It offers

possibility of reparation in the attachment relationship, which previously may have

been detrimentally affected for a child with LD. Further exploration will emphasise

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[5] When stated, this includes research with the general and specialist populations as outlined earlier and the chronic health literature

[6] Grey literature relates to informally published written material

the importance that the therapeutic relationship holds for PwLD (Schoen, 1995) and its critical role in recovery.

Cognitive impairments hinder the interaction and learning between the infant and caregiver, impacting upon many areas including: self-regulation, relationship patterns (object relations) and ego-strength through which society's values and norms are learned (Gaedt, 2000). Disruptions to attachment can also occur through the child incorporating any personal feelings of frustration and inadequacy from the caregiver about its "disability" (Applegate & Barol, 1989; Blackman, 2003; Hollins & Sinason, 2000).

In the absence of a secure and successful relationship to provide a positive image; PwLD have no template to confidently relate to others, seek help and support and practice independence. Hence being listened to and understood in a safe and trusting environment is pivotal to enable recovery.

Recovery for PwLD opens the possibility of closer bonds with others now that the benefits within the therapeutic relationship have been realised. Relationships and 'being part of the community' are reflected in the recovery literature (e.g. Leamy et al., 2011; Turton et al, 2011). Support for "meeting people" and rights to have a family feature within Valuing People Now (DoH, 2009b).

The absence of social inclusion for PwLD is arguably reflected in the aspirations for more relationships, and idealised notions of achieving what Sinason (1992) termed "societal main goals". Genuine inclusion and implementation of rights for PwLD (House of Lords, 2008) is important and demands attention.

The value placed on emotional support and reassurance is prolific within the recovery literature (e.g. Leamy et al., 2011; Jacobsen & Greenley, 2001). In this study, more support was required regarding explaining the referral process, managing

expectations and accessing information throughout recovery (Willner, 2003; Pert et al., 2012). However there was a greater level of need for overall ongoing support, arguably explained by cognitive limitations but also the need to further advance emotional development.

The importance of achieving autonomy, by asserting individual strengths and rights and increasing opportunities in which to do so is also reflected in the recovery literature (e.g. Leamy et al., 2011; Slade, 2009; Bonney & Stickley, 2008). Also pertinent is the literature focussing on 'self determination' (e.g. Wehmeyer & Schwartz, 1998). Considering these findings in light of current policy, it seems important to maintain efforts towards increasing choice, independence and exercising individual rights (e.g. Learning Disability Research Initiative (2007); Valuing People Now (2009b)).

Tension in striking a balance between dependence and independence is evident in older people, as their dementia progresses (Daley et al., 2013) and in specialist groups such as "dual diagnosis" patients (Turton et al., 2011). Given the current climate which battles to reconcile providing care and protection with positive risk-taking (Handley et al., 2012) the need for security and support should be respected and understood as symptomatic of PwLD and moreover the human condition.

Having opportunities to act autonomously is an integral part of emotional development, which PwLD are known to have difficulties with; it therefore follows that this element of recovery is unique to PwLD. Exploring briefly, the psychoanalytic understanding behind this, reveals the benefit of addressing gaps in PwLD's maturational processes.

Enhanced self-understanding and self-affirmation involved in recovery is brought about by a positive perception of the self as seen by others and internalised.

A better personal and interpersonal understanding can also be achieved by integrating

and accepting the good and bad parts of the 'self' and others, resulting in the

"depressive position" (Klein, 1946). Although tolerating ambivalence was apparent

in the experiences of PwLD, the ability to give up an "idealised" notion of the world

was limited. This would have led to realising the world is flawed, that perfection does

not exist and acceptance is needed of the relative strengths and weaknesses of both

LD and non-LD populations. An integration of extreme positions may have

facilitated a normalisation of anger, justifying this emotion rather than being fearful of

it.

PwLD affirming a positive and empowered sense of self is supported by

Bandura (1977) and the importance of self-efficacy for PwLD was highlighted by

Slemon (1998) and Gresham, Evans and Elliott (1998). Similarly, encouraging hope

and empowering individuals to recognise their strengths and realise their potential

underlies many of the key recovery principles (Shepherd, Boardman & Slade, 2008)

and LD policies. Drawing attention to individuals' positive attributes may emphasise

the realisation of one's LD and perceptions of personal shortcomings by encouraging

comparison to the general population. Such comparisons may highlight the contrast

in ability and in social opportunity and level of fulfilment in their lives, despite the

recognition of relative strengths. Research has theorised that comparisons with non-

LD individuals leads to poor self-concept for PwLD, and has looked at how a positive

sense of self is subsequently maintained through how PwLD construct their social

worlds (e.g. Dagnan & Sandhu, 1999).

Recognising the differences in their lives led PwLD to aspire to be "better"

people, a plight which suggests their innate feelings of low self-worth. All this may

explain why valuing the "meaning in life", a key aspect of recovery research, is

noticeably absent in this study. Individuals' desire to be someone new and different, rather than re-discover their existing self, differs from mainstream recovery research and the preoccupation with redefining identity (Leamy et al., 2011).

Aspirations often alluded to recovering from one's LD, rather than their mental health difficulties and emulated a 'non-LD' identity; as a result participants appeared to distance themselves further from their LD (e.g. Sinason, 1992; Finlay & Lyons, 2005). Failure to identify with their lifelong condition may be a protective defence (Szivos & Griffiths, 1990; Simpson, 2004) enabled by a "secondary handicap"[7] (Sinason, 1992) or a way of minimising its impact (Rapley, Kiernan & Antaki, 1998); whereas Cunningham, Glen and Fitzpatrick (2000) suggested that PwLD are not made aware of what LD really means.

Professionals may inadvertently contribute to this disavowal of LD due to their own personal discomfort (Craig, Craig, Withers, Hatton & Limb, 2002; Davidson, Burns & Smith, 2013) and the belief that this information will cause harm.

The level of aspirations expressed within recovery raised the question of what is realistically attainable for PwLD; using fantasy and idealisation provided safe exploration of what may not be. Gaedt (1995) suggests that PwLD adopt an idealised identity to stabilise their fragile self-image. Hollins and Evered (1990) expand upon this, explaining that the gap between the "real" external-self and "ideal" inner-self initially widens as PwLD confront reality, but ultimately closes resulting in improved mental health.

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[7] "Secondary handicap" was termed by Sinason (1992) and emerges as an exaggeration of the primary disability as a defence mechanism, either to protect against memories from any traumatic life experiences such as, abuse, or as a defence against the trauma of living with the psychological and emotional pain of the original LD and society's treatment of this.

Escaping one's reality acted as a defence against stigma (Craig et al., 2002, Rapley et al., 1998), shame and the risk of disappointment. Whereas the recovery literature refers to "overcoming stigma" in relation to other marginalised groups or mental health, (Leamy et al., 2011); the process for PwLD is arguably more passive and unconscious, which may fit with what is known about social, emotional and cognitive influences.

Clinical Implications

These findings stress the importance of therapeutic alliance, information-giving, and emotional development, (and in relation to progress in interpersonal understanding, the potential use of adapted mentalisation) as clinical foci. It also emphasises the value of psychodynamic formulation when working with the unconscious processes, highly pertinent to PwLD and offering narrative work with its use of metaphor.

Clients with LD need ongoing clarity in their expectations throughout treatment, in particular the setting of realistic goals, differentiating between what is recoverable from (pertaining to mental health) and what is not achievable (based on LD) and self-acceptance encouraged. This necessitates an open discussion about LD and how it affects each individual alongside recognition of each client's strengths. Additionally it calls for normalisation and demystification of how it feels to be non-learning disabled.

One way in which this could be enabled is in the presence of PwLD who are leading positive fulfilling lives within society. Peer support workers (Davidson, Chinman, Sells & Rowe, 2006) would offer clients realistic aspirations, hope, helpful information and meaningful supportive relationships with a view to social integration, and further insight into the relative strengths and weakness of people generally.

Equally meaningful service-user involvement would provide this, as would

establishing a self-advocacy movement and participation in initiatives whereby public

perceptions of PwLD are tackled, either through public-speaking, training, or

integrating meaningful roles within the community, based on individuals' strengths.

Other ideas include launching more Recovery Colleges (Perkins, Repper, Rinaldi &

Brown, 2012), which would additionally include and educate local businesses. These

initiatives provide opportunities to express independence, and foster feelings of

reciprocal support[8] which positively impact on self-identity.

Study Limitations

Phenomenological methodology aims to improve understanding of human

experience rather than claim generalizability (Husserl, 1927). Nevertheless, any

transferability (Mays & Pope, 2000) of findings may be limited since the participants

were verbally expressive, and from the same geographical area served by recovery-

orientated teams.

Data was triangulated through co-analysis of the data and quality assurance of

the codes and themes by third parties. Equally, cases at different stages in their

recovery were included (Guion, Diehl & McDonald, 2011) although this could have

been done more extensively. Following recommendations made by Smith et al.

(2009), transcripts were not checked by participants.

Ethical guidelines advised that participants were initially approached by their

practitioner; this may have influenced compliance, however efforts were made to

mitigate this and two participants did decline to continue. Similarly bias may have

occurred in individuals' reasons for participation and there is no guarantee regarding

the participants' honesty or absence of acquiescence.

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[8] Feeling valued by and valuable to the community

Given the importance of non-verbal communication to aid understanding, it would have greatly enriched the data if video-recording had been used. Future studies could incorporate this and use multiple interviews or a longitudinal design to build trust and enhance the understanding of PwLD's experience. Further research would also benefit from more service-user involvement.

Given the interpretative nature of IPA methodology, the researcher's assumptions and experience may have been introduced into the interpretations made, despite addressing this via a reflexive approach (Appendix M).

Conclusion

Irrespective of LD, the recovery experience for PwLD is similar to that of the general population. Recovery is a gradual, variable and on-going process, which values autonomy and support and share: a belief in recovery, self-management of one's mental health, empowered self-identity, and social connectedness.

The experience differs in the significant and ongoing need to balance support with opportunities to live autonomously. Of paramount importance in treatment is the therapeutic relationship, the value of imparting knowledge and information, and seeking to address gaps in emotional development.

Progress in recovery led to aspirations of self-improvement; however, realisation of social and cognitive limitations precipitated the use of idealisation and fantasy in order to achieve this and a longing to be someone new and different. Aspirations were expressed through the belief that LD was possible to recover from, and the denial of a LD identity and idealisation of a non-LD one.

Central to recovery is therefore the need to explore routinely what it means to have a LD and setting realistic and attainable goals. Future initiatives need to focus

on integrating PwLD into society to mitigate fantasy and idealisation of what it is to

be non-learning disabled. Social inclusion will also help build meaningful

relationships providing opportunities for both support and independence whilst

deepening an interpersonal understanding of these; this will help strengthen self-

identity, feelings of connectedness and hopes for ongoing recovery for PwLD.

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EMMA TRUSTAM

Section C:
Critical Appraisal

Word Count (1986)

A thesis submitted in partial fulfilment of the
requirements of Canterbury Christ Church University
for the degree of Doctor of Clinical Psychology

March 2014

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

1. 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?

My previous research experience has been with quantitative data; (albeit any multi-variate analysis), thus I was keen to develop my knowledge and experience of qualitative methodology. It has been useful to experience research methodology which is far less prescriptive and inductive, and immerse myself in exploring and understanding others' perceptions of the personal worlds and experiences that is required of IPA.

The open approach of IPA involving a double-hermeneutic of me understanding and interpreting how others made sense of their experience (Smith & Osborne, 2003) has taught me the importance of remaining mindful of my potential bias, and to try and mitigate this through utilising techniques such as 'bracketing' (Fischer, 2009). Furthermore, I realised the conscious effort required in accounting for unconscious processes on my behalf in order to meet the required standard of quality assurance (Yardley, 2000). By closely consulting the data, I developed ways in which to refine the themes and by interpreting them relationally, develop a structure. I also gained experience in managing the dual role of researcher and clinician; this became apparent when I was carrying out the interviews listening to sensitive and emotive issues, also when I was interpreting the data and thinking about that nature of the therapeutic intervention.

I have gained far more experience and confidence working with people with learning disabilities; in particular I feel more equipped to understand their communication needs and adapt mine accordingly, both in regard to how I phrase things but also in using different visual methods. Given more resources I would like

the experience of experimenting using video or photographic diaries as I think these

hold a lot of potential value in research of this kind. (Knowles & Sweetman, 2004). It

is argued that these techniques contribute a more 'direct' understanding of

participants' experiences (Gibson, 2008).

I think I would benefit from learning more about the philosophy behind

qualitative methodology as I found what I did read about its founding traditions really

enhanced my understanding of it. Learning more about other qualitative methodology

with particular attention to how and where these differ from IPA would give greater

depth to this awareness. Although I did explore this to a certain extent when deciding

upon with method to use for this project, I also became very aware of the breadth of

knowledge available, especially regarding types of narrative analysis.

Mixed methodology has always been an interest of mine and I would like to feel

better informed about how this can be operationalized in practice, especially with

regards to the analysis which would require the integration of findings from different

theoretical bases.

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

The recruitment process proved to be slow despite the research being

championed from within the department and recovery being a service priority. What

may have helped would have been more of a physical presence within the service, had

I been able to attend team meeting and research meetings. I wondered too about the

effect that not offering any remuneration may have had on recruitment (although this

also brings its own ethical considerations); particularly in light of a service-users

consultation group within one of the boroughs which offered vouchers for taking part

in research. (Interestingly this was the borough with the least amount of participants

and the one with the most was the borough that my external supervisor was based at that I visited several times).

A system which flagged all those cases which had closed or which were about to close would have been helpful and may have gone some way in redressing the responsibility held by the practitioners' who acted as gatekeepers and initially approached potential participants. This would have reduced the likelihood of issues of compliance or false expectations influencing the participation of clients; it would also have ensured that the selection of clients was not based on those perceived as having had a positive experience of the service.

Equally if there was a way to capture the experiences of those that opted not to take part in the study or who declined being interviewed after showing initial interest; it would have informed the research to know what might it have been about these participants that set them apart from those who volunteered and completed the study. Working more closely alongside the service or with affiliated organisations may have increased my familiarity with the participants, thereby either improving participation rates or leading to a greater understanding of the drop-out rate.

It became apparent from the interviews the potential value of repeated meetings with participants. This would have allowed a longer time period over which to build a relationship and gain trust. A more thorough understanding of each participant would have provided greater awareness of the nature of their expressive and receptive language skills, thereby enhancing the study by adding greater depth and comprehension to experiences told.

Incorporating more service-user involvement in the study would have been of great value. Although I was able to involve service-users in the research design stage, embarking on a joint research approach may well have positively influenced the

research and made it more clinically relevant (Centre for Recovery in Severe

Psychosis, cited in Trivedi & Wykes, 2002).

3. As a consequence of doing this study, would you do anything differently in

regard to making clinical recommendations or changing clinical practice, and

why?

This study has underlined for me the importance of formulating

psychodynamically and using these principles to understand the less visible processes

at play with someone with LD; the information from which may be especially

valuable given cognitive limitations and difficulties in expressive communication.

The results have drawn attention to the possibility of working to progress the ability to

recognise and tolerate ambivalence and increasing an understanding of themselves

and others; and their interpersonal dynamic. This brings to mind the therapeutic

approach; mentalization (Allen, Fonagy & Bateman, 2008) which if adapted may

offer some value, if not in its entirety, then as indicated by individual need and the

available evidence base. Equally, clinical practice could be informed by assessing the

stage of emotional development and considering the impact of this in the context of

recovery.

Results also stressed the importance of talking openly about LD with clients,

and as a practitioner being self-aware and reflexive regarding the personal discomfort

and feelings this may evoke. In light of the need to normalise what it is to have non-

LD identity, raises the value of appropriately delivered practitioner self-disclosure as

recommended in the recovery literature (Shepherd, Boardman & Burns, 2010).

The study shows how PwLD value advice and guidance and the opportunity to

receive information in a way which may increase their understanding about certain

things. It also illustrated the necessity of managing clients' expectations and keeping

them updated regarding the process of referral, treatment, and expectations regarding their ongoing recovery, as well as the additional effort that may be required in order to ensure this information is accessible and able to be retained.

Given the finding that independence is highly sought after, it seems important for services to involve significant others in view of their frequent role as gatekeepers to managing individuals' autonomy. In addition, studies have highlighted the benefits of carer involvement (Willner et al., 2002; Allot et al., 2013) and Onken et al. (2002) argued that this will also strengthen and integrate knowledge, skills and resources for the individual. Of importance too in promoting self-management is encouraging more positive risk-taking (Shepherd et al., 2010); however this may be harder to influence or action depending on service context and organisational culture.

Encouraging social integration was key to the results and would continue to support the elements of recovery which the study identified as ongoing. Ideas for this are numerous, but include: peer support, advocacy and self-advocacy groups, service-user involvement, Recovery Colleges, and educating communities and developing/joining initiatives to challenge stigma. Once implemented the relative merits for recovery in PwLD would need evaluating to help inform further strategies for social inclusion.

All of the above are important to consider working as an individual practitioner but also in a role which could influence service management and development.

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

Research to date, has predominately focussed on recovery within adult mental health populations; this is the first study to focus on PwLD. Given the comparative differences in this client population in terms of cognitive, emotional, developmental

and social factors; the question of what recovery means for PwLD is still a pertinent one, which could be explored in different ways.

It would be advantageous to get a broader understanding of recovery for PwLD at all stages of their experience, not just focussing on individuals that recognise they 'feel better'. A longitudinal research design or an IPA study exploring the experiences of individuals who were earlier on in their recovery journey or allowed for multiple interviews would add greater depth to the current exploratory structure in these findings. Equally studying differences across stages of recovery using a cross-sectional design could be enabled using outcome measures and selecting samples accordingly.

Analysis of the therapy sessions themselves would allow a deeper insight into recovery process and the dynamics at play, and avoid relying on memories of practitioners, and clients with LD alone. It would also gain insight into the therapy process and relationship between client and therapist.

Future research would benefit from gaining more representation for PwLD, and capturing the views of PwLD who are unable to give capacity to consent, and with less expressive communication skills (Cambridge & Forrester-Jones, 2003). This could perhaps be facilitated by different communication strategies such as AAC (Augmentative and Alternative Communication) which may rely on gesture, symbols or technology. The use of proxy informants could also be considered; asking people who know the individual well to give proxy consent in order to gather and interpret information (Whitehurst, 2007).

As an adjunct, not as an alternative, views from families, carers and professionals could also be researched. This would give a more systemic and holistic understanding of the experiences of PwLD, and potentially also be the first step to

developing a triangulation of measures. Quantitative outcomes measures may offer

easily accessed additional information, for instance, CORE-LD; alternatively

triangulating with other measures for community participation questionnaires may

also be of interest.

 With more research in this area it may then be possible to evaluate the degree to

which services facilitate recovery for PwLD, and how inclusive current service

measures are for PwLD and look to make accountable those that fall short. These

results could be mapped against items within the many existing recovery measures

(i.e. DREEM, Developing Recovery Enhancing Environments Measure), developed

by Ridgeway and Press (2004) to evaluate how the understanding of each experience

compares. This could then be explored further using focus groups of PwLD with a

view to developing or adapting a recovery measure tailored to services for PwLD. In

doing so, this would help bring services for PwLD in line with mainstream services a

concern voiced by Perkins and Repper (2003).

 An appropriate and enriching way for the service to achieve alignment would

be via the meaningful inclusion of PwLD in all stages of the process and as co-

researchers. In the same way, proposed initiatives which aim to increase social

integration of PwLD would benefit from the views of service-users in their role as

experts by experience.

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EMMA TRUSTAM

Section D:
Appendices – Supporting Information

A thesis submitted in partial fulfilment of the requirements of
Canterbury Christ Church University for the degree of
Doctor of Clinical Psychology

March 2014

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY

Search Strategy

An electronic literature search was conducted during October 2013 using the PsycINFO, MEDLINE and ISI Web of Knowledge databases. Searches were limited to publications published in the English language.

Searches were carried out using combined terms which described learning disabilities with those that described the alleviation of or improvement of mental health difficulties. Terms were varied according to categories available within the databases and were taken from keywords found within relevant papers.

The table below shows the results of the search terms used.

Search Terms and Number of Results

Area		Search terms included:		No. of results			After filter/ removing duplicates
			Initial Hits	PsycINFO	MEDLINE	Web of Know-ledge	
Learning disability	1	Intellectual development disorder, or learning disab*, learning disorder, or intellectual disab*, or intellectual impairment, or mental handicap,/mental deficiency/ retardation		23375	12457	1428	
		AND					
Mental health	2	Mental health, or *outcomes, or * treatment, or *intervention, or intervention studies, or *prevention, mental *health, psychotherapeutic techniques, *therapy	1+2	**3848**	**2426**	**590**	**1997**
		OR 1 AND					
	3	mental health*, or mental disorders, or *disorders, or mood, or emotional states, or *anxiety, or *depression, or psychiatry, or psychology					
in conjuncti on with		AND					
	3	Impact, effect*, improv*, influence, outcomes, efficacy, moderat*	1+3	**322**	**74**	**149**	**186**
Recovery (non LD literature)	4	Mental health/ *mental*, or chronic health AND recovery or psychological *adaptation/*adjustment, or recovery of function	4	1144	4720	568	

Relevant searches were refined using filters for Document Type, Research Area and Languages (English) and using terms for Adults. This resulted in 2083 articles. Due to the wide areas of research covered and large numbers of hits, the journal titles were initially screened, which resulted in 130 articles. Each abstract was then read and judged for its potential relevance to the research question, which asked what factors alleviate or improve the mental ill-health of people with learning disabilities.

This identified 48 studies, which were then read in their entirety. These remaining articles were then filtered by applying the inclusion and exclusion criteria (which are detailed on the next page).

Key terms from these relevant articles were then used for an additional search and references from each paper were cross-checked and subsequent articles found. Any additional articles found were again filtered according to the inclusion/exclusion criteria. This resulted in **25** key studies.

Inclusion/Exclusion Criteria

Studies were included on the basis that:
- Participants were considered as having a mild and moderate LD (rather than severe or profound), as diagnosed by the service

- Participants were verbally expressive

- A proportion of participants had a mental health diagnosis (using a broad definition which included offending behaviour, anger/aggression, and bereavement.).

- They discuss factors which are beneficial to the mental health of people with learning disabilities.

- They describe something which could be unique to the intra-psychic experience of PwLD; either by the nature of a finding which is different from that found in general population OR due to the proliferation/prevalence of results

- There is a measurement of client experience/outcome (rather than carer/therapist only)

Studies were excluded if:
- The focus is on a child and young people population, or older persons population (due to differences incurred by development stages)

- The focus was on sexual offending behaviour without mention of concomitant mental health difficulties

- They examined the effectiveness of pharmacological therapy.

Service evaluation is also beyond the scope of this paper.

Appendix B removed

Client has finished treatment (or an episode of care) and is considered as having had an improvement in mental health i.e. "feeling better"

Client meets following criteria:

Demonstrates capacity to consent

- Is over the age of 18
- Has a learning disability and a significant mental health difficulty
- Has been assessed as having a significant mental health difficulty sing the HoNOS-LD at the outset of treatment

Clinician to establish if they are interested in participating in the study

Gain verbal consent for researcher to contact them by telephone

Clinician to offer information sheet (with the name of person to contact if the participant feels distressed after the interview)

If initial consent gained, clinician to pass on potential participant's contact details to researcher, and basic details (age, gender, ethnicity, length of treatment, presenting problem)

Researcher contacts potential participant and answers initial queries.

Researcher arranges to meet potential participant

At the meeting researcher to**:**

Run through information sheet

Run through consent form

Gain consent

(If information sheet has only just been received, then researcher will contact again to arrange an interview and answer any questions)

(If information sheet has been received >48 hours ago, and participant is happy to do so, interview can go ahead, or alternative time scheduled.

Interview

Consent is again established and any questions addressed

Interview goes ahead

Dear Clinician

Recovery and People with Learning Disabilities - "Feeling Better" Research Project – Help with recruiting participants

As part of my Clinical Psychology Doctorate at Salomons, Canterbury Christ Church University, I am looking at what "recovery" means for people with learning disabilities (PwLD) who have experienced mental health difficulties. Although the recovery approach is prominent within mainstream mental health services, it is less clear how this would look within mental health services for people with learning disabilities. The idea for this originated from Psychology colleagues within SLaM Mental Health and Learning Disability Service Line (Handley, Southwell & Steel, 2012) and an approach was made to the University with a project proposal.

I plan to explore the experiences of PwLD and what feeling better means to them using Interpretative Phenomenological Analysis (IPA), and aim to interview 8-12 participants that have been seen by the service for a mental health difficulty, identified by the HoNOS-LD and are now thought of as "feeling better" (i.e. have made improvements in their mental health).

My project has been cleared by NHS ethics to be conducted within SLaM Learning Disabilities Directorate and has been approved by R&D in SLaM. I would really appreciate your help in recruiting participants for my study; I hope to begin conducting interviews from November 2012.

Each client must:

- Demonstrate capacity to consent to participating in the project
- Be over the age of 18.
- Have a learning disability and a significant mental health difficulty
- Be assessed as having a significant mental health difficulty using the HoNOS-LD at the outset of treatment.
- Be identified as having made improvements in their mental health since receiving input, so may be about to be discharged by you

Each interview will take approximately 1 hour, participants will be offered breaks and refreshments. Unfortunately I will not be able to offer participants payment for their help, but I am able to

reimburse travel expenses and include them in the acknowledgements of the written work if they wish to be named. I can arrange to interview them at a location in which the participant feels most comfortable. (I have attached an information sheet and flow diagram for more information).

I would be really grateful if over the next few months, you could identify any clients with whom you have completed your work that fulfils these criteria. I would then ask (as outlined in the ethics approval) that you initially approach the client to see if they would be interested in taking part in this study, ideally in the last session at the end of intervention or by telephone soon after the end of their intervention. I have attached an information sheet for you to offer them, on which there is a space to include the name of someone external to the project that they can go to if the participant feels upset after taking part in the interview. This may be you, a care co-ordinator or another professional. It would helpful if in consultation with the potential participant this name could be filled in on their information sheet.

I would also need for you to have obtained initial verbal consent from the potential participant for me to have their contact details and some basic demographic information (age, gender, ethnicity, length of treatment, presenting problem). I would also ask that you I can then contact them by telephone to follow this up, answer any questions or concerns that they may have and arrange a time to meet if they are still happy to do so.

I have attached a flowchart which summarises the recruitment process. If you have any questions or queries then please contact me at the email address below.

I look forward to hearing from you.

Many thanks

Emma

Emma Trustam
Ejt19@canterbury.ac.uk
Trainee Clinical Psychologist, Canterbury Christ Church University

Supervised by Dr Helen Quigley, Consultant Clinical Psychologist & Dr Jerry Burgess, Senior Clinical Academic Tutor, Canterbury Christ Church University.

Appendix E: Table of participants' demographic information

Participant	Age	Ethnicity	Marital status	Accommodation Status	Employment Status	Mental Health difficulties	Additional diagnosis	Stage of treatment
James	41	White British	Single	Supported accommodation	Not employed	Profound Anxiety Self-injurious behaviour		Previous episodes of care Finished latest episode (up to 3 months ago)
Yvonne	35	Black British	Single (in a relationship)	Supported accommodation	Not employed	Psychotic symptoms Anxiety History of abuse		Finished treatment (up to 3 months ago)
Luke	25	White British	Single	Mainstream housing - family	Not employed	Attachment problems/Trauma Long standing aggression toward parent		Previous episodes of care. At end of current episode
Joe	35	Black African	Single	Mainstream housing - family	Part-time employment	Psychotic symptoms Depression Behavioural problems	ASD	Previous episodes of care Finished latest episode (up to 3 months ago)
Mikey	37	White British	Single	Mainstream housing- family	Not employed	Generalised Anxiety Disorder	ASD	Previous episodes of care Finished latest episode (up to 3 months ago)
Sean	23	White British	Single (in a relationship)	Inpatient forensic unit	Not employed	Complex Personality Disorder with paranoid traits		Previous episodes of care At end of current episode
Cameron	20	White British	Single	Inpatient forensic unit	Not employed	Bi-polar affective disorder	ASD	Previous episodes of care. At end of current episode
Agnes	54	Black Caribbean	Single	Mainstream housing- tenancy	Not employed	Anxieties specific to relationships, History of abuse/trauma		Previous episodes of care. Finished latest episode (up to 3 months ago)
Jenny	29	White British	Single (in a relationship)	Mainstream housing	Not employed	Depression/ PTSD symptoms	Williams syndrome	Previous episodes of care. At end of current episode
	Mean = 33.2							

LOGO REMOVED

Information Sheet – "Feeling Better" study   **<Team Name>**

	What am I doing? I am interested in talking to people with learning disabilities who have come to psychology to feel better. I would really like to know what it has been like to get better. I would like to know what 'feeling better' means to you. I would like to meet you to ask you some questions. I will ask you questions like: What sorts of things have you done that have helped? And in what ways do you feel better about yourself and your life now?
	Do I have to take part? No, you don't have to take part in my study, it is up to you. You do not have to talk to me if you don't want to.
	What happens if I do take part? I will meet with you and answer any questions that you have about the study. I will check that you are happy to take part. If you are ok to take part I will ask you to tick a box. Ticking the box means that you are happy for me to ask you questions. This meeting will last for about one hour, but it may

	be a bit longer or a bit shorter than one hour. We can take breaks during the meeting if you want. I will record our meeting.
	<u>What you talk about will be private</u>. Exactly what you say in the meeting will only be known by me and my two supervisors. My supervisors won't know your name and no-one will be able to know that it was you that said those things. After I have taken notes, I will get rid of the recording. I hope to share with other people the ideas from everyone that I meet with to help teach other people about 'feeling better'. I will write down what you say and share your ideas with others. Nobody else will know your name. Nobody else will know that you spoke to me. You can tell anyone you want about our meeting. If I am worried you might hurt yourself or hurt someone, then I will tell you. I will also tell your GP and your Care Manager.

What could be a good thing about taking part?

Hopefully you will find the meeting with me interesting. You may find it helpful to talk about what you have been through. You may find it helpful to talk about how you feel better since coming to Psychology. You may also find it helpful to talk about how you don't feel better. You may want to tell me that there are things that you would still like to change.

What could be not so good about taking part?

You may find it hard to talk to me about some things and it may be a bit upsetting. If at any point you find it too upsetting, you can stop talking to me. I won't mind. If you are still upset after we have stopped talking, then there will also be a chance for you to talk to

_____

__

outside of this study about how you are feeling.

You can also contact PALS (Patient Advice Liaison Service) on 0800 731 2864

or at pals@slam.nhs.uk

for advice from someone not involved in the study.

Who can you go to if you would like to complain?

If you are not happy about any part of this study you can make a complaint. If you want to make a complaint, you should contact:

Paul Camic

Canterbury Christ Church University,

Broomhill Road,

Southborough,

Tunbridge Wells, TN3 0TG.

Email: Paul.Camic@canterbury.ac.uk.

Telephone: 01892 507773

Contacting me

You can telephone me on 01892 507673 if you have any questions. If you leave a message I will get back to you. Or you can email me at

ejt19@canterbury.ac.uk

Do you have any questions you would like to ask me now?

My project is being supervised by …………………………………………………………………and

Dr Jerry Burgess (at Canterbury Christ Church University).

LOGO REMOVED

Tel: 01892 507673

ejt19@canterbury.ac.uk

CONSENT FORM for "Feeling Better "study

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	My name is Emma Trustam I am a trainee psychologist.
	I am a student at Canterbury Christ Church University in Kent.
	I have written an information sheet which tells you more about this study. If you don't already have this, please ask me for it. **Please read the boxes below and let me know that you have understood**
	Emma has answered any questions that I had.

	If I find any questions upsetting or hard, I don't have to answer them. I can stop talking to Emma at any time and leave the study, and that won't matter at all.
	What you talk to me about will be private. It will only be me and my two supervisors that will know what you have told me. My supervisors won't know your name and no-one will be able to know that it was you that said those things. After I have taken notes, I will get rid of the recording. But if I am worried you might hurt yourself or hurt someone, then I will tell you. I will also tell your GP and your Care Manager.
	Emma will be recording the things that I tell her.

MY DECISION

YES, I would like to take part in the "Feeling Better" study

OR

NO THANKS, I do not want to take part in the "Feeling Better" study

My name is:

…………………………………………………………………………………

YES, I am happy for you to see my outcome data (questionnaires that my Clinician has filled in about how I have done in my treatment).

NO THANKS, I do not want you to see my outcome data (questionnaires that my Clinician has filled in about how I have done in my treatment).

CONTACTING OTHERS ABOUT ME TAKING PART IN THE "FEELING BETTER STUDY

    YES, I am happy for my **Care Co-ordinator**, _____to be contacted about my taking part in the "Feeling Better" study.   ☐

    NO THANKS, I do not want my **Care Co-ordinator** to be contacted about my taking part in the "Feeling Better" study.   ☐

    YES, I am happy for my **GP, _____** to be contacted about my taking part in the "Feeling Better" study.   ☐

    NO THANKS, I do not want my **GP** to be contacted about my taking part in the "Feeling Better" study.   ☐

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Information Sheet for Family & Carers

"Feeling Better" Study

My name is Emma and I am doing some research as part of my studies. This is looking at how people with learning disabilities make sense of their experiences of 'recovery' from mental health difficulties, and what it means to "feel better".

What is this study about?

I am interested in talking to people with learning disabilities that have come to psychology for help for a mental health difficulty. As part of the help received they would have come to talk to someone when they have been feeling bad about things in order to feel better.

The questions that I will be asking are designed to find out what it has been like to get better and what this means to the person coming to the service. I will ask questions like: Do you feel better? What has made you feel better? What sorts of things have you done that have helped? And in what ways do you feel better about yourself and your life now?

Do people have to take part?

No, taking part is up to the individual. If they decide not to take part then that is fine and it will not affect them accessing the service in the future. If they do decide to take part, they can still change their mind at any time.

What does taking part entail?

I will meet with the participant and ask some questions about feeling better or "recovery" as it is sometimes called. This meeting will last for about an hour, although it may be longer or shorter than this. We can also take breaks during the meeting if required. I will need to gain consent of everyone that takes part. After the participant has read the information sheet and asked any questions that they may have, I will ask them to tick a box indicating that they are happy to take part.

What will happen to the things said during the meeting?

Everything told to me by each participant in our meeting will be kept private between myself and the participant, but also with the people who are supervising me with the project I am doing. However, my supervisors will not know the participant by their name. The exception to this confidentiality is if the participant tells me something that means that they or someone else is at risk of harm or in danger, then I will have to tell other people about it.

I will be using the general themes and ideas of what people tell me and report these as my findings. I hope to publish these results and also disseminate them in order to teach others about work in this area. Quotes of what participants have said to me may be used but these will not be identifiable to the participant. No names will be used. I will record our meeting to remind me of what was said and use this to take notes. It will only be me who will listen to the recording. After I have taken notes, I will get rid of the recording.

What are the benefits of taking part?

I cannot promise that taking part in this study will help the participant, but hopefully people taking part will find it interesting, and maybe helpful to talk about their experiences and how they have got better.

Participants may also find talking about these things a little hard to do and it may be a bit upsetting. If this is the case, they are aware that they can stop at any time, and that I won't mind at all. Each participant will also be provided with a name of someone that they have agreed they may like to contact, if they are still upset after we have stopped.

There is also a complaints procedure outlined in each participant's information sheet. And each participant has my contact details for any questions or queries that they may have at any time.

Best wishes

Emma
Emma Trustam
Trainee Clinical Psychologist, Canterbury Christchurch University
Ejt19@canterbury.ac.uk

Appendices 1 and J removed

Interview Schedule

<u>*Aim to relax the participant*</u>
- Offer tea/coffee and biscuits

- Make person feel relaxed and at ease, get them talking and act as a gentle introduction – and to find out more about them.

- Explain what the interview is about (referring to the information sheet) and what will be asked of the participant

- Explain there are no right or wrong answers; that is doesn't matter what they say, they will not be judged. I am interested in hearing their story and what it is like to be them.

- Explain there is the option of taking a break and ask how I will know if they want to take one.

- Remind participants of limits of confidentiality.

- Remind of who they can talk to if they need to after the interview

- Check consent

- Remind participants of voluntary nature of participation

- Answer any questions

- Check/collect demographic information

(Also possibly ask Support worker – if present about what sorts of things the participant likes to do, to help with questions)

Ask who participant is close to, who is it that knows them well (to help with some of the questions)

Interview

<u>Explaining the process</u>
(Have questions laminated with prompts to hand if needed)

Introduce the time map on big paper and explain how it will be used (explaining each column: The Past- before they came to psychology and Now, the bit in-between now and then and the Future).

Explain laminated emotion/activity cards Ask participant to draw/use pictures/cards, (or I/they can write down if prefer) on the time map as relevant and create conversation around this

<u>Questions</u> (**closed ones also listed as contingency plan, from which to follow up using open questions)

<u>Tell me about your experience of attending psychology sessions</u>

1) (Introduction to their time in psychology services) Next I am going to ask you about when you came to psychology

Use time map (in the middle section to represent coming to psychology and list/talk about things under "thumbs up" symbol for good and "thumbs down" for bad and sideways thumb for neither. Also use emotion cards.

- How did it feel coming to talk to X?
- What sorts of things did you do when you came to see X at psychology?
- What else did you do?
- What did you think was good/bad, helpful/unhelpful?
- How did you feel about doing X? (emotion cards) OR What was that like?, How was that?
- Can you tell me why you felt X?/ What was it about X that made you feel Y?
- After coming to psychology, did you feel the same/better/worse? (visual prompts)
- If 10 was the best you could feel and 1 the worse, how do you feel now? (visual prompts)

Closed prompts
➢ *Did it help coming to psychology to talk about your problems?*
➢ *Was that good/bad? (Why….)*
➢ *Did you find this helpful/not helpful? (Why…)*

<u>How did you come to be attending psychology sessions?</u>

2) I would like to hear your story about what led you to psychology…?

- How come you starting to see X in psychology?
- Who thought it would be a good idea to come to psychology?(visual prompts possible for referrers)
- Why did they think that was a good idea? / What made them think that you needed to come and see psychology?
- Why do you think they thought that? / What was happening (in your life) at the time?
- What did you think / How did you feel about coming to psychology? OR what was it like…?
- What did you think would be good/bad about coming to Psychology? / Why did you/didn't you want to come to psychology?
- What did you want to get out of coming? / What did you want help with?
  *What do you think would happen to you when you came to Psychology?
  *What did you think Psychology would change/do for you?

*What did you think you would need to do to feel good?

Closed prompt
➢ *Did you think it was a good/bad idea? (why/why not?)*

Tell me about how you first thought that you were feeling better

3) **Process of getting better - (Assuming that the previous response confirmed that they do feel better) I am going to ask you about the time you first started feeling better)**

- How did you know that you were getting better?
- When did you first think/notice that you might be feeling better? What happened to make you think this? / What were you doing at the time?
- How did this make you feel? (Using emotion cards) OR What was that like, How was that?
- When did you think others (<insert person>) first noticed you feeling better?

Again, use time map to try and explore how feelings and other differences at various times and the progression of these – i.e. when they first felt better, before feeling better and currently.

What changes have you experienced since feeling better? (Feel, think, do)

4) I am interested in changes/anything different you have noticed about yourself over this time…
Using the time map to conceptualise "now" and "then"…explore changes since feeling unwell or first coming to psychology – using different time points already discussed. If changes already mentioned previously then pick up on these and find out more.

Self

- In what ways do you feel different now to how you felt then?
- In what ways are you different now to how you were then?

- How do you feel now?, How did you feel then? (emotion cards) OR What was that like then.now?
- What made you/happened to make you feel X?
OR
- What made you/happened to make you feel X? Why is it that you feel X now but not then? (when unwell, first came to psychology)

Closed prompts
    ➢ *(Referring to time points) Are things good/bad/the same now/then?*
    ➢ *In what ways do you think they are/you feel good/bad/the same? Why?*
    ➢ *What was good/not so good about…? (points in time compared to others)*

- Since, feeling better, how are things different?

- What sorts of things do you do now / did you do then?
- What made you/why did you… do that then/this now?
- Why is that/How did this come about?
- What has been the biggest change (to your life/in you) to since feeling better?
- What made this change happen for you? What helped you …….?

Closed prompts
➢ *Are there things/are you doing things you did "then" that you don't do now? What are they?*
➢ *Are there different/new things about your life? What are they?*

Others
- How do (family, friends, support worker?) say that you have changed from now – then? What do they say is different about you? What do they say you do differently?
- What makes them think/say that?
- Why would they think you do that? ? And they think that because…
- How would someone you've just met describe you now? How would they have described you before? Why are you…..?

Closed prompts
➢ *Would (family, friends, support worker?) say that you have changed/are different now?, if so how?*
➢ *Do they think there are different things about your life? What are they?*
➢ *Would they say that you did things then that you don't do now/do things now that you don't do then? What do they think they are?*
➢ *Do they think things are good/bad/the same for you now? Would they say that you feel good/bad/the same? In what ways? What would they think was good/bad /the same?*

What changes have you noticed in your relationships with others?

5) (Check who is close to them/ important in their lives) I am interested in changes that you have noticed in other people
- How do you get on with X now/ How did you get on with them then?
- What do you think about X now/then?
- Why do you think this is?
- How has this changed from X (time point)?
- What changes have you noticed in other people? Why do you think this is/ Any idea why this might be?

- How has feeling better changed your relationship with your family/friends/partner?, How has/in what ways has 'feeling better' made things good/bad, better/worse with X?

    Closed prompts
    ➢ *Do you think differently about other people in your life? If so, how/what is different?*
    ➢ *In what ways do you feel differently about other people in your life? If so, how/what is different?*
    ➢ *Have you noticed changes in other people?, if so what?*
    ➢ *Has feeling better changed your relationship with your family/friends/partner? In what ways?*
    ➢ *Since feeling better, have you noticed any changes in other people (in how they treat you/in how they are with you? What changes?*
    ➢ *Do you think other people treat you differently, if so how*

Define what "feeling better" means to you

6) These next questions are all about feeling better   (also referring to items on time map)

- What has made you feel better? What has helped you get better?
- Was there anything that didn't help?
- What are good things/bad things about feeling better?
- What is the most important thing to you about feeling better?
- What was the hardest/easiest thing about getting better? / What was hard / easy about getting better? / What has made getting better easier to do?
- What is difficult / easy now?
- What has helped/not helped you get better?
- What would X (people close to you) say about this?

How do you cope with difficulties since feeling better?

7) I want to talk to you next about how you deal with your problems now, (since coming to psychology)
(Using time map, try and explore any changes in ways of coping over time)

- After coming to psychology, how do you cope with/handle <referring problem>? What do you do?
- What helps you with this? What makes xxxxx better? What makes you feel good/ok again?
- Is there anything that doesn't help? Keeps you feeling bad/stops you feeling good again? What makes xxxxx worse?
- What would other people who know you say about this?

- How do you feel about the fact that now you do X, (whereas then you did Y)? (emotion cards)
- What sorts of things worry you now? Did it worry you then? What were your worried about then? Why do you not worry about that now?

Closed prompts

➤ Are there times when you still feel X?

➤ When? What is happening at these times? Can you describe a recent example?

➤ What do you do to help/make you feel better/good again?

➤ What makes you feel bad / doesn't help?

➤ How does that make you feel? (emotion cards)

What would continuing to "feel better" look like in the future?

8) Next, I will ask you about the future (refer to time line …What would you like to be able to put on this in the future….)

- In the future, (refer to time map empty column) What other things would make you feel good/better?
- What other good things would you like to see on here? What else would make you feel good? What else would help you?
- What else would have to happen/be different in order for to carry on feeling good?
- How are you going to do this? What are your plans for how to go about getting this?
- What would X (others close to you) say about this?
- What other things would you like to be doing?
- What have you always wanted to be able to do?

(Past) THEN ⟶ Includes what led to attending psychology, coming to psychology, when first felt better,	NOW	FUTURE

Appendices M and N removed

SECTION D   Appendix O: Table of refined initial codes/themes their
                   relationship with themes in the model

Sub theme	Refined initial themes (related to sub-theme)	Number of participants	Number of references
Seeking Understanding	Questions about relationships	4	14
	Why can't I be treated like an adult?	5	17
	Making sense of family/friend situations	5	6
	Making sense of who I am	1	5
	Questions about other issues	9	20
Valuing Information	Benefits of information given	9	23
	Valuing advice	7	11
	Learning coping strategies	6	7
	Making sense of relationships	3	10
	Understanding precursors to emotions	2	6
	Making sense generally	7	7
Expressing Unfair Treatment in Life	Upset/confusion at people's treatment of each other	3	11
	Bullying	8	10
	Loss of support	4	7
	Problems within the family/friends	8	18
	Problems at work	1	12
	Other unfair treatment experienced	7	26
Management of Expectations	Expectations not managed/kept in dark	5	7
	Unrealistic aims/expectations	4	6
Therapeutic Alliance	Feeling of stuckness	2	7
	Not feeling able to talk	5	13
	Value of talking	9	10
	Talking easier to professionals Vs family	2	7
	Helps to talk about feelings (understand)	9	10
	Feeling understood/understand me!	7	15
	Growing Trust (able to open up/be honest	4	11
	Emotional support of therapist facilitate progress	3	10
Self Management	Knowing how to look after yourself and why	1	2
	Looking after yourself	2	2
	Promotion of coping/ (strategies)	9	25
	Mastery and competence	3	28
	Managing feelings: catharsis	8	15
	Talking helpful	8	22
	Talking cathartic	4	10
	Proactively dealing with problems	7	11
	More treatment (booster sessions) needed	4	6
	Wrestling-learning to cope	3	13
	Wrestling - strategising	3	10
	Escapism	6	9
Emotional Development	Recognition and monitoring of emotions/behaviour	6	12
	Aware of anxiety about difficulties re-emerging	1	4
	Increased awareness and control of behaviour	7	18
	Understanding emotions and behaviour	8	20
	Recognition of others emotions	5	12
	Recognition of interpersonal dynamic (cause and effect)	3	16
	Facilitating communication/identification and expression of emotions	4	5
	Ambivalent perspective re: feeling better	8	19
	Experiencing mixed emotions	6	10
	Feelings context specific	1	3
	Duality Vs dichotomy	1	10
	Holding 2 truths, recovery both better and still v hard	9	16
	Accepting good and bad parts	3	14
	Wanting adult responsibility/treatment	5	13

Appendix O: Table of refined initial codes/themes their relationship with themes in the model

	Valuing adult responsibility	2	6
	Feeling capable/maintaining capabilities	9	19
	Fear of anger	4	5
	Managing fear	2	13
Positive/Empowered Identity	Building esteem/confidence	2	9
	Affirming self	6	19
	Having purpose, feeling useful (a job)	5	11
	Performing	7	12
	Identifying with celebrity	3	4
	Increasing technological capability	4	7
	Ideals of happiness	6	6
	Increasing personal capability	8	23
	Knowing rights	5	6
	Assertiveness	5	18
	Proactive, drive and determination	9	33
	Perseverance	8	12
	Stamina	4	7
	Identifying with wrestling	3	16
	Resourcefulness	5	7
	Strength		
	Self sufficiency	2	2
	Success is possible in spite of difficulty	2	3
	Need for a "Better Me"!	7	14
	Wish for self-development/improvement	7	23
	Beyond an aspirational self	9	32
	Desire for New Me/Identity	9	29
	Realism of aims?	9	15
Connectedness	Affirming existing relationships	3	7
	Getting/feeling involved	2	7
	Need for social/emotional connection	5	12
	Desire for social relationships	4	9
	Desire to be more socially confident	2	5
	Relationships improved	5	15
	Struggle with developing more social relationships	2	5
	Understanding problems in relationships	3	7
	Desire for intimate/special relationships	3	3
	Aspiration for social conventions/norms	4	4
	Talking to others facilitates feeling of connection	5	7
Autonomy vs. Support	Valuing independence	9	28
	More opportunities for independence wanted/Striving for…	6	19
	Personal responsibility for recovery	5	14
	Seizing control	8	13
	Taking Action	8	13
	Personal decision made to feel better	1	3
	Choice	4	5
	Seeking freedom	4	4
	Available emotional support important	9	30
	More support needed	9	29
	Always there for me	2	2
	Support offers security & containment	8	21
	Clear about goals, not sure how to achieve	5	14
	No control/ownership over feelings/difficulties	6	7
	Changes located in others, not internally	2	2
	Passive role	9	16
	Feeling/coping better, desire to be OK	8	15
	Things will change	3	8

Appendix O: Table of refined initial codes/themes their
relationship with themes in the model

	Faith/Spirituality	4	11
Belief in Recovery	Focus on goals	4	9
	Everything recoverable from?	3	6
	Why aren't I better yet?	1	4
	Uncertainty of future	2	7
	Look forward	3	16
	The future (having something to look forward to)	5	17
	Recovery on-going,	8	32
	Long, hard process	4	4
	Difficulties remain/Issues remain un-tackled	9	12
Process of Recovery	Aware of anxiety about difficulties re-emerging	1	4
	Recovery not linear, oscillates	8	15
	Gradual no quick fix	5	7
	Progression/momentum	1	5
	Variable/context specific	6	20
	Difficulties remain	9	19
	Recovery as an absolute	2	3
	No perfect solution	2	2
	Some things remain the same	5	7
	No change in relationship with others	4	5
	Wrestling with Recovery	4	18

<div align="right">**March 1st 2014**</div>

Dear Chair

Please find enclosed my end of study report for:

Ref: 12/LO/1032: What does "recovery" mean for people with mental health difficulties and learning disabilities?

Background: Recovery as an approach has gained momentum over the past 20 years and is now a prevalent feature within mainstream mental health services. There has been a proliferation of research which explores what recovery means within adult mental health populations, but no research to date which has focussed on recovery in people with learning disabilities.

Aims: The aim of this study was to explore the experiences of recovery for a group of individuals with learning disabilities and mental health difficulties and examine these results in light of the findings from the existing recovery literature.

Method: A qualitative design using Interpretative Phenomenological Analysis was applied and nine interviews were conducted. Interviews were transcribed and analysed and a model developed to describe the recovery experience.

Results: The analysis revealed that the recovery experience for PwLD can be conceptualised as the **Mental Health/Therapy Experience** and the Client Recovery Experience. The former depicts the early experiences of mental health as participants enter the service, and describes what is perceived as helpful in terms of what the therapy/service provides. Four distinct themes elaborate upon this experience: Expressing Unfair Treatment, Seeking Understanding, Valuing Information, and Managing Expectations.
Aspects of the mental health and therapeutic experience are all facilitated by the **Therapeutic Alliance**. Building a relationship based on trust, respect, and feeling understood, enabled the issues participants brought to the service to be listened to, creating a space where interventions

could be most effective. This relationship enabled all elements within the Client Recovery Experience.

The Client Recovery Experience includes three phases of recovery that describe participants firstly, "feeling better", and secondly require or are perceived to require additional input and continuing support ("ongoing recovery"). Thirdly, the phase "attainability" questions the realism of attaining some of the goals expressed and the role that fantasy played in accomplishing or striving for these. Seven themes define the Client Recovery Experience; each of these will be described briefly in relation to each phase of recovery.

Self-Management of mental health problems

Participants found it beneficial to use various kinds of coping strategies, which allowed them to monitor and manage their emotions. Some difficulties remained in the implementation of these indicating that ongoing support was required, equally most participants has been referred to the service at least once before. Less overt coping strategies were expressed as forms of escapism, catharsis and displacement and incorporated elements of fantasy; this was particularly evident in the use of "wrestling" as a metaphor for the struggle involved in "feeling better".

Emotional Development

Participants visibly benefited by addressing gaps in their emotional development; this included being treated like an adult, an increased understanding of behaviours and emotions in oneself and in others, and the recognition and tolerance of ambivalent feelings. All aspects were progressive and needs were identified as ongoing in all areas. In terms of emotions, anger was feared by many and reconciling or understanding these feelings was still difficult, but was in part able to be explored through the use of metaphor.

Autonomy/Support

Recovery means navigating a personally satisfying balance between independence and dependence, assuming personal responsibility for recovery, whilst appropriately drawing on the resources of others and gaining reassurance. Strengths of PwLD were particularly salient in the resourcefulness demonstrated regarding managing their mental health. However, this balance was hard to maintain and there was both an ongoing need for emotional and practical support and opportunities to express autonomy, which were often expressed through the use of analogies comprising idealisation and fantasy. More input was required with regards to managing expectations of the service/treatment and accessing information/knowledge.

Connectedness

Participants valued improvements in relationships with others and defined recovery as feeling more accepted and being more engaged in life, which in turn, improved one's self-concept.

Participants aspired to have more friendships, relationships and ultimately a family; these aspirations were influenced by societal ideals and conventions. These ideals raised the issue of

realistic goal-setting and question as to how attainable these wishes were, and perhaps more importantly, how else could similar levels of satisfaction and meaning in life be achieved.

Positive/Empowered Identity. Recovery brought with it a feeling from participants that they had had acquired a sense of purpose and they felt more capable and competent; all of which was self-affirming and empowering to their sense of identity, and encouraged participants in the pursuit of becoming an even "better person". Possible comparisons and idealisations of the type of lives being led in the general population gave rise to aspirations to be a new and different person, a non-LD identity and live according to the perception of a "normal life". This desire was managed by the denial of ones learning disability or consideration that their LD was recoverable from and once again questions the realism regarding these aspirations.

Belief in Recovery

There was generally optimism and determination that "things would get better". This was expressed as current belief and hopes for the future. However, as recovery progressed, participants aspired to recover from more than their mental health difficulties; they also aspired to recovery from their learning disability.

Process of recovery

Process of Recovery represents the abstract experience of what it is like to feel better and recognises multiple interactions amongst themes from both dimensions of experience (Mental Health/Therapy and Client Recovery). The process was described as a slow and gradual one which is ongoing and progressive.

Conclusion: Results stress the importance of reaching a balance between support and autonomy for each client with LD, and the consideration of emotional development, information giving and education, and self-management strategies.

There is also a need to discuss openly about what having a LD means and what it realistically achievable in terms of setting goals. It would also be of benefit to normalise what it is to have a non LD identity. One way in which these objectives could be met is through the use of role models of PwLD who are leading positive fulfilling lives within society; whilst also aiming to socially integrate PwLD and proving the opportunities for independence, support, relationships, practical and emotional understanding and ultimately a positive sense of self that individuals seek. Ideas for which include increasing the presence of meaningful service-user involvement peer support workers, self-advocacy movement, and Recovery Colleges.

If you would like any further information then please don't hesitate to get in touch.

Kind Regards

Emma Trustam

Trainee Clinical Psychologist

Canterbury Christ Church University

Appendices R and S removed.