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## **Counselling Psychology in IAPT**

Kate Anne Bexley

## Portfolio submitted in fulfilment of the requirements for the Professional Doctorate in Psychology (DPsych)

City, University of London Department of Psychology September 2016



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## TABLE OF ACRONYMS

AR	Action Research
CBAR	Community Based Action Research
CBT	Cognitive Behavioural Therapy
CLDT	Community Learning Disability Team
DoH	Department of Health
ER	Emancipatory Research
GLTK	Green Light Toolkit
HI	High Intensity (Therapist)
HRA	Health Research Authority
IAPT	Improving Access to Psychological Therapies
LD	Learning Disabilities
LD-PPG	Learning Disability – Positive Practice Guide
MDS	Minimum Data Set
NDTi	National Development Team for Inclusion
NICE	National Institute for Clinical Excellence
NHS	National Health Service
PAR	Participatory Action Research
PWP	Psychological Wellbeing Practitioner



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# THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:

**Section B- Client Case Study** 

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Last, but certainly not least, a particularly huge thank you to each and every participant for their instrumental wisdom and commitment during the research.

### Declaration of powers of discretion

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### Preface

Before embarking on my Counselling Psychology Doctorate, I had worked as a High Intensity (HI) Therapist within Improving Access to Psychological Therapy (IAPT) for three years. This was a natural progression having completed the IAPT HI Training resulting in a Post Graduate Diploma in Cognitive Behavioural Therapy (CBT), which focused on treating anxiety and depressive disorders. Whilst this training and experience provided an excellent foundation in offering a particular kind of therapy, to a particular group of people, I quickly became aware that I needed a broader knowledge of therapeutic modalities and service user groups. Invariably, I would be allocated individuals whose presentations I perceived beyond my remit. A desire to broaden my knowledge and skillset was thus a key impetus for embarking on the Counselling Psychology Doctorate. I nonetheless, continued to work as a CBT Therapist in IAPT throughout my Doctorate.

In many ways, this portfolio reflects a transition from being a CBT therapist in IAPT to becoming a Counselling Psychologist in IAPT. It is of note, that IAPT has been questioned and critiqued by several British Counselling Psychologists (e.g. Cooper, 2009; Moller, 2011). Perhaps most prominently, from Counselling Psychologist, Rosemary Rizq. Rizq has accused IAPT of leading to a 'perversion of care' within the NHS (Rizq, 2012), proposed that IAPT clinicians are considered to be 'expendable' and 'unwanted' (Rizq, 2011), and uses the Orwellian notion of 'thoughtcrime' to suggest that IAPT is minimising clinicians' abilities to appreciate the emotional realities of suffering through its ideology, framework and adherence to evidence-based protocols (Rizq, 2013).

During the past three years, I increasingly endeavoured to encompass the principles of Counselling Psychology, and Counselling Psychology research within the IAPT service in which I was based. It was, at times, difficult to balance the ideals of IAPT, which undoubtedly emphasises adherence to National Institute Clinical Excellence (NICE) approved and 'least burdensome' (i.e. briefest) interventions, with the ideals of Counselling Psychology, which I interpreted as altogether more patient, holistic and flexible. The theme that accordingly binds the components of this portfolio together is that incorporating the principles of Counselling Psychology, as a CBT therapist within IAPT whilst challenging, is possible. This portfolio is comprised of: Section A: Research, Section B: Extended Case Study, and Section C: Publishable Piece. As we shall see, this theme is reflected in varying ways across all three components.

#### Section A: The Research

The first component of this portfolio comprises of an original piece of research aimed at exploring the feasibility of making an IAPT service more accessible to people with learning disabilities. This was

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borne out of my awareness anecdotally and through research (e.g. National Development Team for Inclusion; NDTi, 2012) that people with learning disabilities and common mental health problems were not guaranteed equitable access to IAPT; despite various polices and legislations underscoring inclusion (e.g. Disability Equality Duty, 2006), including IAPT's own 'Commissioning for the Whole Community' document (DoH, 2008). The research took place within an Inner-London IAPT service where I was, at the time, working as a CBT therapist. An action research framework, which is fundamentally a reflective process of progressive problem solving guided by those effected by a particular challenge, was used. Action research typically consists of three phases: 'planning/data gathering', 'implementation' and 'evaluation'. This framework was chosen as it ensured changes would be implemented and evaluated as part of the study, and because it allowed those most affected by this matter, service users with learning disabilities and IAPT clinicians, the opportunity to have their 'voices heard' and participate in the research process. Action research thus enabled and supported the importance ascribed to Counselling Psychologists of learning from, and working with, service users and other professionals (Kanellakis, 2010).

The sample consisted of seven IAPT service users with learning disabilities and 12 IAPT clinicians. The Green Light Toolkit (GLTK; NDTi, 2013), an audit tool designed to help mental health services assess how accessible they are to people with learning disabilities, was used to guide semi-structured interviews with participants. In the 'planning/data gathering' phase, the GLTK (2013) was used to elicit participant's views on how accessible they thought the IAPT service was, and put forward recommendations for improvement. The 'implementation' phase consisted of the collaborative implementation of these recommendations over a six-month period. In line with the cyclical nature of action research, the third and final 'evaluation' phase consisted of re-interviewing participants, again using the GLTK (2013) as a guide, to evaluate the success of the implementation phase and elicit suggestions for further improvements.

Findings from the planning/data gathering and evaluation phases, which were interpreted using thematic analysis, highlighted many overlaps between service users' and clinicians' views on the accessibility of the service and how this might be improved. Key differences included service users appreciation of being included, on many levels, and the importance of clinicians and the service recognising individual differences and their increased needs. Whilst these were also acknowledged by clinicians, far greater emphasis was given by them to the uncertainty they felt toward working with this group in IAPT. In line with existing professed challenges and access barriers for people with learning disabilities in IAPT (e.g. Chinn, Abraham, Burke & Davis, 2014), this manifested in forms of feeling "ill-equipped". Many clinicians appeared to conclude that an ongoing commitment within this IAPT service and further commitments from commissioners and service leads would be necessary to facilitate comprehensive inclusion of this service user group within IAPT.

There is an increasing emphasis placed on Counselling Psychologists to take action on the values we uphold, including facilitating growth, orientation towards empowerment and commitment to democratic, non-hierarchal relationships (Cooper, 2009; Orlans & Van Scoyoc, 2008). In line with this, the current study demonstrated that effective and collaborative changes could be implemented in a way that enabled one IAPT service to adapt to better meet the needs of people with learning disabilities within a brief timeframe. This topic and outcome is particularly relevant for Counselling Psychologists as it underscores the requirement for those in our field to attend to discrimination and use our skills to influence others, including our colleagues, as well as society at large as represented by legal and social care systems (Kanellakis, 2010).

#### Section B: Extended case study

The case study offers a reflective and reflexive account of the application of CBT in the treatment of social anxiety within an IAPT service. Although there is emerging evidence for alternative approaches for the treatment of social anxiety (e.g. Hunger et al., 2016; Norton, Abbott, Norberg & Hunt, 2014), the only psychological therapies currently recommended in the NICE guidelines (NICE, 2013) are CBT based (e.g. Clark & Wells, 1995). Due to a commitment to evidence-based therapy, and implementation of NICE guidelines, IAPT services favour CBT-based approaches for anxiety-related disorders (Clark, 2011; NICE, 2013), hence why this model was chosen with this individual.

This case study predominantly highlights the interpersonal challenges of working with social anxiety, namely the feedback loops between the service user's self-consciousness and my own, using a modality that whilst recognising the importance the therapeutic relationship, appears to omit attention to feelings invoked within a therapist in sessions (i.e. counter-transference). The case study begins with an overview of the cognitive model of social anxiety (Clark & Well's, 1995; Wells & Clark, 1997; Clark, 2005) before introducing 'Simon' and summarising his first session, evolving longitudinal formulation and idiosyncratic version of the cognitive model of social anxiety. There is then an outline of the therapeutic plan, which is followed by a review and reflection of the development of therapy with reference to techniques, session content, therapeutic processes, changes in these over time, and how clinical supervision was utilised.

In particular, this case study considers two keys areas relating to the therapeutic alliance. Firstly, the extent in which a socially anxious individual's anxiety can cause uncomfortable feelings in a therapist and thereby 'contaminate' the therapeutic process (Wells & Papageorgiou, 1999). This is particularly

<sup>1</sup> A pseudonym is used for confidentiality purposes

relevant to Counselling Psychologists trying to make sense of this phenomena within the CBT framework favoured within IAPT. Secondly, this case study discusses how the client's manifestations of social anxiety, such as his self-focused attention and difficulties maintaining eye contact, appeared to initially inhibit development of a therapeutic alliance. In contrast to a key counselling presupposition that the strength of the therapy relationship is central to bringing about change (e.g. Rogers, 1965), my relationship with Simon appeared to strengthen with each successful CBT intervention. Over time, cognitive-behavioural strategies fundamentally shifted Simon's unhelpful appraisals of how others, including me, perceived him, and empowered him to break the feedback loops that maintained his social anxiety in his day-to-day life, and in therapy. The therapeutic ending is reflected upon before an evaluation of the work, with reference to learning points about psychotherapeutic theory and practice, and myself as a Counselling Psychologist practicing CBT in IAPT.

#### Section C: Publishable Paper

Counselling Psychologists are particularly interested in addressing 'real-world' challenges encountered by professionals in Counselling Psychology and beyond (Kasket, 2012). The research reported on in the first component of this portfolio sought to address an existing challenge (the potential inaccessibility of IAPT services for people with learning disabilities) by eliciting, implementing and evaluating IAPT service users and IAPT clinicians' suggestions for improvement. It aimed to do this within a relatively brief timeframe and without funding or additional resources in order to enhance its applicability to other IAPT and mainstream psychological services. As a discipline, Counselling Psychologists are increasingly encouraged to 'think bigger' (Vermes, 2014), strive towards more practical fields including service management (Douglas, Woolfe, Strawbridge, Kasket, & Galbraith, 2016), and aspire to have more of an impact on the research community (Gordon & Hanley, 2013). Fundamental to all of these points is the public dissemination of our research findings.

The current study and its findings are especially relevant to Psychologists at both practitioner and managerial levels, both within IAPT and specialist learning disability services. The '*Journal of Intellectual Disabilities*', aimed at those involved with people with learning disabilities, was chosen as it focuses on publishing papers on issues relevant to the promotion of services for people with learning disabilities. Its principle aim is to provide a "medium for the exchange of best practice, knowledge, and research between academic and professional disciplines...*to bring about advancement of services for people with intellectual difficulties*" [emphasis added]. Several IAPT clinician's reported that they lacked confidence in working with people with learning disabilities due to the low numbers of this population currently accessing IAPT. Publication and dissemination of the

current study through the '*Journal of Intellectual Disabilities*' has the potential to increase referrals of people with learning disabilities and common mental health problems to IAPT. It is possible that in addition to the existing legislation, greater numbers of referrals of people with learning disabilities may inspire further IAPT services to consider their accessibility and implement adaptations where necessary. This may accumulatively increase clinicians' confidence in working with this population, thereby enabling them more equitable and effective access to IAPT.

#### **Concluding comments**

Until recently, I had anticipated that upon completing my Doctorate, I would leave IAPT and attempt to work within a Community Learning Disability Team (CLDT). Because of my existing desire to work with this service user group, I had been allocated clinic space within a local CLDT to offer IAPT services for people with learning disabilities and common mental health problems. Although I had been a strong advocate of inclusion of this service user group into mainstream services, it was not until recently, when a service user with learning disabilities asked if they could see me at the main IAPT service base (instead of the CLDT base), that it truly hit me how important 'full' inclusion was. This occurred around the same time I had completed the taught component of the Doctorate and was faced with the dilemma of accepting a position with a CLDT, or a managerial position within another IAPT service. Above all else, what swayed me to accept the latter (in a different service to where the research was conducted) was the belief that my chances of making access to IAPT more equitable for people with learning disabilities, would be infinitely greater from working within such a service.

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## **SECTION A: DOCTORAL RESEARCH**

## Improving access to psychological therapy for people with learning disabilities from service users' and clinicians' perspectives: An action research approach

Kate Anne Bexley

Supervised by Dr Kate Theodore and Dr Jessica Jones Nielsen

#### ABSTRACT

**Background**: Despite legislation commanding equitable access to all mainstream services, reports continue to question Improving Access to Psychological Therapies (IAPT) accessibility for people with learning disabilities (LD). Related research typically excludes service-users with LD perspectives' and overlooks implementation of findings. This research aimed to elicit, implement and evaluate IAPT service users with LD and IAPT clinicians' suggestions for improvement regarding the accessibility of one IAPT service.

**Method**: An action research design comprised of: planning/data gathering (phase one), action/implementation (phase two) and evaluation (phase three) was undertaken within an inner-London IAPT service. Seven IAPT service-users with LD and 12 IAPT clinicians were interviewed using a revised version of the *Green Light Toolkit* (National Development Team for Inclusion, 2013). Qualitative data from phases one and three were analysed using thematic analysis. Phase one recommendations were collaboratively implemented over a six-month period in phase two. Phase three consisted of evaluative interviews with service-users with LD and IAPT clinicians and elicitation of further recommendations.

**Results:** Phase one found both service-users' and clinicians' believed that the service was 'doing well'. Both also proposed recommendations for clinician and recommendations for the service. However, clinicians' recommendations were underpinned by their 'uncertainty' in working with this population. Phase two's implementation of recommendations included: adaptations of existing written texts, creation and distribution of easy read promotional material on IAPT, and three training events. Phase three saw both groups commend the actions taken and propose further recommendations for clinicians and for the service; however, clinician's continued to express doubts about whether IAPT could fully adapt without systemic changes.

**Conclusion**: Whilst effective changes can be made 'on the ground', in order for people with LD to receive equitable access and adequate support within IAPT, 'LD' needs to be prioritised by IAPT commissioners, service leads, and training course providers. This project is particularly relevant for Counselling Psychologists as it embodies the requirement for us learn from and work with service users and other professionals, attend to discrimination and work towards social justice.

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#### CHAPTER ONE: INTRODUCTION

#### 1.1 Overview

Despite higher prevalence rates of mental health problems among people with learning disabilities (Cooper, Smiley & Morrison 2007; Hatton & Taylor, 2010), and a requirement for all mental health services to meet the needs of all disabled people (Department of Health; DoH, 2011), people with learning disabilities continue to be denied access to a range of psychological therapies (Corbett, 2011; Taylor, 2010; Whitehouse, Tudway, Look, & Kroese, 2006). In 2012, the NHS Confederation, on behalf of the DoH, commissioned the National Development Team for Inclusion (NDTi) to report on the reasonable adjustments<sup>2</sup> being made in mental health services for people with learning disabilities and autism. The resulting report, *Reasonably Adjusted?* (NDTi, 2012) highlighted few services comprehensively and systematically audited their practice and redesigned accordingly. The NDTi was asked by the DoH and NHS Confederation to develop an audit framework applicable to all adult mental health services in England. This resulted in the *Green Light Toolkit* (GLTK; Turner & Bates; NDTi, 2013). Nevertheless, a recent study by researchers from Kings College, London and the *Foundation for People with Learning Disabilities* (Chinn, Abraham, Burke & Davis, 2014) reported some Improving Access to Psychological Therapy (IAPT) services still used 'learning disability' as an exclusion criterion.

This chapter critically reviews the literature regarding access to psychological services for people with learning disabilities and mental health problems. It will highlight two recurring omissions, which this study sought to address: 1) A lack of implementation of research findings, and 2) An absence of people with learning disabilities' views, particularly those who have accessed talking therapies within mainstream psychological services, such as IAPT. What follows begins by discussing the definition of learning disabilities and the higher prevalence of mental health problems among this population. There is then a review of historical and contemporary policies and treatment of people with learning disabilities and mental health problems. This is followed by an appraisal of the debate regarding mainstream versus specialist services for this group. This chapter then assesses ideas surrounding talking therapies for people with learning disabilities, with specific reference to cognitive-behavioural therapy; it then evaluates research that has sought to consider the views of clinicians and people with learning disabilities on this topic broadly, then with specific reference to IAPT. Following this, there

<sup>2</sup> The term 'Reasonable Adjustments' was first used in Disability Discrimination Act 1995 and refers to the duty on those providing goods, service and employment opportunities to ensure that their arrangements do not discriminate against disabled people.

is consideration of the relevance of the current study to the field of Counselling Psychology. The chapter ends with a summary of this study's rationale, research aims and questions.

#### 1.2 Definition of learning disabilities

Although 'intellectual disabilities', is a widely accepted international term, 'learning disabilities', (which equates to 'intellectual disabilities'), is used throughout this study as this term is currently adopted by health and social care organisations in England, and within DoH documents associated with this group (e.g. *Valuing People*, 2001; *Valuing People Now*, 2009). Learning disabilities are defined by three core criteria: 1) A significantly reduced ability to understand new or complex information, or learn new skills (impaired intelligence), with; 2) A reduced ability to cope independently (impaired social functioning); which; 3) Started before adulthood, with a lasting effect on development (DoH, 2001; 2009). In contrast, 'learning difficulties' refer to 'specific learning difficulties' (e.g., dyslexia), and do not require the presence of the three aforementioned criteria.

#### 1.3 Prevalence of mental health problems among people with learning disabilities

Compared to the general population, people with learning disabilities are more likely to experience psychiatric problems, including anxiety, depression, psychosis, dementia, attention deficit hyperactivity disorder, and conduct disorders (Hatton & Taylor, 2010; Lindsey, 2002; NICE, 2014; Ruedrich, 2010). Prevalence rates of psychiatric problems among people with learning disabilities are estimated to be between 20.1% and 40.9% (Taylor & Knapp, 2013). Point-prevalence rates of 3.8% for depression and 2.8% for anxiety (Cooper et al., 2007) are thought to be significant underestimations (Hatton & Taylor, 2010). An accurate appreciation of prevalence rates is particularly important when considering if people with learning disabilities are proportionally represented in mainstream psychological services. Awareness of the higher prevalence of mental health problems among people with learning disabilities is also important in the context of access to mainstream mental health service; this increased prevalence may be partially attributed to marginalisation (Foundation for People with Learning Disabilities, 2002; Nezu, Nezu, Rothenberg, Delli-Carpini & Groag, 1995). Jahoda, Wilson, Stalker and Cairney (2010) stated that awareness of stigma, and struggles to establish or maintain positive social identities can increase vulnerability to emotional, interpersonal, and mental health problems among this population. Jahoda et al. (2010) accordingly concluded that 'inclusion' may contribute to positive mental health. That is, people with learning disabilities may be a greater risk of mental health problems due to social exclusion, therefore, greater social inclusion could reduce prevalence rates of people with learning disabilities with mental health problems.

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#### 1.4 Services and policies

People with learning disabilities have been largely excluded from mainstream psychological services until relatively recently. Exclusion, together with discrepancies in socio-economic power, can lead to harassment of people with disabilities There is thus immense value in Psychologists understanding the repercussions of historic and present day exclusion, in terms of helping people learning disabilities feel understood, and in terms of guiding therapeutic formulations (Holzbauer & Berven, 1996). Knowledge of current services, polices and legislation is also important to all supporters of people with learning disabilities as such awareness can enable effective problem solving. Awareness historic and current services, polices and legislation may be particularly important to Counselling Psychologists; while the standards for the accreditation of Doctoral programmes in Counselling Psychology encourage appreciation of this topic, it is not currently mandatory to gain in-depth knowledge in this area (British Psychological Society; BPS, 2015).

#### 1.4.1 History of services and policies

Until the late 19th Century, people with learning disabilities were termed 'idiots' and distinguished from those with mental health problems ('lunatics'); causes for 'idiocy' were purported to be organic and irreparable (Rushton, 1996). The late 19<sup>th</sup> century saw people with learning disabilities being constructed as a social problem; lacking in general reasoning ability and resulting in large scale institutionalisation. As general reasoning was considered a defining feature of humanity, 'idiots' were considered less than human (Goodey, 2005). The early 20th Century saw people with learning disabilities viewed as a threat to society with little hope of 'cure', and eugenicists proposed they be prevented from having children. This inevitably reiterated existing ideas that they were qualitatively different and 'less than' mainstream society. To save money and protect those with 'mental deficiency' from themselves and society (Jackson, 1996), as reflected in The Royal Commission on the Care and Control of the Feeble-Minded (1904-1908), segregation became the objective. The 1940s-1960s saw continued segregation and isolation through hospitalisation or institutionalisation. The White Paper of 1971 Better Services for the Mentally Handicapped generated an increase in community-based services, and notions of normalization and inclusion increased over the 1970s and 1980s (Stalker, 1996). The 1990's saw increased societal reflections of common Counselling Psychology values, including facilitating growth, orientation towards empowerment and commitment to democratic, non-hierarchal relationships (Cooper, 2009; Orlans & Van Scoyoc, 2008), which intersected with the principles of 'Community Psychology', in addition to person-centred planning (O'Brien & Lovett, 1992), and self-advocacy (Mental Health Foundation, 1996). However, as we shall see, despite numerous policies emphasising inclusion over the last three decades, people with

learning disabilities continue to face barriers accessing talking therapy within mainstream settings (Corbett, 2011; Chinn et al., 2014; Emerson & Baines, 2011).

#### 1.4.2 Contemporary services, polices and the development of the Green Light Toolkit (2013)

In line with concepts of normalisation and social role valorization (Wolfensberger, 1998), numerous contemporary social care and health agencies have emphasised the inclusion of people with learning disabilities into mainstream services. This is especially supported by those who argue inclusion will minimise stigmatisation, labelling and negative professional attitudes that result from segregation (Rose, O'Brien & Rose, 2007). To facilitate access to and accommodate the needs of people with learning disabilities within mainstream services, the Disability Discrimination Act (2005), Disability Equality Duty (2006) and the Equality Act (2010) place 'reasonable adjustments' centrally. The No Health Without Mental Health strategy (Department of Health; DoH, 2011), and the ensuing Implementation Framework (DoH, 2012) further purported mainstream mental health services implemented reasonable adjustments, and that staff within these services had the appropriate skills to meet the needs of people with learning disabilities (NHS England, 2015). Nevertheless, the Reasonably Adjusted? report (NDTi; 2012) found few mental health services were adjusting to meet the needs of people with learning disabilities. The NDTi was thus asked by the DoH and NHS Confederation to develop an audit framework applicable to all adult mental health services in England. The scope of the report was that all mental health services have a duty to presume people with learning disabilities would want to use their services, and therefore, should make arrangements to accommodate them. In addition to improving individual services, this audit framework intended to build a national database of reasonable adjustments in mental health services. The result was the updated Green Light Toolkit (GLTK; Bates & Turner; NDTi, 2013), and this tool was used to guide data gathering within the current study.

The GLTK (2013; Appendix 1 for example excerpt) is a self-assessment tool, also available in an accessible, easy read format, comprised of three increasingly comprehensive audits (Basic, Better and Best). The tool uses a 'traffic light' system that allows respondents to rate various domains (e.g. safeguarding, assessment) within mental health services from 'green' (achieving highly) to 'grey' (not achieving). The development of a tool that intended to encourage mental health services to consider accessibility for people with learning disabilities and, moreover, create a national database of suggested adjustments is admirable. However, the GLTK (2013) may be critiqued on many grounds, including: 1) people with learning disabilities and autism are collapsed into one category, 2) not all domains are applicable to all services, 3) self-audit tools may produce inaccurate or socially desirable responses, 4) the 'audit completer' in the national GLTK database is unknown (i.e. whether completed

by managers, clinicians, service users); nor is the specific service (i.e. whether primary, or secondary care, forensics, or third sector), and 5) no steps are taken to ascertain what the suggested improvements are, or whether they are implemented, or evaluated. The GLTK (2013) allows for quantitative data to be captured in terms of figures that individual services can measure themselves against and look for changes over time. However, whilst informal feedback was sought from over 80 users of a draft version, there does not appear to be any 'hard' (i.e. methodologically rigorous) research data available about its reliability or validity. It may therefore be considered to be a 'soft' (less reliable) measure. To enhance both content and face validity of the GLTK, the current study, which focuses on learning disabilities, omitted references to 'Autism', removed domains not relevant to primary care psychology (e.g. those concerning secure settings), and offered one-to-one interviews to allow respondents to elaborate on their responses, and for the researcher to note who the respondent was. Most crucially, the current study implemented and evaluated the suggested improvements. Although the GLTK (2013) audit tool was designed for all mental health services, IAPT services are likely the most widespread mainstream psychological services in England, and perhaps warranted the most attention regarding current access by people with learning disabilities.

#### 1.4.3. Improving Access to Psychological Therapies

Improving Access to Psychological Therapies (IAPT) aimed to ensure people with common mental health problems had fast, easy access to evidence-based (NICE approved) psychological therapies in primary care (DoH, 2008). IAPT aimed to reverse the inequalities that existed in terms of those receiving treatment by being especially responsive to marginalised communities, including black and minority ethnic communities, older people, people with medically unexplained physical symptoms, and people with learning disabilities. The intention was to effectively meet the needs of local communities and engage with different communities (*Commissioning for the Whole Community*, 2008). The rollout of IAPT was greatly facilitated by the economic arguments proposed by Lord Layard (2006), who stipulated welfare benefits, including sickness absence could be reduced should those in receipt due to common mental health problems 'recover' through therapy. Specifically, a net financial benefit of £4,640 million was expected by the end of 2016/17 as the provision and utilisation of accessible evidence-based therapies increased (DoH, 2012).

'Recovery' in IAPT is measured by services and commissioners through the Minimum Data Set (MDS; IAPT, 2011). Measures within the MDS ask respondents to estimate the frequency of symptom occurrence over the preceding two weeks, and many items have numerous questions within one item. For example, '*How often have you been bothered by moving or speaking so slowly that other people could have noticed - or the opposite - being so fidgety or restless that you have been moving around a lot more than usual*?' (Item 8; Patient Health Questionnaire-9; IAPT, 2011). Such

questions could be confusing for some people, which in turn gives rise to concerns about its ecological and content validity amongst the learning disability population.

IAPT services predominantly offer cognitive-behavioural therapy (CBT) due to its evidence-base in the treatment of common mental health problems, particularly anxiety and depressive disorders (NICE, 2011). CBT is a time-limited, problem-goal-orientated therapeutic model, which emphasises the reciprocal relationship between cognitions, emotions, physiology and behaviours. IAPT services also use a stepped-care approach where Psychological Wellbeing Practitioners (PWPs) who have relatively brief training in CBT-based interventions, predominantly offer guided self-help and psychoeducational groups. High Intensity (HI) Therapists, mainly offer one-to-one and group CBT. Although CBT remains the dominant therapeutic model, IAPT is increasingly providing qualified clinicians with training in other NICE approved interventions, including Dynamic Interpersonal Therapy (DIT) and Interpersonal Therapy (IPT). Unlike CBT, both DIT and IPT place great emphasis on the role and influence of interpersonal relationships in terms of the onset and maintenance of psychological problems such as depression (cf. Beck, Rush, Shaw, & Emery; Lemma, Target, & Fonagy, 2011; Weissman, Rabinovitch, & Verdeli, 2013). Regardless of the intervention offered, IAPT is a high volume service; clinicians may see up to eight service users per day and are required to record all clinical contacts on services computer systems (which is reviewed by commissions and the DoH), to ensure service access and treatment targets are met (Binnie, 2015; Chinn et al., 2014). Emphasis on targets within IAPT, together with a lack of specialist knowledge among mainstream clinicians more broadly has undoubtedly contributed to the debate regarding whether mainstream or specialist services are more helpful for people with learning disabilities.

#### 1.4.4 Mainstream or specialist services?

The debates surrounding access to mainstream psychological services for people with learning disabilities are numerous and complex (e.g. Chinn et al., 2014; Rose et al., 2007). However, legislations clearly advocate inclusion (e.g. *Equality Act*, 2010) and the *Learning Disabilities Mental Health Outcomes Charter* (NHS, 2013) states: "It is imperative that people with learning disabilities who have mental health needs have the same access to generic mental health services as the general population using reasonable adjustments where needed" (pp. 3). In a similar vein, the recently published *IAPT Learning Disabilities-Positive Practice Guide* (LD-PPG; Dagnan, Koulla-Burke, Davies & Chinn, 2015) states that IAPT cannot exclude people with learning disabilities. However, it also states that only specialist services are likely to have the skills and service structures for some people with learning disabilities. This possibly highlights the need for better awareness of the heterogeneity within this group (National LD Professional Senate, 2015), perhaps particularly among some mainstream clinicians, responsible for decisions about who accesses which service.

In a qualitative investigation of mainstream and community learning disability team (CLDT) clinicians' attitudes to working with people with learning disabilities with mental health problems, Rose et al. (2007) found both groups believed 'specialist' expertise was more appropriate for this group. They reported mainstream staff did not consider working with people with learning disabilities part of their role, and felt inadequately trained to deal with their mental health needs. Conversely, a recent large scale survey found a majority (74%) of IAPT clinicians and specialist learning disability staff answered 'no' to the question "should ALL psychological therapies be delivered by specialist services?" (Chinn et al., 2014). Specialist learning disability staff in Chinn et al's. (2014) study reported their main reason for saying 'no' as the importance of people with learning disabilities accessing mainstream services, perhaps due to their greater awareness of the historical exclusion of, and importance of inclusion for this group. IAPT staff reported their main reason for saying 'no' as IAPT's commitment to evidence-based interventions, perhaps due to their training which emphasises adherence to this to achieve successful therapeutic outcomes. It is also noteworthy that over a quarter (26%) of respondents believed that ALL psychological therapies should be delivered by specialist services. This suggests a need to better understand how effective IAPT services currently are for people with learning disabilities and what measures could be taken to improve them, as the current study aimed to do.

Overlapping and expanding on Rose et al's. (2007) findings, recent research has reported that clinician's lack of confidence in working therapeutically with people with learning disabilities is a key access barrier to mainstream services (Dagnan, Masson, Cavagin, Thwaites & Hatton, 2015). This was also noted with specific reference to IAPT in Marwood's (2015) recent study on HI clinicians' experiences of working with people with learning disabilities. Both Dagan et al. (2015) and Marwood (2015) found positive correlations between clinicians' experience and confidence levels. Notably, without training or experience, minimal opportunities for mainstream clinicians to increase their confidence levels exist. It could also be argued that NICE-approved interventions based on clinical trials with non-learning disabled participants do not necessarily, or easily generalise to people with learning disabilities, and ambiguity concerning the applicability of the evidence-based protocols in which IAPT clinicians are trained to deliver further undermines their confidence levels.

#### 1.5. Talking therapies and people with learning disabilities

The limited evidence base on talking therapies for people with learning disabilities has not gone unnoticed (e.g. Sturmey, 2005; Willner, 2005). Reasons for this have included an over-reliance on psycho-pharmacy for the purposes of social control, ease and cost effectiveness (Caine & Hatton, 1998), 'therapeutic disdain' (Bender, 1993), presumptions that people with learning disabilities are unable to develop insight (Moore, 2001), and/or recognise the consequences of their actions (Hurley,

1996). Nevertheless, studies have increasingly demonstrated that talking therapies can yield effective outcomes for this client group (e.g. McGillivray & McCabe, 2010; Nezu et al., 1995; Willner, 2005; Willner & Goodey, 2006) and frameworks have been put forward to help clinicians select interventions when working with them. For example, Emerson, Caine, Bromley and Hatton (1998) proposed psychological interventions should be: 1) socially-valid, 2) functionally-based and 3) constructional. 'Socially valid', refers to interventions being understood in the context of socially significant problems, which are in themselves, socially constructed. This would thereby require full acknowledgement of an individual's wider contextual factors, which could prove to be difficult for IAPT clinicians given the high numbers of services users they see, and the limited number of sessions they have. 'Functionally based' similarly infers a need to consider that individuals are enmeshed within a social system and that problems can only be understood and dealt with in this context. Thus Emerson et al's. (1998) first two types of intervention may present challenges within high volume, uni-disciplinary IAPT services. The third type, 'constructional' refer to interventions constructed as part of, or within the intervention. It is also debatable whether CBT in IAPT falls within a 'constructional' or 'pathological' camp. Certainly, there is an emphasis on the reductions of symptoms, as is evident on 'recovery' targets measured through use of routine outcome measures in CBT (Westbrook, Kennerley &Kirk, 2011). However, CBT also aims to equip someone with tools, and can include a resurgence of those they already have, or newer ones collaboratively designed.

#### 1.5.1 Cognitive Behavioural Therapy and people with learning disabilities: A critique

Queries about CBT's appropriateness for people with learning disabilities fall into two main categories. The first category is the level of cognitive ability required to benefit from CBT (e.g. Gerry & Crabtree, 2013; Sams, Collins, & Reynolds, 2006). Interestingly, founders of CBT, Beck et al. (1979) purported high intelligence in not necessary for CBT to be effective, but what was necessary, was for clinicians to adapt to meet the intellectual and verbal abilities of each client. However, it could be unrealistic to expect clinicians with no prior training or experience in learning disabilities, such is the case for many IAPT clinicians (Chinn et al., 2014), to effectively adapt their standard practice.

The second category is CBT's emphasis on the thought-feeling-behaviour connection as a means of understanding the development and maintenance of psychological issues (i.e. locating the source of distress within the individual). People with learning disabilities are much more likely to be effected by complex psycho-social difficulties (Emerson & Baines, 2011), including: abuse, separations, poverty/deprivation, unemployment, limited social networks and intimate relationships; constitutional vulnerabilities, bullying, birth trauma, less capability to change circumstances and a reduced capacity to cope independently (Bernal & Hollins, 1995; Caine & Hatton, 1998; Borthwick-Duffy, 1994;

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Emerson, 2003; Winter, Holland & Collins, 1997). CBT's potential to neglect the wider role of an individual's experiences has led to its appropriateness for people with learning disabilities being questioned (Hebblethwaite et al., 2011).

In a review of the mediating role played by cognitive factors in the genesis and maintenance of depression, Jahoda et al. (2006) highlighted the role of factors beyond unhelpful thoughts, noting that these do not simply arise in people heads, they are a product of real life experiences, and awareness of the psycho-emotional impact of disabilities is crucial to achieve real, sustainable change. Jahoda et al's. (2006) article admirably offers a clear examination of a social-cognitive model of depression; a thought provoking reflection on whether therapists enhance or hinder autonomy or sociotropic tendencies, and the struggles those who are socially marginalised may encounter trying to imagine more helpful interpretations of themselves and events. However, Jahoda et al. (2006) offer little by the way of unambiguous recommendations. It would have been helpful to have suggested how these findings may apply to clinicians with little awareness of the social-context of depression amongst people with learning disabilities. Providentially, Jahoda et al. (2009a) suggested as well as adapting CBT into accessible formats, CBT ought to incorporate theoretical and formulaic differences, such as experiences of marginalisation. This underscores a gap between recommended practice and available therapy in IAPT.

Promising attempts to adapt standardised CBT protocols in light of the life experiences of people with learning disabilities have been proposed by Jahoda and Dagnan (2006). They adapted the cognitive model of social phobia to include recognition of research on social context and developmental factors predictive of anxiety in people with learning disabilities. It is commendable that they did not simply rephrase an existing evidence-based model, but incorporated factors unique to this client group. Although they suggest this approach is applicable to other anxiety presentations, it is uncertain whether clinicians with little to no experience with people with learning disabilities would have awareness of (or time to research) such factors when formulating and treating this group. A solution may be for the CBT models associated with all of the disorders IAPT clinicians are trained to treat, be modified in this way, and for this to be taught during or post training. However, such adaptions to existing models may require further research and validation before being officially endorsed by IAPT. Moreover, as we shall now see, CBT is not a panacea necessarily suitable for everyone.

#### 1.5.2 Assessing for CBT suitability

In their *Suitability for CBT Scale* designed for the general population, Safran and Segal (1990) suggested criteria, such as having the ability to access automatic thoughts and take 'personal responsibility', could determine who might benefit from CBT. More refined suitability criteria for CBT for people with learning disabilities have since been suggested, including the ability to

differentiate emotions and understand a cognitive model (Hatton, 2002), having social support to facilitate learning and engagement (Dagnan & Chadwick, 1997), appropriate environmental conditions (Kroese, 1997), motivation to engage, and self-efficacy (Willner and Goodey (2006). Whilst such criteria could be helpful when determining if an individual with learning disabilities is suitable for CBT, it is possible these criteria may also lead to the exclusion of people with learning disabilities from mainstream services should clinicians deem service users as not meeting them 'at first glance'. Moreover, it is possible that such criteria alone are not sufficient in determining suitability for CBT.

Oathamshaw (2007) published a case study of a young man with learning disabilities who met learning disability specific suitability criteria for CBT and was accordingly offered a series of CBT sessions for anger management. His therapy, however, ended prematurely as existing problematic environmental factors were found to interfere with CBT; difficulties managing anger were retrospectively attributed to the client's support network (rather than 'unhelpful' cognitions), and the decision to commence CBT was questioned. Oathamshaw's (2007) case study illustrated that even where suitability criteria are met, systemic factors can undermine CBT, and necessitate proactive systemic interventions. Oathamshaw (2007) concluded a more suitable intervention would have involved meeting with the service user's wider network. A call for more systemic awareness and interventions, arguably has implications for many IAPT clinicians who are only trained in CBT.

As with all case studies, the question of generalisability arises. However, the author cites other cases rendering similar results. Oathamshaw's (2007) case study highlighted that a suitability for CBT assessment is no substitute for a comprehensive assessment and formulation. Again, this has implications for IAPT clinicians who may have 30 minutes to assess, formulate and decide upon an appropriate service and/or intervention (Binnie, 2015). A solution might be allowing extra time for assessing people with learning disabilities within IAPT as a reasonable adjustment, although clinicians may not be aware an individual has learning disabilities prior to assessment. As assessments have the potential to form access barriers to CBT in IAPT, it is important to understand, as this study intended, how successful IAPT clinicians and service users with learning disabilities felt assessments were for this population and how this might be improved.

Another means of determining suitability for and facilitating access to CBT within mainstream psychological services may be joint working with Community Learning Disability Teams (CLDT). In a six-month prospective audit of a referral pathway between a CLDT and an IAPT service, Goodey and Stirk (2014) suggested CLDTs assess suitability of service users with mental health problems for CBT prior to referring to IAPT. They reported that where this had occurred, the CLDT care co-ordinator described support within IAPT as useful and normalising for the service users. Whilst this paper commendably and judiciously demonstrates a constructive and innovative referral pathway,

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whereby CLDT service users may be supported in IAPT, it is unfortunately unclear how those with learning disabilities requiring, but without access to, or eligible for additional support (such as support workers), might be helped in IAPT. It is also unfortunate that the service user's own experiences were not noted, as the current study proposed to do, as this may have differed from the care co-ordinator's opinion.

# **1.6 Mental health support for people with learning disabilities: Clinicians' and service users' perspectives**

People with learning disabilities self-reported experiences have been overlooked in much of the research about them (e.g. Brown, Duff, Karatzias & Horsburgh, 2011; Jones, 2014; Marwood, 2015). In addition to discernible concerns about marginalisation, this exclusion may lead to inaccurate conclusions about their well-being (Flitton and Buckroyd, 2005; Rose et al., 2013). The potentially partisan view of the effectiveness of psychological interventions among people with learning disabilities may have unintentionally thwarted attempts for their access to mainstream psychological services, including IAPT. This underscores the need acknowledged in the current study to obtain the views of both clinicians and people with learning disabilities when considering making effective changes within mainstream mental health services.

#### 1.6.1 Mental health support for people with learning disabilities: Clinicians' perspectives

Rose et al's. (2007) investigation into the views of specialist and mainstream clinicians' on working with people with learning disabilities in mental health services found four central themes: 1) uncertainty about the definition of learning disability and mental health problems, 2) perceived staff competence, including mainstream clinicians' lack of training/experience, 3) current service delivery issues, pertaining to uncertainty about which service was most appropriate, and 4) future service delivery issues, including learning disability staff's apprehensions that mainstream services would struggle to meet the needs of people with learning disabilities due to inadequate training and heavy workloads. Rose et al. (2007) noted that their findings supported previous research highlighting that mainstream clinicians felt uncertain about working with this client group within already overstretched services (Bouras & Holt, 2004).

A limitation of Rose et al's. (2007) study is that of their 29 participants, only eight of worked within psychology (the remainder were comprised of Speech and Language Therapists, Occupational Therapists, and Nurses) and it is not noted whether these eight were affiliated with CLDT's or mainstream services. This may mean that their results inadvertently favoured the perspective of either mainstream, or specialist clinicians. It is also noteworthy that whilst one subtheme was 'training',

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many believed expertise in this field was predominantly acquired by 'learning on the job'. The LD-PPG (2015) similarly notes IAPT clinicians' competencies will improve through gaining experience in working with people with learning disabilities. Further support for this notion is evident in Holland's (2007) article: *So much policy, so little change*, which proposed proficiency in this area may only occur through more people with learning disabilities accessing mainstream services. This suggests experiential training, including learning how to relate to this population, may supersede technique-based training.

Counselling Psychologists may be suitability placed to understand the role of non-technique based elements of therapy, such as the therapeutic relationship when working with people with learning disabilities. Jones (2014) interviewed eight Counselling Psychologists working therapeutically with this client group and found a resounding acknowledgement that the therapeutic relationship was fundamental. Stenfert-Kroese et al. (2014) also explored views of mental health professionals as well as support workers, specifically regarding CBT for people with learning disabilities. They found staff reported improved psychological well-being for service users, but did not perceive CBT as a long-term solution. They concluded that for CBT to be effective in the long-term, therapists should consider a wider systemic approach (one which aims to introduce change to the way in which social systems operate) and sharing psychological formulations with 'significant others'. Whilst Jones (2014) and Stenfert-Kroese et al.'s (2014) studies provide valuable information regarding clinicians' perspectives of talking therapies with people with learning disabilities, it is unfortunate that they did not incorporate the views of people with learning disabilities, nor did they implement implications for practice, as this study aimed to.

#### 1.6.2 Mental health support for people with learning disabilities: Service users' perspectives

The perspectives of service users and staff regarding psychological service provision to people with learning disabilities, and desirable staff qualities, were investigated by Stenfert-Kroese, Rose, Heer and O'Brien (2013). Four focus groups were conducted, two with service-users with learning disabilities, and two with learning disability support staff. Individual interviews were also conducted with staff from learning disabilities services, but not service users. Unfortunately, it is not noted in their article why service users were not interviewed. Themes elicited from analysis of the focus groups included the importance of communication styles, awareness of past-present links and staff training. Staff, but not service users, often mentioned the importance of having a 'family-centred' approach and the need to look after staff. Service-users, but not staff, highlighted the importance of staff 'being interested, not just there for the money'. Sternfert-Kroese et al. (2013) also commented that staff frequently utilized their focus groups and interviews as opportunities to describe challenges of their jobs, and managerial lack of empathy towards them in favour of the demands of higher

management. Considering that prioritisation of targets over attention to individual needs in IAPT has been noted (Rizq, 2012), the last two points may be particularly relevant in IAPT settings, where clinicians may feel under intense pressure to meet targets, thus may struggle to be fully attentive to service users.

There are numerous commendable qualities within Sternfert-Kroese et al. (2013) study. The researchers met with a small steering group, which included clinicians, academic staff and a service-user, to discuss project aims and how to achieve them. Informants included a range of staff drawn from urban and rural areas, residential and community settings, qualified professionals and unqualified staff. Credit is also given for providing service users with learning disabilities a voice, leading to valuable insights into their experiences, and ideas about how services might improve. For example, by highlighting desirable staff qualities such as their having good knowledge of their past, 'being interested' and need to receive ongoing and relevant training and supervision. Somewhat regrettably, individual interviews with service users were not conducted, and there are no references to implementation nor evaluation of the plethora of recommendations made by service users.

Pert et al. (2012) interviewed 15 people with learning disabilities about their experiences of CBT. They reported three overarching themes; the first, 'talking in therapy', implied that participants valued the opportunity to talk about their difficulties confidentially. The second, 'feeling valued and validated' denoted an appreciation of difficulties being acknowledged, respected, understood and authenticated, and perhaps overlaps with Sternfert-Kroese et al's. (2013) reference to the importance of staff being genuinely interested. The third theme, 'change in therapy' included a subtheme, 'change is fragile', which indicated concerns about changes being short lived. It may be that these concerns were more prominent as the interviews took place in the early phases of therapy, likely before a 'blueprint' (an end of therapy relapse-prevention worksheet often completed in CBT during the final stages of therapy) was introduced. Therefore, this particular finding may have been less prominent had the interviews occurred post-therapy, as was the case in the current study. Participants' concerns about the sustainability of changes might also be linked to CBT's briefness compared to other modalities. This is particularly relevant to CBT within IAPT, where treatment can be limited to four 30-minute sessions. One way of lessening this concern may be for IAPT clinicians to pay greater attention to the therapeutic 'blueprint', as described above, and make explicit reference to this in the early stages of therapy. Pert et al. (2012) concluded participants most valued the opportunity to talk and the therapeutic relationship. This suggests that 'common factors' not unique to, or arguably as emphasised in CBT compared to other modalities, were most helpful. This in turn, suggests CBT may not be the most favourable therapeutic intervention for this client group, and possibly calls into question the helpfulness of CBT dominated IAPT services. A key limitation of this study is that findings were not validated by participants. This could be rectified through participant validation or 'member checking' as occurred in the current study.

So far in sum, we have seen that people with learning disabilities are at increased risk of mental health problems, which is arguably perpetuated by exclusion from mainstream services. In order for those in helping professions to better understand and support people with people with learning disabilities, it was considered important that they understood the drive for inclusion in the context of historical discrimination and segregation. The development of the GLTK (2013) as a means for mainstream psychological services to assess accessibility for people with learning disabilities was considered commendable, but the lack of evidence surrounding its use was also noted. The ambiguity regarding the appropriateness of specialist versus mainstream services was reflected on. CBT, including assessment of suitability of this modality, was critiqued with references to the importance of incorporating systemic factors, which fits well with one of Counselling Psychology's focus on personenvironment interactions (Gelso, Williams & Fretz, 2014). Despite the likelihood that staff and service users' views about emotional well-being differ, there has been a lack of studies including the view of people with learning disabilities, that should be rectified in future studies. Similarly, there is a need to elicit the views of mainstream clinicians, who will likely accept and treat such referrals in IAPT services.

# 1.7 IAPT and learning disabilities: Current status

Funded by the DoH and completed by the Foundation for People with Learning Disabilities in partnership with Kings College London and The Cumbria NHS Foundation Trust, the Learning Disabilities Positive Practice Guide (LD-PPG; Dagnan et al., 2015) aimed to inform all involved with IAPT on making services accessible to people with learning disabilities. The LD-PPG (2015) proposes three possible service models to achieve this: 1) 'Standalone LD-IAPT' (i.e. a completely separate IAPT for people with learning disabilities), 2) 'Separate but embedded' (i.e. having specialist learning disability clinicians in IAPT), and 3) 'Wholly integrated' (i.e. all IAPT clinicians seeing people with learning disabilities). The guide states that a standalone LD-IAPT advantageously means more specialised care for people with learning disabilities, but disadvantageously, enables ongoing exclusion from 'mainstream' services. It notes the 'separate but embedded' model circumvents such exclusion, but poses problems whereby 'learning disabilities' is not noted on a referral. The wholly integrated option, advocated by Dagnan et al. (2015), would mean all staff were able to work in an adapted way. Whilst appreciating the rationale for a wholly integrated model, it is not unthinkable that IAPT's exclusion criteria (e.g. those with complex psycho-social factors, those who do not seem motivated to engage), may mean people with learning disabilities continue to be excluded from IAPT. It is still unknown which model IAPT will adopt, or whether different models will be decided upon locally; however, the above reflection suggests that should either of the latter two options be adapted, careful consideration will need to be given to IAPT inclusion and exclusion criteria.

Data regarding access and treatment outcomes for the learning disability population are underdeveloped compared to that of the general population and other marginalised groups (Dodd et al., 2011). Difficulties auditing access to IAPT by this group may be attributable to the ambiguity surrounding 'flagging' that someone has a learning disability on IAPT computer systems. Some systems have a box that can be ticked to indicate that someone has a disability. Within this, there is a category termed 'Memory or ability to concentrate, learn or understand (Learning Disability)'. Possibly, some non-learning disabled service users may indicate having difficulties concentrating or remembering, or may confuse learning disability with learning difficulty (e.g. dyslexia), which could inaccurately inflate the data. Although some services now have a specific 'Learning Disability' label (i.e. administrative flag applied to the service's computer system to indicate that someone may have a learning disability; Theodore, Chatters, Bexley et al., 2015), where 'learning disability' is not noted on the referral, mainstream clinicians may struggle to ascertain this, and thus indicate on systems who may benefit from reasonable adjustments. To help with this, a screening tool was designed to 'flag' people of lower intellectual ability as they enter IAPT by asking questions such as: 'Do you ever need someone (like a family member, friend or professional) to help you read letters and information leaflets?'; Hatton, 2009). Use of this screening tool may help monitor data and allow clinicians to know where reasonable adjustments may be required. Whilst the LD-PPG (2015) provides explicit recommendations of reasonable adjustments, history suggests that 'top-down' guidelines and policies do not necessarily instigate changes 'on the ground'. It is the author's view that meaningful changes are likely to occur when clinicians 'on the ground' perceive IAPT to be a suitable option for people with learning disabilities, as well as service user endorsement.

# **1.7.1** Clinicians' and service users' perspectives on the barriers and facilitators for people with learning disabilities accessing IAPT

Two recent studies sought to explore the views and experiences of IAPT clinicians working with people with learning disabilities. Shankland and Dagnan (2015) conducted an online survey of IAPT practitioners to collect quantitative and qualitative data on their experiences, confidence levels and attitudes towards this client group, as well as their thoughts on barriers and solutions to accessing IAPT. Their findings, which were interpreted using thematic and statistical analysis, indicated most IAPT clinicians had worked with people with learning disabilities and believed therapy should be offered within mainstream services. However, they also found that the majority emphasised a desire for better adaptations, training, and adjusted pathways to facilitate this. Using a purely qualitative approach, Marwood (2015) interviewed HI Therapists in IAPT, that had delivered CBT to at least one person with learning disabilities in IAPT. Marwood's (2015) thematic analysis of the interview transcripts similarly found that clinicians were unsure how to modify CBT to best meet their needs,

and identified a need for training opportunities and specialist supervision to better support them. Whilst both Shankland and Dagnan's (2015) and Marwood's (2015) studies help determine the view of IAPT clinicians specifically, as many studies before them, data from services users with learning disabilities was not gathered, and no steps appeared to have been made to actively implement findings as this study intended.

At present, only one published study has elicited the views of IAPT clinicians and people with learning disabilities on the latter's access to IAPT. Chinn et al. (2014) carried out a large scale nationwide online survey. They also interviewed 10 people associated with learning disability services (including one social worker, one commissioning manager, one outreach project manager, one advocate, two learning disability community nurses, two consultant psychiatrists and two learning disability and mental health liaison nurses), as well as seven people associated with IAPT (one CBT therapist, one PWP, two mental health nurses and three service managers), and four experts by experience (three people with learning disabilities and one carer). Their study, which included a total of 452 respondents, 193 affiliated with IAPT and 259 with CLDT services, investigated barriers and facilitators for people with learning disabilities accessing IAPT, and strategies and practices employed to support them. Barriers were identified within both CLDT and IAPT services. Echoing the views of specialist clinicians in Rose et al's. (2007) study, barriers within CLDTs concerned ambiguity about whether IAPT staff would understand the needs of people with learning disabilities. Barriers within IAPT included a 'lack of flexibility' due to an emphasis on adherence to protocol-driven approaches and 'workload pressures'. IAPT clinicians noted IAPT's endeavour to see high volumes of clients left staff without time to make reasonable adjustments. Concerns were also expressed about whether CBT in IAPT was based on concepts too cognitively complex for people with learning disabilities, the frequent use of telephone sessions, and the extent of written texts used in IAPT, particularly the Minimum Data Set (MDS; IAPT, 2011), which has yet to be formally adapted for people with learning disabilities (Radcliffe, O'Connor, Pollard & Coopoosamy, 2011).

The qualitative component of Chinn et al's. (2014) study identified two discourses regarding IAPT's core purpose. One was termed 'managerialism', referring to a system of organisational and budgetary control directed at effective use of resources (Syrett, Jones & Sercombe, 1997). Reminiscent of Stenfert-Kroese et al's. (2013) reference to staff utilizing focus groups and interviews to express objections about managers being more responsive to higher management demands, this discourse reflected references to the importance of efficiency, through-put, and targets in IAPT. The second somewhat conflicting discourse was termed 'IAPT is for everyone'. This discourse reflected beliefs that as a public service, IAPT has a duty to see everyone and in line with Oliver's (1990) social model of disability, society, not disabilities created barriers. IAPT staff also indicated paradoxical ideas, such as a need for better promotion of IAPT for people with learning disabilities, and anxieties about increasing access without having funding or training. 68% of respondents felt training should be

targeted at all staff, possibly because two thirds reported having no training. The desire for training could be considered attributable to low confidence levels among IAPT clinicians, however, Chinn et al. (2014) also reported 72% of IAPT staff felt 'somewhat' or 'very' confident working with this group, with confidence being greatest amongst those with learning disability experience. However, they also reported that PWPs, likely to be the least experienced, were more confident than HI Therapists that people with learning disabilities would receive good service in IAPT. This may be attributable to PWP interventions being more manualised, less cognitively demanding and designed for milder clinical presentations. These contradictions suggest further investigation of the views of both PWPs and HI therapists, as occurred in the current study, was warranted.

Chinn et al. (2014) synthesised their findings with reference to 'candidacy' (Dixon-Woods et al. 2012), a multi-dimensional and contingent process whereby eligibility for medical attention and intervention may be jointly negotiated by individuals and health professionals in light of organisational contexts and available resources. The construct of candidacy is divided into seven dimensions, the first six being junctures in a health-care trajectory where a person's candidacy can be negotiated. The seventh concerns operating conditions that impact service users and practitioners. Chinn et al. (2014) add to candidacy, 'recursivity'; the impact of past experiences of a health service in terms of future actions a person might take to seek help. They note the importance of mediators in these processes, particularly family and support staff, as they are most likely to be responsible for initiating contact with services and ensuring ongoing engagement. Chinn et al. (2014) suggest people with learning disabilities may not see themselves, nor be viewed by their systems, as candidates for IAPT, and argue candidacy highlights how access to IAPT is shaped by values, assumptions and practices in IAPT, as well as those of CLDTs, and commissioners. They conclude by recommending ways to promote candidacy and recommend IAPT introduce more robust systems for recording uptake and renegotiate contracts with commissioners to increase hope for flexible working. They further recommend adaptation of outcome measures and a need for a better awareness of the evidence-base for CBT for people with learning disabilities.

Chinn et al. (2014) are to be commended for their enlightening report, which included the views of three people with learning disabilities as well as a large number of clinicians from CLDTs and IAPT services, and which led to insightful suggestions of ways access barriers to IAPT may be overcome. Credit is also given for developing their questionnaires based on stakeholder's views rather than relying on 'expert opinion'. However, there are limitations. The sample may not have been representative of all IAPT clinicians. It is possible that the IAPT clinicians who opted to complete the online survey were those working in more flexible and less demanding IAPT services, and thus felt more optimistic about IAPT adapting to meet the needs of people with learning disabilities, whilst clinicians who opted not to, were those based in more demanding services, and may have been less hopeful about inclusion. Therefore, the results from the online survey may have painted a biasedly

hopeful picture of inclusion. The response rate would have helped explore this further, although unfortunately, this was not reported by the authors. It was also unfortunate that the online survey only included clinicians as it was not in a format accessible to people with learning disabilities. One recommendation would be to create an adapted version of this survey so that people with learning disabilities could also express their views through this means.

The qualitative aspect of the Chinn et al. (2014) report also suggests a paucity of IAPT clinicians whose primary role was offering therapy in IAPT (just one PWP and one CBT therapist). Moreover, only three people with learning disabilities were interviewed, and it is unclear whether they had any experience of psychological support within IAPT. These limitations could be rectified by interviewing a larger number clinicians and service users with learning disabilities who had accessed IAPT. As with much of the research before it, Chinn et al's. (2014) report culminates in a series of recommendations, but no comment on any direct actions taken as a result. Implementation of the recommendations and a follow-up on this would have been useful. Finally, the authors do not 'own' their positions in the report or refer to how this may have influenced their interpretation of the data. It is possible that their affiliation with learning disabilities services meant an 'outside-in' rather than 'inside-out' interpretation of the data. A balance might be redressed through collaboration with researchers affiliated with IAPT as well as service users with experience of IAPT.

# **1.8 Relevance to Counselling Psychology**

Consideration of all disabilities is important to all Counselling Psychologists. Like all professionals, we are obliged to exercise professional practice in the context of legal and statutory obligations, such as the *Equality Act* (2010). A significant amount of the work of Counselling Psychologists is covered under this legislation. However, within the field of Counselling Psychology, there is a dearth of literature on learning disabilities; the first three editions of the Handbook of Counselling Psychology (Woolfe & Dryden, 1996; Wolfe, Dryden & Strawbridge, 2003; Strawbridge & Woolfe, 2010), omitted 'disabilities' entirely. There is also little research on and/or including people with learning disabilities within Counselling Psychology, particularly with a view to increase inclusion at a service-level. This is surprising because training and experiences as a Counselling Psychologist provides a strong foundation for diversity focused clinical work, training and research (Hetzel, 1999). Counselling Psychologists are known to have a high regard for both equality and taking action (Milton, 2010), and can use their knowledge and experience to support people with learning disabilities at organisational, as well as psychological counselling/therapy levels (Kanellakis, 2010).

The absence of attention to learning disabilities in Counselling Psychology literature and research, particularly compared to Clinical Psychology, may be due to 'learning disabilities' not being a mandatory topic on Counselling Psychology doctorate courses, as it is with Clinical Psychology

doctoral courses (BPS, 2014; 2015). This may be attributed to the historical settings each specialty has evolved from. Clinical Psychology predominately originated in hospital settings, Counselling Psychology originated from the voluntary sector and worked largely with families and couples after the Second World War. As we have seen, people with learning disabilities have historically been 'treated' using a primarily medical model. At the same time, the 'medical model' of professionalclient relationship was questioned by Counselling Psychologists and a move towards a humanistic value base was encouraged (Woolfe, 1990).

Fundamental in humanistic approaches, such as Carl Roger's, to counselling/psychotherapy is the ability to meet clients at 'relational depth'. That is, to be able to form a connection on the same wavelength (Cooper & Mearns, 2005). Bender's (1993) concept of the 'unoffered chair' describes a possible prejudice of mental health professionals toward learning disabled people. He reported similar prejudice in Roger's inability to engage with "the unattractively distressed" and suggested that the intensity and intimacy required in therapeutic relationships with some clients, including people with learning disabilities, was harder to tolerate and necessitated greater energy, resulting 'therapeutic disdain'. It could thus be argued that a deficit in experience and training on working with this group within Counselling Psychology has resulted in lower aspirations regarding having a psychological awareness of people with learning disabilities (Hollins, 2014). This may also explain why this topic appears to have been neglected within Counselling Psychology research.

# **1.9 Rationale for current study**

Current legislations (e.g. *The Equality Act, 2010*) emphasise the importance of including people with learning disabilities in mainstream psychological services. However, people with learning disabilities continue to face barriers accessing such services (Chinn et al., 2014, Dodd et al., 2011). The literature review, which predominantly consisted of UK based research, highlighted two main gaps; an omission of the views of people with learning disabilities, particularly those who had accessed IAPT, and an omission of implementation of findings to improve psychology services, including IAPT. There was also disappointingly little acknowledgement of existing policies and guides that promoted inclusion, such as the GLTK (2013).

Three recent studies have specifically elicited the views of IAPT clinicians regarding people with learning disabilities (Chinn et al., 2014; Marwood, 2015; Shankland & Dagnan, 2015), but the views of people with learning disabilities were excluded bar Chinn et al's. (2014) research, where it is unclear whether the participants with learning disabilities had accessed IAPT. This is especially relevant for many reasons, such as when considering Mpofu and Conyer's (2004) proposals that those without disabilities (including professionals) oppress the expression of people with disabilities. It is also relevant when considering that the views of people with learning disabilities can provide valuable

insights into their experiences, which can inform the development of mental health services (Melville, Cooper, Morrison et al., 2006). Finally, when considering the Counselling Psychology values of inclusivity and non-hierarchal relationships (Cooper, 2009; Orlans & Van Scoyoc, 2008), elicitation of people with learning disabilities' views are deemed imperative in the current study. Counselling Psychology is also particularly attentive to therapists' experiences (Jones, 2014), and as we saw in the literature review, IAPT clinicians may determine whether someone accesses the service, and once accessed, service users' experiences. Hence, eliciting IAPT clinicians' views was considered equally important.

Additionally, existing research frequently culminated in a series of recommendations, with no clear actions to implement and/or evaluate said recommendations. Counselling Psychologists are known to apply systematic research based approaches to help themselves and others understand problems and develop potential solutions to them (Napier, 1995). We are further increasingly encouraged to bring social justice and action more explicitly into our research through participatory and enabling means (Vera & Speight, 2003). Perhaps most crucially and in line with Counselling Psychology's current striving towards more practical fields including service management (Douglas, Woolfe, Strawbridge, Kasket, & Galbraith, 2016), the current study fundamentally sought to collaboratively implement and evaluate suggested service-level improvements made by and with people with learning disabilities and clinicians.

Finally, although the GLTK (2013) provides a comprehensive tool for assessing how accessible psychological services are for people with learning disabilities, there is little evidence if and how it is used. The current study utilised a revised version of the GLTK (2013) to guide ideas about changes that might be implemented to enhance IAPT for this population.

# 1.10 Research aims and questions

Counselling Psychologists especially emphasise learning from clients and the other professionals that work with them, rather than trying to ascribe to a specific model or technique (Kanellakis, 2010). Accordingly, as elaborated on in the following chapter, this study used an Action Research approach to answer the following questions:

1. How well do IAPT service users with learning disabilities and IAPT clinicians, think IAPT fares in relation to the GLTK (2013)?

2. In relation to GLTK (2013), what do IAPT service users with learning disabilities and IAPT clinicians think can be done to improve IAPT for people with learning disabilities?

Following a six-month implementation period of suggested improvements:

3. How successful do IAPT service users with learning disabilities and IAPT clinicians think the changes implemented have been?

4. What further actions do they think could be taken to improve IAPT?

## **CHAPTER TWO: METHODS**

## 2.1 Overview

Counselling Psychologists emphasise reflective and reflexive practice (Van Scovoc, 2005). A key contributor to the theory of organisational learning, Schon (1983; 1987) described two types of reflexivity 1) Reflection-in-Action, and 2) Reflection-on-Action. Reflection-in-Action proposes a variation on 'traditional' top-down approaches whereby evidence guides practice. Schon suggested more helpful knowledge could be generated through understanding and operationalising the existing guiding principles of those 'within' the context being studied. Reflection-on-Action elucidates Schon's promotion of practiced-based evidence, which encourages and incorporates continuous reflective learning to consolidate knowledge. In line with these principles, the current study sought to obtain information from IAPT clinicians and service users, and use a reflective cycle where their suggested improvements were implemented and evaluated. The best framework to achieve this was considered to be Action Research (AR) as described by organisational psychology pioneer, Kurt Lewin (1946). AR is known to be an established research paradigm for organisational development (McArdle & Reason, 2008), and an increase in AR based designs by Counselling Psychologists for people with learning disabilities was invited by Walker (1993). However, sparse literature reflects this request to date. What follows expands on the rationale for using AR, a qualitative method, the study's epistemological underpinnings, and how this relates to the method used. There is then an overview of the study's procedure, ethical issues, analytic procedure, and rational for using this. It concludes with statements of methodological, epistemological and personal reflexivity.

## 2.2 Research design

Counselling Psychology aims to unify the scientific demands of robust, empirical enquiry with a base grounded in the therapeutic relationship, and draws on both the scientist-practitioner and reflectivepractitioner models of psychology to do so (Kasket & Gil-Rodriguez, 2011). It thus felt important to draw on my own experiences in this area, to research what I am practicing, then practice what I have researched. Counselling Psychologists are also encouraged to consider the contributions that we can make beyond therapy, to wider society, including social concerns, and policy development (Milton, 2010). We are urged not only to speak of the values we uphold, such as prioritisation of subjectivity and intersubjective experience, empowerment of clients, and commitment to egalitarian, non-hierarchal relationships, but to *apply* these principles (Cooper, 2009; Orlans & Van Scoyoc, 2008). It is perhaps unsurprising that action research (AR) is considered to be the foundations of Counselling Psychology research (Zuber-Skerritt, 1991). AR has also become increasingly popular in learning disability research as it offers dual advantages of empowering people with learning disabilities, through their active participation in decisions on matters that affect them, and enhances research's validity through clear utilisation of their expertise (Stack & McDonald, 2014).

The terms 'action research' and 'participatory action research' (PAR) are often used interchangeably (Wallerstein & Duran, 2003), and grouped with other variations of research that aim to include effected parties to bring about change, including emancipatory research (ER; Oliver, 1992) and community based action research (CBAR; Israel, Schulz, Parker & Becker, 1998). AR approaches may be seen on a continuum, with the more practical problem solving 'Lewinian' model at one end, emancipatory approaches at the other, and PAR, CBAR somewhere in the middle (Wallerstein & Duran, 2003). Although these approaches share key principles, points of emphasis vary. Traditional Lewinian studies of this nature typically use the term 'action research' (e.g. Reason & Bradbury, 2001), which Schneider (2012) noted places the focus on what the researchers consider to be the most important aspect- action. As the name suggests, emancipatory approaches emphasise empowering oppressed people to "challenge both the traditional academic knowledge- making practices and their own political domination" (Schneider, 2012. p154). However, it is not possible to 'do' ER-researchers may only engage with those already seeking to emancipate themselves (Barnes, 2002), thus ER was not considered practical for doctoral level research.

Emphasising inclusion and personal transformation of those involved, participants in PAR and CBAR frameworks are typically involved in every aspect of carrying out and disseminating research and are accordingly termed co-researchers. Most crucial in PAR is the attainment of three goals, 1) production of practical knowledge, 2) actions to make that knowledge available, and 3) transformation, socially and for co-researchers (Schneider, 2012). The current study aimed to meet the first two criteria, but for practical reasons, less so the third. Whilst it was hoped that participation in the project would facilitate social and personal growth, time and resource constraints of this doctoral level study inhibited possibilities of it being fully 'participatory' or 'emancipatory'. Furthermore, implementation and reflection on this was considered paramount in the current study, and it thus accordingly most closely resembles the approach described by Lewin (1946), and latterly, Hart and Bond (1995).

Lewin (1946) described AR as a "spiral of steps, each of which is composed of a cycle of planning, action and fact finding about the result of the action". (Lewin, 1946: 206). There are typically three overlapping phases to this: 1) planning (data gathering), 2) implementation and 3) evaluation, with participants being involved in the change process (Hart & Bond, 1995: 37-38). Acknowledging that the current study utilised a Lewinian approach, and out of respect for those operating from more participatory and emancipatory perspectives, the term 'participants' rather than 'co-researchers' is used throughout.

## 2.2.1 Rationale for qualitative analysis

Qualitative methodologies are distinguished from quantitative through their emphasis on understanding, interpretation and representation of participants' experiences they encounter them in context-specific settings (Elliot, Fischer & Rennie, 1999). They intend to describe the particulars of human experiences, including history and discourses, of those being studied and those studying. Such methods are considered more appropriate when analysing data provided by people with learning disabilities because they enable a better appreciation of their quality of life (MacDonald, Sinason & Hollins, 2003). Qualitative methods are also better suited to AR, where knowledge generally derives from an understanding of meanings (Bergold & Thomas, 2012). Qualitative research methods are also believed to play a crucial role in advancing the field of Counselling Psychology (Ponterotto, 2005), and are becoming increasingly common in health services (Mays & Pope, 2000). Although some of the data collected in the current study (i.e. traffic light colour rating allocated to domain on GLTK) was quantifiable, the GLTK (2013) states "the true value of these audit tools lies in the conversation, action planning and service improvement, rather than the scores on their own" (GLTK, 2013. p. 17). A purely quantitative approach could have led to prioritisation of performance, based on quantifiable externally imposed targets over 'ecologies of practice' informed by experiential knowledge of service users and clinicians (Sallis, Fisher & Owen, 2008). As this project was interested in finding meaningful and useful answers to the research questions based on participants' accounts of their experiences of IAPT, a qualitative approach was considered most appropriate.

#### 2.2.2 Research or service evaluation/audit?

As this study predominantly occurred within one service and used a standardised tool to guide interviews, it could be misconstrued as a service evaluation or audit. Many overlaps exist between service evaluations, audits and AR; all typically occur within, and aim to improve an existing organisation. However, several features distinguish research, and this study, from service evaluations and audits. For instance, unlike service evaluations and audits, research attempts to generate original, generalisable knowledge. Originality in this piece of work particularly stemmed from interviewing services users with learning disabilities who had received therapy in IAPT. Questions added to the GLTK (e.g. "Can you tell me why you think that?" "What do you think we can do to make this better?"), led to an array of unrestricted and innovative responses. In addition, 'IAPT' is a relatively standardised model, thus findings may be transferable to other IAPT services. Moreover, barriers faced by this client group within IAPT, (e.g. a lack of accessible information), are likely to arise in other mainstream psychological services, such as secondary care and third sector psychological services. As this study's results may be extrapolated to a broader range of clinical settings, it fell in line with the Health Research Authority's (HRA; NHS, 2015) definition of research. Another

distinction is that service evaluations are "designed and conducted solely to define or judge current care" (HRA; NHS, 2015), whilst AR, "seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions" (Reason & Bradbury, 2001; p:1). This study went beyond defining participants' views of current care, to understanding what they thought might improve it; and from there, sought to collaboratively, implement and evaluate suggested improvements. The theoretical underpinnings and procedures used are thus more aligned with AR. Finally, use of a recognised, sophisticated analytical procedure to interpret the data, as will shortly be discussed, further elevated this study from service evaluation or audit into research realms.

## 2.3 Epistemological position

Counselling Psychologists aim to provide valid scientific evidence whilst recognising individuals', subjective phenomenology (Kasket & Gil-Rodriguez, 2011), and are known to adopt a bricolage (doit-yourself) style to achieve their research goals (Ponterotto, 2005). This project began with a pragmatic paradigm, not obligated to any singular philosophy or reality. It was primarily concerned with the 'what' and 'how' of a research problem, and the application of appropriate approaches to understand and resolve it (Creswell, 2003, p.11). As this study progressed, and as indicated by the assumptions underpinning the research questions and methods employed to investigate them, this project ultimately embodied a critical-realist paradigm. Although qualitative methods are typically aligned with relativist notions that multiple constructed realities exist, and quantitative methods with positivistic (and realist) notions that objective and universal knowledge can be obtained, critical realism accepts that an underlying reality can be studied, albeit imperfectly (Mays & Pope, 2000) and can thus provide a coherent and productive stance for conducting qualitative research (Maxwell and Mittapall, 2010, p. 145-167). Olsen (2009, p. 13) highlighted that fundamental to AR is human equality; placing researchers in powerful positions where they attribute their values and truths to some ideas whilst dismissing others risks rendering participants as passive subjects. Mixed method (i.e. integration of qualitative and quantitative research data and analysis) approaches are therefore considered to have the best potential to challenge "elite powers". Accordingly, a mixed method approach was contemplated but deemed unfeasible due to the low numbers of people with learning disabilities currently accessing IAPT. It was thought improbable that a sufficient sample to apply inferential statistical analysis to quantitative data could be recruited within the time-limits of this project. The qualitative data analysis is nonetheless supplemented with descriptive, quantifiable information regarding the frequencies of participants' GLTK (2013) colour ratings and a calculated mean per GLTK domain, although this was not intended to reflect a perfectly measured 'truth'.

## 2.4 Method

# 2.4.1 Service setting

The study and recruitment took place in an inner-London IAPT service. This service offers NICEapproved interventions by PWPs and HI Therapists, delivered in both individual and group formats, including: CBT-based guided self-help and CBT, behavioural-couples therapy, and individual IPT and DIT. The service comprised of approximately 40 members of staff including two joint Clinical Leads, four full time Senior High Intensity (HI) Therapists, approximately 15 full time equivalent HI Therapists (including trainees), and approximately 17.5 full time equivalent Psychological Wellbeing Practitioners' (PWPs; including trainees). Since the study began, three clinicians were identified as 'LD Champions'; two HI's (including the author) and one PWP. There had been no dedicated funding, commissioning or additional resources allocated for offering therapy to people with learning disabilities.

# 2.4.2 Inclusion/ exclusion criteria and sampling considerations

Inclusion criteria for service users consisted of those identified within IAPT as having learning disabilities. This included those with a formal diagnosis of global learning disabilities, as well as those with a 'working diagnosis' (i.e. those without a formal diagnosis, but known to local learning disabilities services, and presenting with 'learning difficulties' thought clinically substantial enough to mean that they would benefit from reasonable adjustments within mainstream services such as IAPT). All service user participants were also required to meet the IAPT services eligibility criteria (e.g. over 18, experiencing anxiety, depression and/or anger), and who had at least one assessment and six treatment sessions within the IAPT service within 18 months of the initial interview. Exclusion criteria for service users consisted of those who had received less than one assessment and six treatment sessions and/or those who were discharged from the service more than 18 months before the interview date. This was because it was anticipated that they would be less able to estimate how well the service presently fared in relation to the GLTK (2013). Those who were considered to have not met current IAPT eligibility criteria, such as those who lacked capacity to provide informed consent, were also not included as they were beyond the IAPT service's remit at the time of recruitment.

Inclusion criteria for clinicians was all clinicians within the IAPT service who currently offered CBT. To avoid biasing results, exclusion criteria for clinicians consisted of those who also acted as interviewers. IAPT staff who did not work therapeutically with service users (i.e. those in purely managerial roles) were also not included. This was in order to allow the views of those who would potentially assess, determine eligibility, and work therapeutically with people with learning disabilities to be heard and acted upon.

## 2.4.2.1 Sampling considerations: Service users

In line with the LD-PPG (2015) observation that some people with learning disabilities require skills and structures only available in specialist learning disability teams, it was believed that those with moderate-severe-profound learning disabilities and/or those who lacked capacity were unlikely to have been referred, offered an assessment and/or have received treatment within IAPT. There was a high likelihood that anyone with moderate-severe learning disabilities referred to this IAPT service would be referred to specialist services at the point of referral, or post-assessment given that they even modified CBT was unlikely to be appropriate. This study therefore focused on those with borderline to mild learning disabilities. Before starting treatment, all service user participants had undergone an initial assessment to establish whether the service was suitable for their needs. There was no restriction regarding gender or ethnicity.

As illustrated in Table 1. the seven service user participants were five women and two men; age ranged from 18-54 years and there was diversity in terms of self-reported ethnicity. Most had received 12 or more 50-minute CBT sessions, although the number of sessions ranged from 6-15. Knowledge of IQ was not considered necessary, as it is not something typically obtained in IAPT and is not considered indicative of whether someone is able to benefit from talking therapies in IAPT (LD-PPG, 2015). One service user who participated in phase one was uncontactable after this and the decision was made to recruit a 'new' service user.

## 2.4.2.2 Sampling considerations: Clinicians

As Lewin (1946) maintained individuals are more likely to adopt changes if they are active in decisions effecting them, it was equally important to recruit clinicians within the service. To allow for an array of views to be heard, no restrictions were placed on professional background, level of post-graduate qualification(s), years in service, age, ethnicity or gender. However, all clinician participants worked within the IAPT service at the time of interviews, and actively offered CBT based interventions. As shown in Table 2. below, there was a relatively equal division of PWPs and HI Therapists. Time in service ranged from 4 months to 4.5 years. To manage concerns that clinician participants may be inclined to provide misleading responses out of loyalty to the service, anonymity and confidentiality was strongly reiterated verbally and in writing prior to interviews. Three clinicians (one HI Therapist and two PWPs) who participated in phase one left the service during phase two (implementation period). Consideration was given as to whether to recruit 'replacement' clinicians for phase three (evaluation interviews). In line with Chinn et al.'s (2014) findings that PWPs were typically more optimistic about IAPT adapting to meet the needs of people with learning disabilities, it was believed not recruiting another two PWPs may negatively bias the overall results in phase three, thus two 'new' PWPs, in post before the study began, were recruited for phase three.

Participant	Age	Gender	Self-reported ethnicity	Number of IAPT sessions	Presenting problem	Phase participated in
'Sally'	54	Female	Black –British	13	Anger	1 and 3
'Clara'	21	Female	White-British	15	Depression/ Irritability	1 and 3
'Jade'	23	Female	White- British	1 and 3		
'Dena'	18	Female	Pakistani- British	12	Anger	1 and 3
'Alan'	24	Male	Pakistani- British	12	Panic/ Anger	1 and 3
'Daniel'	32	Male	White- British	6	Depression	1
'Kayleigh'	24	Female	White-British	12	Anger /Trauma	3

Table 1. Service users' demographic details, number of sessions in IAPT and presenting problems at first interview. Pseudonyms are used to protect service-users' anonymity.

# 2.4.3 Procedure

## 2.4.3.1 Recruitment

A screening tool within the IAPT services computer system enabled identification of eligible service users, who were initially contacted by telephone. To avoid putting undue pressures on service users to participate, the caller was a clinician with whom they had no previous contact with. During this call, service users were advised of the study's aims and asked if they wished to participate. If interest was expressed, they were offered an accessible information leaflet (Appendix 2) via email or post. Support was offered for service users with lower literacy levels to review the information sheet with them. The caller advised that they would call back after seven days 'thinking time'. If expressions of interest persisted at this follow-up call, a day and time for an interview with the caller was arranged. IAPT clinicians were recruited through a service-wide email outlining the study's background and aims, with the clinician participant information sheet attached (Appendix 3). Similarly, if they expressed interest in participating by responding to the email, and this continued after seven-days, a day and time for an interview was arranged. The sample was thus self-selected.

Participant	Age - range	Gender	Job title	Approximate time worked in service a phase one	Phase participated in		
'Emma'	30-34	Female	Psychological Wellbeing Practitioner	1.5 years	1 and 3		
'Jasmine'	35-39	Female	Psychological Wellbeing Practitioner	4.5. years	1 and 3		
'Priya'	30-34	Female	Psychological Wellbeing Practitioner	1.5 years	3		
'Tanya'	25-29	Female	Psychological Wellbeing Practitioner	2 years	3		
'Rachel'	25-29	Female	Psychological Wellbeing Practitioner	2 years	1		
'Amy'	25-29	Female	Psychological Wellbeing Practitioner	1 year	1		
'Anthony'	35-39	Male	High Intensity CBT Therapist	2.5 years	1 and 3		
'Adam'	30-34	Male	High Intensity CBT Therapist	4 months	1		
'Joe'	45-49	Male	High Intensity CBT Therapist	4.5 years	1 and 3		
'Harriet'	35-39	Female	High Intensity Clinical Psychologist	3.5 years	1 and 3		
'Nancy'	35-39	Female	Senior High Intensity- Clinical Psychologist	2 years	1 and 3		
'Ben'	40-44	Male	Senior High Intensity- Counselling Psychologist	3.5 years	1 and 3		

Table 2. Clinician's demographics, job title and approximate time in service at the time of the first interview, or at the second interview if a 'new' participant. Pseudonyms are used to protect clinician's anonymity.

Service user participants received £10 per interview and reimbursement for travel expenses. This fee reflects good practice in valuing service user time and participation in research (INVOLVE, 2012).

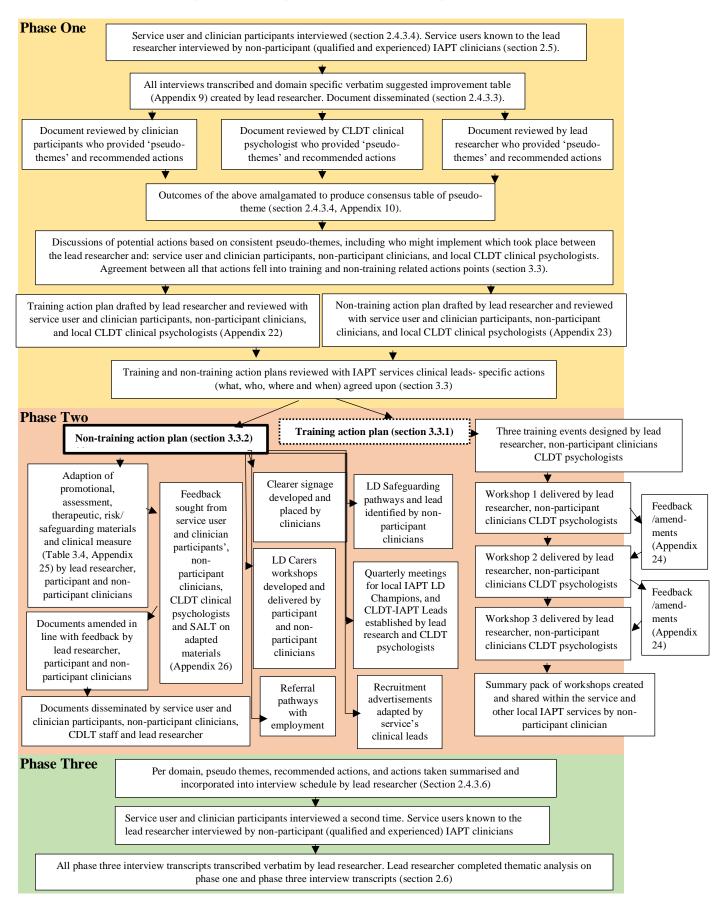
Clinician participants were not offered monetary incentives or travel expenses as the interviews took place during their working hours at their workplace.

## 2.4.3.2 Research materials and resources

Interview schedules (Appendix 4 and 5) were used as guides. All participants were provided with a printed copy of the relevant sections of the GLTK (2013; adapted version, Appendix 6; non-adapted version, Appendix 7). Not all GLTK (2013) domains are relevant to primary care psychological services such as IAPT (e.g. questions about secure / forensic settings) and it is documented within the GLTK (2013) guidance that only relevant domains need be included when assessing services. On reviewing the domains with a Clinical Psychologist who specialises in learning disabilities, it was agreed that service users could not realistically be expected to know the answers to some of the questions that clinicians might (e.g. current local data capture or planning for service developments). Thus, of a possible 27 domains, the revised copy of the GLTK distributed to clinicians omitted seven domains, and the revised copy of the GLTK distributed to services user's omitted 12 domains (Appendix 8). Minor changes were made to the wording of the GLTK so as not to confuse participants. For example, 'mental health services' was amended to 'this IAPT service'. As this study solely focused on learning disabilities, references to autism were also omitted. Adaptations may be seen by comparing the participants' GLTKs (Appendix 6 & 7) and the official GLTK (2013; Appendix 1).

All interviews were audio-recorded using a digital recording device. Hand written notes were made during the interviews to allow interviewers to note relevant non-verbal factors or influences. All data was stored according to the UK Data Archive guidelines. Clinic rooms, telephone calls and printing within the IAPT service were used for with permission for free. Support in generating accessible materials from the CLDT Clinical Psychologist was also free. The only cost incurred was service user payment incentive which totalled £120 and was incurred by the Lead Researcher only.

A flowchart depicting the key steps within the ensuing action research process that took place, including the participatory aspects of the implementation phase leading the thematic analysis process, can be seen in the following section (section 2.2.4.3).



## 2.4.3.3 Flowchart depicting key steps in the action research process

### 2.4.3.4 Phase one: Planning and data gathering

'Data gathering' occurred through face-to-face interviews lasting between 30-80 minutes. These interviews aimed to investigate how well service users with learning disabilities and IAPT clinicians thought the IAPT service fared in relation to the GLTK (2013). For each domain, participants were asked to provide a rating according to the GLTK's traffic light colour coding system of grey ('in the garage, not yet started'), red ('on the journey, but stuck at red'), amber ('ready for more') or green ('continuous progress'). This phase also included questions regarding reasons for stating a particular rating (e.g. "Can you give me an example of why you have given this area that rating?"). Data gathering also included enquires about how domains could be improved (e.g. "What do you think we could do to improve in that area?"). As depicted on the interview schedule, prompt questions were used to encourage elaboration of responses where necessary. To facilitate discussions with service users, prompt questions designed in consultation with a Clinical Psychologist who specialises in learning disabilities were also used.

Feedback of results was the subsequent use of participant validation or 'member checking'. In this study, member checking consisted of providing clinician participants with a table displaying verbatim extracts from all phase one interview transcripts that related to recommended improvements, categorised by GLTK (2013) domain. Specifically, this referred to all participant's responses to the question "what do you think we could do to improve?" for each GLTK domain (Appendix 9). Clinicians were asked to note what they considered to be key 'themes' per domain based on the verbatim extracts. To distinguish themes proposed during this preliminary analysis and those that emerged from the more formal thematic analysis of the interview transcripts (whereby the terms 'higher order themes' and 'subthemes' are used), the themes elicited at the preliminary analysis are termed 'pseudo-themes'. The document containing verbatim recommendations (Appendix 9) was as the same time, sent to a clinical psychologist within a local CLDT with a view to also carry out a preliminary analysis in the same manner, and the lead researcher simultaneously carried out this same task.

Initial analysis of phase one interviews was for the purposes of generating recommendations for the action research. Due to time constraints, this analysis consisted of a pragmatic review and summary of ideas and possible action points based on participant's responses to the question "what do you think we could do to improve?" for each GLTK domain (i.e. a preliminary analysis). Following the first set of interviews. A further table constructed to assess for consistency across researcher and participant 'pseudo-themes' (Appendix 10). A high level of uniformity was confirmed by an independent reviewer. Broad topics and ideas were then reviewed with the service's 'LD Champions' and local CLDT Psychologists before being discussed with the service's Clinical Leads.

## 2.4.3.5 Phase two: Action/ Implementation

Phase two involved carrying out suggested improvements such as the adaptation of several key documents into an easy read format and training events for IAPT staff, that had been elicited from the preliminary analysis, over a six-month period. The various actions are expanded on in the 'results' chapter. In line with the principles of AR, collaborative implementation with service user and clinician participants', as well as other members of the IAPT service and local learning disability services occurred.

## 2.4.3.6 Phase three: Evaluation

Phase three occurred approximately six-months after the final interview from phase one. With the addition of a discussion of pseudo-themes and subsequent actions taken, it consisted of a repetition of the interview procedure that occurred in phase one. For all participants, this phase involved, per domain, a summary of phase one responses, pseudo-themes (i.e. themes noted by clinicians during the post- phase one preliminary analysis), and a description of the actions during phase two taken. All participants were then asked to provide a traffic-light colour rating for the domain being discussed and explain why they had selected that colour, using examples where possible. In line with the cyclical process of AR, participants were asked for further suggestions for improvement for each domain.

# 2.5 Ethics

This research complied with the BPS, HCPC, and City, University of London Ethical Guidelines. Ethical approval was obtained from City, University of London Ethics Committee (Appendix 11), and approval to conduct the research was granted by West London Mental Health Trust Research and Development Team (WLMHT R&D). Ethical consideration from an NHS Ethics committee was sought and it was advised that the study did not require review by an NHS Ethics committee.

WLMHT R&D were informed of this and provided approval for the study to go ahead in accordance with their procedures and following the review by City, University of London Ethics Committee. Permission to carry out the research in an inner-city IAPT service was obtained from the IAPT service's Clinical Leads, who were open to implementation of suggested improvements in line with the principles of AR. Regular and ongoing consultation with a Clinical Psychologist specialising in learning disabilities took place throughout the research.

Further ethical issues that were carefully considered given that the research involved potentially vulnerable service users included: informed consent, right to withdraw, confidentiality, information recording and management of possible emerging risk issues or emotional distress. All participants

were briefed of the study's background and aims via information forms (Appendix 2 & 3) at recruitment stage. Prior to all interviews, consent forms were verbally discussed and signed (see Appendix 12 for accessible consent form and Appendix 13 for unadapted consent form). All participants were asked if there was anything they did not wish to discuss, informed of boundaries of confidentiality, their right to withdraw, and were advised that they did not have to answer any questions should they chose not to. Service user participants were also advised that any decisions made would not lead to any negative repercussions for their clinical care.

As the lead researcher had a prior therapeutic relationship with some of the service users, to avoid being in a 'dual role' and putting undue pressures on participants to give socially desirable responses, another interviewer (a qualified clinician within the service) was appointed. The second interviewer left the service during the course of the research and was replaced with another qualified clinician within the IAPT service; hence there were three interviewers in total. As people with learning disabilities can have greater difficulties talking about events and beliefs (Hebblethwaite, Jahoda, & Dagnan, 2011), all three interviewers were experienced in working with people with learning disabilities, and were well-practiced at assessing and managing risk and distress.

Although it was expected service users would experience the opportunity to provide their views on how IAPT might be improved for people with learning disabilities as positive and empowering, there was a small possibility that they might find discussing matters linked to their experiences of psychological therapy distressing, and/or that participants would disclose safeguarding or risk issues during their interviews. All interviewers knew to follow the risk protocol as identified in the service's Operational Policy should concerns emerge. Possible psychological distress caused as result of the study was assessed in the post-interview debrief. Participants were asked how they felt and if they had any questions or comments and consideration was given as to whether further psychological support could be helpful. Although this was not necessary for any participants, interviewers were prepared to advise on further sources of support and to refer to an appropriate service if necessary. Debrief forms were also provided for all participants (see Appendix 14 for accessible debrief form and Appendix 15 for unadapted debrief form).

With participants' consent, all interviews were recorded on a digital recording device. Immediately post-interview, recordings were copied onto a password protected computer drive and deleted from the digital recording device. Identifying information on written transcriptions was anonymised to protect confidentiality. Participants were advised, and consented to: recordings being permanently deleted following examination, anonymised interview transcripts being kept on a password protected computer for five years' post-interview, anonymised transcripts being read by the researcher's supervisors and/or assessing examiners, and anonymised segments of transcripts being used for additional articles or publications.

## 2.6 Analytic procedure

Thematic analysis (TA) is considered to be an appropriate method when investigating underresearched areas, or whereby participant's views are less well known (Braun & Clarke, 2006), as was the case with this study. Moreover, TA was used in the few qualitative studies that have included mental health service users with learning disabilities (e.g. Kilcommons, Withers, Moreno-Lopez, 2012; Wilner, Rose, Jahoda, Kroese, Felce et al., 2013) and IAPT clinicians' views on this client group (e.g. Chinn et al., 2014; Marwood; 2015 Shankland & Dagnan, 2015), suggesting it is an appropriate means of analysis for the current study. TA was also favoured over other methods used to analyse qualitative data due to its theoretical-flexibility (Braun & Clark, 2006). For example, IPA is epistemologically and ontologically predetermined, and imposes constrictions on research questions, sample size and sampling strategy (Clark & Braun, 2013). IPA also has a greater emphasis on the unique characteristics of participants and can thus demand more homogeneity in samples whereas TA has a greater focus on patterning of meanings across participants (Clark & Braun, 2013). As this study sought to simultaneously consider views of two quite different 'groups' (service users and clinicians), IPA was considered less appropriate. The process of analysis in TA is similar to grounded theory in that both involve coding, generation and interpretations of a broader pattern of data. Contextualist TA and grounded theory-lite are thought to result in similar outcomes, however, TA was favoured over grounded theory as it fitted with this study's aims of providing a conceptually informed interpretation of the data, rather than development of a theory. Grounded theory is also better suited to research questions that focus on social processes, which was not an emphasis in the current study.

There are various approaches to TA and whilst commonalities exist, differences arise in theoretical underpinnings. For example, Joffe's (2011) method of TA is argued to be closely aligned with realism, and Guest, MacQueen and Namey's (2012) method is considered to be more aligned to phenomenology (Clarke & Braun, 2013). This study followed Braun and Clark's (2006) method as it is not beholden to any predetermined theoretical positioning. This allowed greater freedom to choose research questions, epistemological stance, sample size and sampling strategy in line with the principles of AR and the aims of the current research. The analytic phases followed were thus those outlined by Braun and Clark (2006) and below<sup>3</sup>.

1) Familiarisation with the data: Audio-recorded data was listened to and transcribed verbatim. Transcripts were read and re-read to gain a feel of their content. All initial analytic observations (that is, possible initial codes) were noted by hand on the transcripts (Appendix 16) and an initial code list was generated (Appendix 17).

<sup>&</sup>lt;sup>3</sup> Braun and Clark (2006) stress TA is a recursive process and thus these phases were not followed in a strictly linear fashion.

2) Coding: Succinct codes for important features of data relevant to the research questions were generated. Codes intended to capture both semantic ideas (i.e. discourses explicitly associated with the specific research questions, such as suggested improvements to a particular domain) and conceptual ideas (i.e. discourses not directly related to the research questions, such as references to therapist inexperience and uncertainties about working with people with learning disabilities) were summarised in code form. Each interview transcript was coded this way, and an initial 'coded extracts table' was produced. Transcripts were then reviewed to see if further data extracts matched the existing extracts associated with the codes. Codes were then checked and amended where necessary to ensure that they reflected the extracts they represented. This phase was repeated until it appeared all data had been appropriately coded and all codes had been appropriately named. It concluded by organising all relevant data extracts and their associated codes and into the final 'coded extracts' table (Appendix 18)

3) *Searching for themes*: Themes (meaningful patterns relevant to the research questions) were actively developed based on the codes to identify similarities within the data. Software for developing mind-maps was used to begin to map out possible themes and subthemes the codes may have represented (Appendix 19).

4) *Reviewing themes*: Themes were checked to see if they fitted with the coded extracts (quotes) and full data set (responses to the research questions) and if they offered a realistic, convincing account of the data. This was where definitions of the nature of each individual theme and the relationships between them began, and where it was decided where themes could be amalgamated, 'split', or discarded and final 'frequency of codes' tables (Appendix 20) and thematic mind maps were produced (Appendix 21).

5) *Defining and naming themes*: This entailed writing a detailed analysis of each theme, identification of its 'spirit' and construction of a concise, informative name for each theme, and of each subtheme within it.

6) *Writing up:* The final phase 'wove together' the analytic narrative and vivid data extracts to provide a coherent story about the data. Identifying pseudonyms and the GLTK (2013) domain from which the extract was located in participants' transcripts is noted below each quote in the results chapter. Though initially transcribed verbatim, single repetitions and brief interruptions were not attentively analysed and were omitted from the write up to improve readability. Text added later to further assist readability is shown in square brackets [text]. Words less relevant to the analysis omitted from extracts to reduce length is represented by "...".

As the analysis was coding for specific research questions, and sought to provide a more detailed analysis of predetermined areas governed by GLTK (2013) domains, theoretical ('top-down') TA was favoured over inductive ('bottom-up') TA. As themes were identified based on explicit surface

meanings with the data, semantic coding was primarily used. This meant a more descriptive, realist account of participant's responses occurred. Latent coding may have allowed for a more subjective interpretation of the data, which would have conflicted AR's endeavours to avoid placing the researcher in a position of power (Olsen, 2009). However, it is acknowledged that using theoretical analysis and semantic coding, in addition to the structure of the GLTK (2013) based interview schedule restricted the scope of interpretation based on participants' transcripts. This is discussed further in the discussion chapter.

The GLTK (2013) is not designed with the intent to have statistical analysis applied to it. However, in order to compare service user and clinician ratings across and between phases, a mean score was calculated per domain. Numerical values were assigned to the GLTK (2013) traffic light coding as follows: 'grey'- 1, 'red'- 2, 'amber'- 3, 'green'- 4. The total numeric value of colours for each domain was added together and then divided by the total number of participants to give a mean score per domain for services users and clinicians at phase one and again at phase three. Participants gave a '?' when they were unsure of the answer. '?' ratings were treated as 'missing' data (i.e. if one person scored '?', the mean was calculated by adding the other scores and dividing by one less participant). There was therefore a range of ratings from 1 - 4, where 4 was the highest possible mean score per domain.

# 2.7 Reflexivity

Reflexivity is the attempt "to explore the ways in which [the] researcher's involvement with a particular study influences, acts upon and informs such research" (Nightingale & Cromby, 1999; p228). Kasket (2012) draws a distinction between methodological, epistemological and personal reflexivity and argues all needed to be acknowledged and managed.

# 2.7.1 Methodological and epistemological reflexivity

This refers to how the research questions can define and limit what could be found; how the design of the study and method of analysis constructs data and the findings, and how research questions may have been investigated differently (Ponterotto, 2005). Although there was some overlap in the reflexive factors regarding the action research process and thematic analysis, there were many differences; these are therefore considered separately.

### 2.7.1.1 Methodological and epistemological reflexivity: Action research

**Phase one: planning.** The outcome of this phase (i.e. pseudo themes and suggested actions) was greatly determined by the second research question "*In relation to GLTK (2013), what do IAPT service users with learning disabilities and IAPT clinicians think can be done to improve IAPT for people with learning disabilities?*" This question restricted participant's responses, and subsequent themes and suggested actions to specific domains identified by the NDTi, and further to those considered relevant to IAPT by myself and a CDLT Clinical Psychologist. The planning phase aimed to lead to a plan for actions, and was successful in this. However, retrospectively, I greatly underestimated the number of suggestions that would be put forward by the participants and at times doubted whether all could be achieved within the time constraints.

**Phase two: implementation**. The current study was also influenced by the decision to follow a 'traditional', Lewinian AR design, as opposed to one of the 'offshoots', such as PAR, or ER. Following a Lewinian approach meant that many of the decisions regarding the design of the project were made alone. Nonetheless, I was surprised by how forthcoming service user and clinician participants, as well as non-participant clinicians, the service's clinical leads and members of the local CLDT were in facilitating this phase. Although several others contributed to the implementation of action points in phase two, and efforts were made to redress imbalances through 'member checking', ideally, 'power' would have been more evenly shared. A more inclusive approach would have had a greater impact on the social relations of research production (Oliver, 1992). Unfortunately, the time constraints of this doctoral level study rendered it impractical to make this a wholly collaborative production.

#### Phase three: evaluation.

Perhaps more so in the evaluative phase, I was conscious of how my dual roles as the lead researcher in this project *and* colleague of the clinician participants interviewed had the potential to influence responses given in this phase, despite the assurances of confidentiality. This is reflected on further in the discussion. This phase also brought home a drawback of this approach being the limits to its generalisability. The decision to carry out the study within one IAPT service was also a consequence of time constraints, and although operating via and within one organisation is common practice in AR, the decision to do this inevitably prohibited a broader array of ideas from being put forward. As considered further in the discussion, this weakens the generalisability of the study to other IAPT services. However, it is also noteworthy action research emphasises the importance of practitioners', service-users' knowledge, and community members' knowledge, emphasises the value of 'local' advances in practice, and prides itself on producing specific practical changes and 'empowerment effects', at least as much as on any generalised findings.

## 2.7.1.2 Methodological and epistemological reflexivity: Thematic analysis

As alluded to above, the content of the data gathered available for interpretation during the thematic analysis was reduced to areas determined by the GLTK (2013; and NDTi), and then further to domains a Clinical Psychologist who specialises in learning disabilities and I considered relevant to participants in the current study. Use of the GLTK (2013) therefore limited the participant's responses, thus what could be found in relation to this question. Rather than use a tool based on literature and 'expert opinion', at the outset, I could have collected views and ideas from a range of stakeholders, including service users with learning disabilities, IAPT staff, as well as the family and carers of people with learning disabilities, and commissioners, as occurred in Chinn et al's. (2014) study. This may have enabled a more relevant and valid interview guide, and produced data more representative of what stakeholders considered most important. The decision to use TA was carefully considered, but it is undeniable that a different methodology such as content analysis, IPA, or grounded theory may have rendered different answers to the research questions. The possibility that I was more hypervigilant to certain themes owing to my position within the project, and within the service was observed from the outset. In particular, that I would be more likely to notice other clinicians expressing concerns that mirrored my own during the data analysis, and positive biased appraisals of the success of the implementation phase reported in phase three. This is also reflected upon in the discussion.

# 2.7.2 Personal reflexivity

Reflexivity is especially imperative for researchers like myself; closely involved with the subject and context in which it occurs. This study was inspired by my participation, in my capacity as an IAPT HI CBT Therapist, in the *Foundation for People with Learning Disabilities* (2013) initiative to increase access for people with learning disabilities to IAPT. Their project, which occurred through a series of action-learning sets between 2012-2015 comprising of IAPT and CLDT staff, left me with an internal conflict. I value equality and acknowledged that separation in care delivery perpetuated the marginalisation and social exclusion of people with learning disabilities (2013) recommendations to improve access to IAPT for people with learning disabilities, such as increased joint-working, flexibility in appointment days, times and locations, and making materials (clinical measures, tools, formulations) accessible seemed theoretically sound, but to me, seemed out of step with the IAPT model and largely unachievable without making significant demands on already overstretched IAPT clinicians' time. I thought inadequate measures to support such an initiative neglected the realities of working within

IAPT, a need to have knowledge and experience of two complex areas (learning disabilities and mental health problems).

My ultimate fear was that hastily increasing access to IAPT for people with learning disabilities would greatly disservice these individuals. My hope was that with the support of IAPT service users with learning disabilities and IAPT clinicians, realistic changes could be considered, implemented and evaluated. From there, that further IAPT and mainstream psychological services would be inspired to implement similar, realistic adaptations, and thus people with learning disabilities could equitably access psychological support in a considered and effective manner. As I was conscious of my fears and hopes from the outset, measures were taken to enhance the quality and validity of the data, as elaborated upon below.

# 2.7.3 Measures taken to enhance data validity and quality

Steps taken to manage the effects of researcher biases and improve validity included, as alluded to above, 'owning one's own perspective'. A key credibility check was 'member checking', which involved comparing my own and participants' accounts of data from the phase one interviews to establish a degree of association, and the subsequent incorporation of this into the overall findings. However, it was acknowledged that member checking inevitably required further interpretation, and thus may be better viewed as the production of further data and a process of error reduction (Mays & Pope, 2000). Another quality check was the transparent explanation of data collection and analysis. I refer the reader to Appendix 17-21 for illustration of the analytic steps taken and 'paper trail' of the analytic process. Here, it may be seen where steps taken to carefully consider ideas that did not 'fit' with broader emerging themes to cultivate the overall analysis occurred.

As attention to negative cases can improve quality of qualitative research, efforts were also made to ensure that as wide a range of perspectives as possible occurred, within the time limits of the current study, to ensure that there was a level of 'fair dealing' (Mays & Pope, 2000). The procedural overview noted in this chapter and ensuing results chapter elucidates how primary systems of classification evolved into more refined coding structures, and then clearly defined concepts and explanations for the data. It is hoped that these, together with interview quotations contain adequate information to allow the reader to determine whether the themes reflect the raw data and vice versa. It is further anticipated that the level of reflexivity that occurred throughout this study and as noted above, enabled the author to sensitively consider how they, and the processes used, influenced the findings.

Triangulation of data occurred through comparison of two different methods of data collection (interview transcripts and traffic light colour ratings on the GLTK), and through different sources,

(service users as well as junior (PWP), HI, and senior HI clinicians). The analytic procedure sought to elicit patterns of convergence across methods and sources to establish a corroborated interpretation of the data. However, it has been suggested that triangulation as a 'quality check' is used with caution due to the implicit, arguably misleading assumption that weaknesses in one method are compensated by strengths of another (Mays & Pope, 2000). Regarding this research, it should also be noted that whilst the traffic light coding added an additional layer to understanding participants' views, this data was not inferentially statistically analysed, and is therefore not a true example of triangulation. Mays & Pope (2000) also refer to the possibility of arbitration of different sources. Whilst effort was made to fairly analyse all sources, it is more appropriate to view triangulation as enhancing the inclusiveness and reflexivity of this study.

## **CHAPTER THREE: RESULTS**

# 3.1 Overview

The following section is divided into three sections to reflect the three phases of action research: 1) Phase one: planning/data gathering, 2) Phase two: implementation of actions and 3) Phase three: evaluation, including 'participant validation'/ member checking. Phases one and three are further subdivided to reflect service user, then clinician themes and subthemes. An overview of the higher-order themes and subthemes found in service user and clinician interviews in phases one (planning/data gathering) and three (evaluation) can be found in Figure 1. Each theme and subtheme are discussed with raw data extracts to support and illustrate them<sup>456</sup>.

# 3.2 Phase one: Planning and data gathering

As illustrated in Table 3.1 through the greater number of 'greens' and corresponding higher mean scores, service users reported that the service was faring better in relation to the GLTK (2013) compared to clinicians. Table 3.1 also shows that clinicians gave comparably more 'lower' (i.e. grey and red) ratings, and that as the audit progressed from 'basic' to 'best' (areas services are finding easiest to hardest to do well in, respectively; GLTK, 2013. p. 18), the frequency of grey and red ratings and indications of uncertainty (i.e. '?') increased.

<sup>&</sup>lt;sup>4</sup> Identifying pseudonyms and the GLTK (2013) domain from which the extract was located in participants' transcripts is noted below each quote.

 $<sup>\</sup>frac{1}{2}$  Some participants occasionally used the term 'learning difficulties', when referring to 'learning disabilities'. Where this term occurs, it is with reference to 'learning disabilities'.

<sup>&</sup>lt;sup>6</sup> A pen table of a service user and clinician participants can be found in sections 2.4.2.1 (Table 1) and 2.4.2.2 (Table 2), respectively, within the methods chapter.

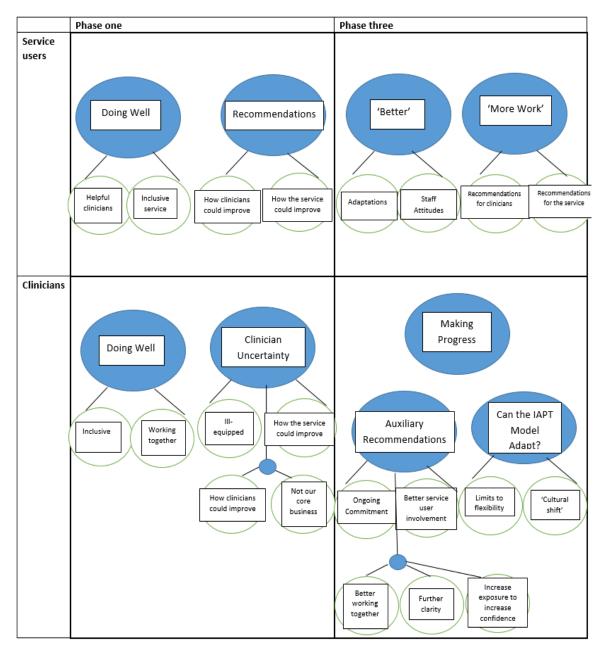


Figure 1. Service user and clinician higher-order themes and subthemes in phases one and three

		Phase one: Planning and data gathering																
Audit tool	Domain Clinician Participants					Mean Service user Participants score						Mean score						
Basic	Eligibility and Access										3.2	?						4
	Safeguarding										3.3							3.6
	Assessment	?									2.3							3.3
	Equalities										3							3.3
	Staff Attitudes										3.2							3.8
	Accessible information	?									2.4							3.3
Better	Research										3.5							3.3
	Local plans	?									3	/	/	/	/	/	/	/
	Skilled workforce	?									2.1	/	/	/	/	/	/	/
	Service user involvement	?	?								2							4
	Psychological Therapies	?									2.2							3.1
	Working together	?									2.2	?						3.8
Best	Buildings and environments	?									1.6							3.3
	Leadership										3.1	/	/	/	/	/	/	/
	Friends and family										1.8							3.6
	Employment support	?	?	?							2.2	?						3
	Checking services	?									2.5	/	/	/	/	/	/	/
	Monitoring	?									2.6	/	/	/	/	/	/	/

Table 3.1 Participant GLKT traffic light scores at phase one

Response	Meaning	Numerical value used to calculate mean
		score
?	Unsure of answer	0
Grey	'In the garage, not yet started'	1
Red	'On the journey, but stuck at red'	2
Amber	'Ready for more'	3
Green	'Continuous progress'	4
/	Domain was not asked about	/

# 3.2.1 Phase one: Service user results

As displayed in Table 3.2 two higher order themes, 'Doing well' and 'Recommendations', each with two subthemes, were identified from the thematic analysis of service user transcriptions in phase one.

Higher Order Theme	Subtheme
1. Doing Well	1. Helpful Clinicians
	2. Inclusive Service
2. Recommendations	1. How clinicians could improve
	2. How the service could improve

Table 3.2. Phase one service user higher-order themes and subthemes

## 3.2.1.1 Service user theme one: Doing well

This theme reflected services users' recognition that the service was relatively successful in most GLTK (2013) domains. It comprised of subthemes separated into positives attributed to clinicians, and those attributed to the service. It is noteworthy that the majority of positive responses were attributed to individual clinicians rather than the service. This is understandable given that service users had little awareness of 'behind the scenes' service-level processes and policies. For example, service users commended individual clinicians for helping them to stay safe, but were unlikely to be aware that clinicians were actually following the service's safeguarding policies, such as completing a 'safety plan' where risk had been indicated.

## 3.2.1.1.1 Subtheme one: Helpful clinicians

All service users commended individual clinicians. For many, this took the form of having a positive therapeutic alliance e.g. a clinician with whom "you get along". One service-user expanded on this by suggesting that the positive alliance instilled a sense of hope.

# ...when you get along so well you can work on anything. (Clara: 'Staff Attitudes')

Many positively remarked on how clinicians were helpful through acknowledging and adapting to meet their increased needs, such as putting things "in words I can understand" (Daniel: 'Assessment') or taking their time to understand their unique difficulties and explain things in simpler terms. Three service-users noted clinicians helped by providing information, be it psycho-education of presenting difficulties or information about how to keep safe.

...that's what we need. We need people who like, who like...give you information and keep you safe. (Clara: 'Safeguarding')

Three service-users reflected how talking therapies positively impacted on emotional wellbeing. One noted:

...it actually made a huge impact in my life. I've changed quite a lot since the first session, and been more positive and more courageous. It's very good. (Jade: 'Psychological Therapies')

Another service user indicated that therapy can be helpful personally, as well as systemically.

Because they... help them improve in their social life and sometimes mental life, and like at home with family and stuff. (Alan: 'Eligibility and Access')

3.2.1.1.2 Subtheme two: Inclusive service

In four cases, inclusiveness was associated with the reality that service users had learning disabilities and had received therapy within the service. However, three service-users further commented on a sense of being included by the wider team:

... They are always lovely, the receptionist always talks to me and asks me how am I today, they are very lovely and make me feel welcome. (Jade: 'Staff Attitudes')

The impression of inclusion further encompassed a sense of being involved in service development. All service users rated the service highly in this area, although associated comments suggested that this might be by virtue of being involved in the current project.

...you are fantastic as well for giving me this opportunity to let me come and talk about this. (Jade: 'Staff Attitudes')

Several service users also appeared to recognise inclusion of their family in service development.

...as their relatives are getting involved as well, helping the service get better and better and better. (Clara: 'Service-User Involvement')

Also noting inclusion of their wider networks, two services users referred to the support suggested for their family.

...when I first came here, [treating clinician] asked me what it was like at home and asked if I needed family therapy, help with like, my behaviour at home, if there was any help that my mum and dad could get as well as me, and that's when she recommended family therapy. (Alan: 'Friends and Family')

## 3.2.1.2 Service user theme two: Recommendations

Recommendations put forward by service users could be broadly separated into two subthemes: 1) 'How clinicians could improve', such as acknowledging increased needs, acknowledging individual differences, asking questions, and providing information or advice, and 2) 'How the service could improve', including reasonable adjustments, staff training, service promotion and joint working with other services.

# 3.2.1.2.1 Subtheme one: How clinicians could improve

Four service-users conveyed that their increased needs ought to be acknowledged by clinicians. As one service user explained:

... people like learning disabilities need more help...to doing what they need to be doing. (Dena: 'Eligibility, Access')

Three service-users specifically proposed how clinicians might provide additional support with written information:

[make] things easier to read, not long words...break it down. (Sarah: 'Equalities').

A further service user spoke of this with regards to adapting appointment duration given the increased time it might take for some people to communicate:

Someone with learning disabilities can't always talk, like, properly, they need time to try to get the words out. (Jade: 'Equalities')

One service user's reference to requiring support with the minimum data set (MDS) potentially suggested an overlap in clinicians needing to acknowledge increased needs and individual differences when considering whether, and how, administrators offered this prior to sessions.

I ask the receptionist, I said "I don't understand this" [pointing at the MDS] she just said "[the clinician will] try and help", I just didn't bother asking again...a lot of people they can't see very well...they can't read very well. I can't do it. (Daniel: 'Staff Attitudes')

The importance of clinicians acknowledging individual differences, or the diversity within this group and adapting accordingly, was further highlighted by three service-users.

... if it's a bit more severe, like Down Syndrome, they could have on the assessment, like give them like a sheet with faces on it so they can point at how they are feeling, like different sad faces. (Jade: 'Assessment')

When asked how psychological therapies might be improved, one service user simply remarked:

It all depends on the individual. (Sarah: 'Psychological Therapies')

Three service-users recommended clinicians asked questions to help them comprehend individual's idiosyncratic needs, be this about an individuals' learning disability, assessment needs, or safeguarding issues.

...ask them questions, probably if they have any problems or if they don't keep it safe, and ask them if they have any problems. Ask them questions and then they will answer you. (Dena: 'Safeguarding')

Whilst clinicians were commended for providing information, provision of information was also noted as a recommendation by all service-users. Although this recommendation occurred across domains, it most frequently occurred in the 'Safeguarding' and 'Employment Support' domains, as the following excerpts illustrate:

To keep people safe outside? ...tell them to get in touch with family and friends either the police...Doctors, speak to the social worker, if they got a social worker, tell them they can't keep themselves safe. (Sarah: 'Safeguarding')

... *just give them more information on what services can get them into employment.* (Jade: 'Employment Support')

These comments also possibly reflect service users' desires for clinicians to be more didactic and direct with advice given to them.

3.2.1.2.2 Subtheme two: How the service could improve

Many service-level recommendations reflected reasonable adjustments. Overlapping with earlier references to acknowledging increased needs of people with learning disabilities, three service-users' advocated additional and/or longer sessions:

... 15 or 20 minutes longer sessions, or more than once a week...because once a week I don't think will be enough for people that have quite, if they have disabilities. (Alan: 'Equalities')

Overlapping with earlier noted suggestions that clinicians recognise the increased needs of this group, five service-users suggested the service acquire a broader range of means of communication:

...information in different sorts of ways people with disabilities like braille and pictures, faces just like that, and also maybe audio? (Jade: 'Accessible Information')

The final key area service users spoke of in terms of reasonable adjustments involved suggestions that IAPT buildings became more accessible, for example by making them easier to locate through:

...posts, signs, signposts up, to make it easy for people to find. (Sarah: 'Buildings, Environments')

The other means of making the buildings more accessible, as noted by five service users, was ensuring that one of the IAPT buildings upstairs that was inaccessible to those unable to use stairs, was made accessible. Suggestions included installing a "lift", or "chair lift" (Jade: 'Buildings, Environments').

Three service-users recommended staff have training to better understand and accommodate their needs, as one service user noted:

Sometimes therapists need to learn a bit more about needs', that's why is good to research it, so some people have never heard of a learning disability, some people hardly know about global developmental delay... (Jade: 'Research')

Another recommended service-level improvement concerned greater promotion of the service. Two service users suggested greater advertising in the community, such as "Doctors, Health Centre...The chemist as well?" (Sarah: 'Eligibility, Access'). A further recommendation was working better with other services including CLDTs and GPs, as one service user remarked:

*Communicate if you want to work together and understand each other, and individual people.* (Sarah: 'Working together')

The interview structure and use of the GLKT (2013) to guide this at times rendered in depth interpretations of transcripts problematic. This is recognised to be a key limitation of the study and is further reflected on in the discussion.

# 3.2.2: Phase one: Clinicians' results

Whilst service users provided direct responses to the interview questions, perhaps wider awareness of the context and controversies surrounding proposals to improve IAPT for people with learning disabilities led clinicians to offer contrasting, and sometimes contradicting viewpoints. These tensions appeared to reflect a respect for egalitarianism whilst acknowledging the constraints of IAPT. Nonetheless, due to the similar interview structure, many key themes elicited from clinician transcripts echoed those found within service user's. As reflected in the traffic-light ratings (Table 3.1), clinicians largely seemed to agree that the service was successful in some areas whilst others required attention. Two higher-order themes and their associated subthemes are provided in Table 3.3.

Higher Order Theme	Subtheme
	1. Inclusive
1. Doing well	1. Inclusive
	2. Working together
	1. Ill-equipped
2. Clinician uncertainty	2. How clinicians could improve
	3. How the service could improve
	4. LD is not our 'core business'

Table 3.3 Phase one clinicians higher order themes and subthemes

### **3.2.2.1** Clinician theme one: Doing well

Every clinician referred to at least one area that they felt was successful in terms of offering a service to people with learning disabilities. These aspects could be broadly subcategorised into two subthemes, 1) 'Inclusive', which included adaptations that occurred to accommodate the needs of people with learning disabilities, and 2) 'Working together', which included having points of contact for learning disability related matters, and good working relationships with local learning disabilities services.

# 3.2.2.1.1 Subtheme one: Inclusive

Five clinicians referred to the service's openness to working with people with learning disabilities. Of these comments, some referred to the service having a "clear expectation" (Ben, 'Eligibility, Access') that this population could access support within the service. Comments also suggested a personal openness towards working with this population.

...people work with people with LD and seem happy and confident to do so. (Amy: 'Staff Attitudes')

Another stream of inclusiveness reflected recognition that both clinicians and the wider service made adjustments where possible to support people with learning disabilities:

...where we can make those adjustments, that the clinician will go out of their way to ensure that they get that, the adjustments that are the most helpful. (Emma: 'Staff Attitudes')

Three clinicians indicated that the service as a whole was relatively accommodating, as one clinician remarked:

... I do think it's definitely a good service for having those adjustments available, um and ... work with people ... creatively. (Amy: 'Equalities')

A further two clinicians referred to adaptations being made to the delivery of therapy, that is "making them more accessible" (Harriet: 'Leadership'), pertaining to some workshops being adapted into a format more easily understood for people with learning disabilities.

It is noteworthy that the above quotes illustrate that although many clinicians perceived the service to be inclusive, their comments were often vague and the particulars of the ways in which this occurred were unspecified, suggesting a lack of awareness of precisely how this was being achieved.

# 3.2.2.1.2 Subtheme two: Working together

The second subtheme involved appreciation of clinicians and services working well with each other; one stream within this indicated that clinicians felt that the IAPT service itself offered a supportive, sharing environment.

A lot of people who are more skilled, are happy to share their knowledge, and you can always go and speak to people.... I think the team is good at sharing experience and knowledge. (Amy: 'Skilled Workforce')

Six clinicians indicated that the service was working well with the CLDT in particular.

... there's very good links thanks to [LD leads] with the Learning Disability Team, for sure. (Ben: 'Working Together')

Again, whilst clinicians made clear statements that indicated that the service was working well with others, these assumptions were often not elaborated on, perhaps suggesting a lack of awareness as to how this was achieved.

#### 3.2.2.2 Clinician theme two: Clinician uncertainty

The second higher-order theme consisted of clinicians' concerns about working with people with learning disabilities. It was difficult to untangle uncertainties, and explanations for these, and the suggestions for improvement; origins of these uncertainties and solutions were frequently expressed in the same sentence.

...I know that I haven't been given any particular training, and I know, other people I know, don't have any other training in LD, and struggle working with LD, so I think that's where more progress needs to be made, training and confidence building. (Anthony: 'Assessment')

Despite frequent discourses of intertwined anxieties, explanations and proposed solutions, the overarching theme of 'clinicians' uncertainties' could be largely subcategorised into four key areas. Firstly, were clinician uncertainties linked to their sense of being ill-equipped to work with people with learning disabilities due to lack of knowledge, experience and accordingly, confidence. The sense of being ill-equipped also included uncertainties regarding the service's official stance on this group. Secondly, were expressions of uncertainty linked to solutions arguably feasible 'on the ground' without managerial improvement ('how clinicians can improve'). Thirdly, were expressions of uncertainty linked arguably requiring 'top down', managerial input ('how the service can improve'). The fourth stream of clinician uncertainty reflected clinicians' doubts about the 'achievableness' of working effectively with this population in IAPT ('LD is not our 'core business''). These concerns often related to competing demands and strained resources within IAPT.

## 3.2.2.2.1 Subtheme one: Ill-equipped

One key discourse in terms of feeling ill-equipped reflected a sense of not knowing what the service's policies and procedures were on 'learning disabilities'.

...you're not aware of the range of adjustments that could be made...[it] can be tricky because not having an understanding, or knowing, s'almost like not really knowing the full extent of treatments that you offer...so you can't really know if someone's really suitable for your service or not... (Emma: 'Equalities')

Nine clinicians referred to feelings of inadequacy regarding therapeutic work with people with learning disabilities; two specifically indicated a personal sense of being unskilled in this area:

... I feel I lack crucial skills for working with people with LD, not that I haven't worked with people in the service with these things, but I have quite felt underprepared (Harriet: 'Skilled Workforce')

Potentially exacerbating anxieties about working therapeutically with this group, several clinicians expressed concerns about identifying whether someone had a learning disability.

I wouldn't necessarily pick up on a learning disability that wasn't very 'there' in terms of its presentation. (Rachel: 'Eligibility, Access')

During discussions about accessible information, other clinicians linked their anxieties with a lack of awareness and understanding of LD centric materials:

... how you can use them, are they typically best used with people that present different things? (Jasmine: 'Accessible Information')

It was clear in at least two cases that perceived inadequacies and corresponding fears of doing a disservice led to a reluctance to work with people with learning disabilities.

...I'd be really annoyed if I had somebody on my caseload who had a learning disability, not because I don't want to work with them...because I've received no training on it...It's not that we don't want to, I don't feel equipped to and often, and I feel like I'm doing a disservice to somebody. (Rachel: 'Staff Attitudes')

...I fear learning difficulties. Erm, I don't like working with it. I don't think it's something I'm good at...I always wonder how effective I am being and that makes me reluctant to work with things like LD. (Anthony: 'Staff Attitudes')

Expanding feelings of being ill-equipped, three clinicians conveyed anxieties about causing offense or patronising people with learning disabilities.

...how do we talk about that, you know, in a way that isn't offensive to the client? (Emma: 'Eligibility, Access')

The last thing you want to do is come up with a, [be] patronising to somebody, so, how do you pitch at the right level for someone so it's understandable? You don't want to belittle. (Rachel: 'Staff Attitudes')

Related to apprehensions about making errors, five clinicians expressed concerns about being held responsible for this:

*I don't think that we had a healthy learning culture rather than a blame culture.* (Rachel: 'Safeguarding')

...someone recently said to me, "Well, everyone knows who those 'anonymous' people are" and of course there is blame. (Ben: 'Safeguarding')

Nine clinicians linked their uncertainties to a lack of training on working with people with learning disabilities:

... it can be quite difficult to assess and know what we're meant to be assessing and I haven't had any training in sort of LD. (Amy: 'Assessment')

.....I don't know; this is probably a training thing...I would feel a bit anxious...asking whether someone has any difficulty reading or writing. (Emma: 'Assessment')

Several clinicians spoke of their uneasiness due their lack of "exposure" to people with learning disabilities:

...my own lack of exposure to this stuff... means that I'm not very sure if I'm right (Joe: 'Staff Attitudes')

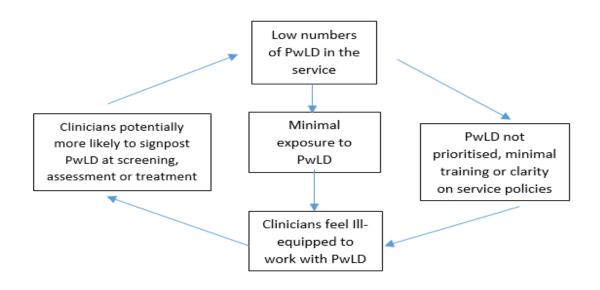
Exposure to people with learning disabilities was further noted by some as a way to increase confidence in this area:

...maybe it's about getting experience of working with people with LD more specifically. I don't know, expose myself to my fear? Because I just don't feel skilled in it. (Anthony: 'Staff Attitudes')

However, some noted difficulties to this solution of "exposure" given the low numbers of people with learning disabilities entering IAPT:

... because we only have, like odd scatterings of cases come through it's really difficult for people to build up their confidence (Nancy: 'Safeguarding')

The 'ill-equipped' subtheme could be summarised in the cycle shown in Figure 2. Low numbers of people with learning disabilities minimised opportunities to gain exposure to this group, and conceivably resulted in learning disabilities not being seen as requiring specific training, or clear policy guidelines on, both of which fed into IAPT clinicians sense of feeling ill-equipped. Although not explicitly noted, this may have meant clinicians were more inclined to signpost people with learning disabilities to other services, such as the CLDT, and thereby perpetuating low numbers of people with learning disabilities accessing IAPT.



*Figure 2. Self-perpetuating cycle of clinician uncertainty* PwLD: People with learning disabilities

# 3.2.2.2.2 Subtheme two: How clinicians could improve

One suggestion made by several clinicians feasibly achievable without managerial involvement was improving links with other services. For example, one clinician suggested an improvement could be to:

...improve the links between CMHT [Community Mental Health Team] and us in terms of working with LD, and also joint working will be really important with LD services (Harriet: 'Working Together').

Often underpinning these suggestions were clinicians' uncertainty about what other services offered. For example, uncertainty about what the CLDT offered was mentioned by seven clinicians, with one clinician noting:

... knowing what the LD team do as well, I genuinely don't know.... (Rachel: 'Assessment')

Nine clinicians spoke of having "reciprocal arrangements" (Joe: 'Assessment') whereby staff shared knowledge, skills and resources to facilitate access for people with learning disabilities:

... maybe getting Assessment Team to come and talk or LD team to come and talk about what they do what they can offer, how we can work better in partnership with them, what from our side is missing. (Adam: 'Assessment')

Throughout the domain of 'Working Together', there were multiple references to this being somewhat arduous, a desire by many for this to be simpler, and the links to be made more obvious.

...I don't think that is so easy for us to refer for an LD assessment, well I haven't found it that easy, I find it quite difficult...I think if we were linked with an LD service, then at least we would know who to refer to, and it will be quicker, and it will be less sort of, running around the houses. (Jasmine: 'Assessment')

The additional time joint working might take and apparent frustrations thereof, perhaps stemmed from the time pressures they already felt from trying to achieve their job plans.

The other problem perennially, would be is IAPT is timed, the time to do joint working, and the time to do the necessary liaison that is important for work with this population... (Harriet: 'Working Together')

Also contributing to concerns and suggestions about working together were beliefs that CLDTs were not sure of IAPT's remit or model:

...they don't always understand what we do, because for them, working with learning disabilities is second nature and so they don't... they don't understand why we find it so difficult (Nancy: 'Working Together')

References to improving by working better together occurred internally as well as externally. Two clinicians proposed better working together might be achieved by clinicians within the service through a "Journal Club" (Joe: 'Psychological Therapies'), or:

...clinical skills maybe on a step two level...someone who does know could do something...a peer training if someone is more familiar with that area? (Emma: 'Working Together')

Echoing suggestions proposed by service-users, another clinician-led recommendation included acknowledging individual differences and asking questions about how best to support them:

...I'm just thinking of someone that I saw, that...had problems understanding...he just said 'use simpler language'... suppose it's just putting it back...maybe put it back to them at the very first point of contact. (Emma: 'Eligibility, Access')

Similar ideas occurred when considering how to improve the 'Friends and Family' domain.

Trying to spend a bit more time asking who is close to them, who do they like spending time with, who seems to be helpful? Getting more of an idea about their support network...(Rachel: 'Friends and Family')

Many also suggested providing support to carers themselves through "a specific LD carers support group" (Harriet: 'Friends and Family'). One clinician noted:

That's something we can do, get people to be more involved with family and friends? Because they need that support, we could be routinely checking in with them. (Joe: 'Friends and Family')

Another area in which clinicians could improve on, suggested by seven clinicians, was obtaining a greater awareness of the evidence base on therapy for people with learning disabilities. One clinician highlighted this desire was linked to IAPT's commitment to evidence-based interventions.

...so there is quite an interest in evidenced-based practise in IAPT, and I think most people that work here kind of hold that interest, or some scientific values as a part of that (Adam: 'Research')

Whilst many of the suggestions noted here are categorised as improvements for clinicians, it is worth noting that sometimes, these comments appeared to hint at a lack of ownership, or acceptance of responsibility to seek to make such changes:

...we need more specified, standardised tools, more evidence informed interventions, and also to know why we using them, why they're helpful (Anthony: 'Research')

This thus suggests that whilst these recommendations have come under 'how clinicians could improve' subtheme, as they were perceived to not necessarily require managerial support, some clinicians may see these suggestions as requiring service-level intervention.

## 3.2.2.3 Subtheme three: How the service could improve

Service-level recommendations included: advertising, training, reasonable adjustments, clarity on service policies and protocols, including the 'LD label' (i.e. the administrative 'flag' applied on the service's computer system to record that an individual has a learning disability), service user involvement, reflective practice, and permission to make errors, or not want to work with this population.

The foremost suggestion noted by every clinician as a means to increase confidence and/or alleviate anxiety was training. All 10 clinicians stated training should be broad and practical:

...it would be good to have that in a practical, "This would be a good way to work with this group of people," and to offer some practical advice (Ben: 'Equalities')

Key training topics included how to adapt current practice, "how to actually apply techniques and the ideas in the things we do" (Joe: 'Eligibility, Access'), and assessments, "in terms of assessing it, what sort of questions to ask and how to assess it thoroughly" (Amy: 'Assessment'). Seven clinicians proposed training should cover information about other services, including; "getting a talk from the LD team" (Adam: 'Working Together'). Training on safeguarding procedures was highlighted by seven clinicians, incorporating: "what sorts of vulnerabilities there are maybe...things that you need to listen out for a little bit more, noticing bad relationships...generally raising awareness of what that means" (Anthony: 'Safeguarding'). Understanding LD-centric materials was also mentioned by five clinicians, for example: "...getting training, knowing what materials are available and how to work with them" (Amy: 'Equalities') and experiences of IAPT clinicians who had worked with people with learning disabilities as mentioned by two clinicians, and illustrated below:

...other people who have by chance ended up with having people with LD on their caseload, what have they done? What did they find difficult? How did they manage time with the rest of a caseload? Informal in-house training, hearing more about experiences and thinking about what we can do. (Rachel: 'Staff Attitudes')

Every clinician asserted that everyone ought to receive training in this area, "...it's about training everybody in the service" (Joe: 'Eligibility, Access'). Possibly reflecting anxieties about working with people with learning disabilities as a PWP, where sessions limited to four-six 30 minute appointments, all four PWPs indicated 'step-specific' training would be helpful:

*I think training specific to the steps as well because I think it will be different too* (Jasmine: 'Skilled Workforce')

Eight clinicians requested that the service provided better clarity on policies and its remit regarding people with learning disabilities:

...that could be something that could be rolled out in terms of training, like "This is what we do", "This is the way that we work", and erm...I mean, this is a sort of stupid question, but again shows my level of sort of not really knowing, but, what would be the sort of exclusion, like, if there is some exclusion criteria, what would it be? What would, like, well severe, then that's understandable, but when it's the mild to moderate let's say? Well what is that? (Emma: 'Equalities')

Relatedly, seven requested clarity on what the 'LD label' represented. Several noted this would enable more accurate monitoring/auditing of access and the effects of reasonable adjustments. As one clinician noted:

I'm guessing LD isn't being labelled properly, which means it will be really hard to audit the data, it will be really low quality...I would be a little bit squeamish about putting down 'LD'. (Anthony: 'Monitoring')

Also in line with service-user recommendations, nine clinicians referred to reasonable adjustments in the form of more accessible forms of communication. Some suggestions were quite broad:

...definitely improve, just by having some easy to read materials or materials that appeal to other senses besides just reading. (Ben: 'Accessible Information')

Mostly, acquiring more accessible communication referred to adapting existing service documents and "obviously the website as well" (Nancy: Accessible Information'). A further reasonable adjustment based service-level recommendation possibly proposed to manage uncertainties regarded the restrictions placed on therapy session duration. Many clinicians spoke of this as an impediment to their work with people with learning disabilities, and therefore, a need for this to be more flexible. As one PWP remarked:

I have tried to do 30 minute sessions with a lady [with learning disabilities] and it was tricky...some people might need less time and some people might need more time... (Jasmine: 'Skilled Workforce')

Another clinician indicated that the restricted time IAPT clinicians have available *between* sessions might make working with people with learning disabilities harder. This again implies a need for the service to allow greater flexibility when working with this population.

...suppose it's having more space as clinicians to do that creative work that you need to do with people with LD, so to make things more accessible in terms of information, in terms of psycho-education materials, you sort of need the extra time as a clinician to be able to...do that effectively. (Harriet: 'Accessible Information')

Pre-access reasonable adjustments were also noted by seven clinicians as a means to improve access.

...what do we have that is accessible for them at that stage, not at this stage, where they can ask for help, basically before that stage (Emma: 'Staff Attitudes')

Also relating to pre-access adjustment and further echoing service-user suggestions, five clinicians suggested more could be achieved to promote that the service did work with people with learning disabilities.

...there needs to be something a bit more transparent about the fact that we are open to [working with people with learning disabilities]. I think maybe just on the website like, 'call us

if you need this and this' and 'if you have difficulty reading this page'...maybe a leaflet that says you know, 'having difficulty reading?' (Emma: 'Accessible Information')

Better advertising was also linked to increasing the number of people with learning disabilities accessing the service, and thereby having the potential to increase clinician's confidence.

... if there were more people referred... by getting more people in, more people would feel more confident and it would improve even further. (Amy: 'Staff Attitudes')

The final discourse regarding how the service could improve appeared to reflect clinician's wishes to have permission to not feel comfortable, or not want to work with people with learning disabilities:

... something that will helps us we feel confident saying 'I don't get it'...I think it's important to have permission to know that it's not always going to go well. (Anthony: 'Eligibility, Access')

...there should be a space for other kind of discourses on working with learning difficulties. I mean, I think that would be quite hard to say, "Actually I don't want to work with this group of people" (Ben: 'Staff Attitudes')

As well as a desire to increase the level of specialist knowledge of this area within the service, suggestions made by three clinicians to recruit specialist practitioners may further reflect the uncertainties some clinicians had about themselves working with this group. One clinician commented:

...going right back to the recruitment phase is, like putting in advert, in particular looking for people that have these specialist interests, because I think that otherwise you know, you might not be attracting the right people... (Nancy: 'Skilled Workforce')

Perhaps these comments tied into clinician's sense of feeling ill-equipped noted earlier, and the following subtheme regarding working with people with learning disabilities not being a primary objective within IAPT.

### 3.2.2.4 Subtheme four: LD is not our core business

The final subtheme reflected references to learning disabilities not being the service's or IAPT's "core business" (Ben: 'Eligibility, Access'), or as one clinician noted:

...my initial thought was just like, people feel so far removed from that, I think people don't see it as part of their core job. (Nancy: 'Research')

Such allusions were implicit and explicit across clinicians and domains. Sometimes this was with clear reference to learning disabilities not being a priority within the service and/or IAPT in general.

... I suppose our leaders, I don't know to what sense they are involved or, to, what priority this is for them, probably not that much... it's not on top of the to-do list (Nancy: 'Leadership')

Some clinician's doubts about the feasibility of working effectively with people with learning disabilities linked more broadly to what might be considered IAPT ideologies.

... when you've got high pressure, high volume services, people under pressure, umm, can you expect if you say "I need hour long instead of 30 minutes", or "I need an hour and a half session instead of an hour"...in practical terms is not always doable... (Anthony: 'Equalities')

When I think about the context of what IAPT is actually trying to do, it's trying to reach out everywhere, it is very hard to be aware of everything all the time. I think as clinicians we don't have the headspace to, all the time for that...there has to be a limit. (Joe: 'Local Plans')

Four clinicians linked limitations in IAPT to budgetary constraints, overstretched resources, and time pressure, as one clinician noted: "...obviously with money and time these things aren't always feasible" (Rachel: 'Employment Support'). There were consequential repeated references to learning disabilities being of less significance in comparison to "competing demands" (Nancy: 'Research'),

...people with LD are not talked about in general terms by all staff, and you know accessibility, is not kind of in current parlance, I guess you know we all talk about wheelchair accessibility or BME and that kind of thing, loads of initiatives on that, but, these, it just feels like this is something on its own that you guys are working on. (Harriet: 'Staff Attitudes')

Thus, several clinicians made references to the dilemmas of prioritising limited resources.

...it's a question of deciding where the balance lies, how detailed do we want it to be? We have to be pragmatic about this, training costs money and where do you deploy limited resources? (Joe: 'Skilled Workforce')

Nine clinicians proposed that 'learning disabilities' would need to be prioritised for changes to occur.

...obviously, we need an understanding at the higher levels, otherwise, things get messy on the ground...Maybe build in LD into targets? (Anthony: 'Equalities')

Whilst most clinician's responses appeared to express tensions between their desires for equality and the practicalities of attaining this within IAPT, it appeared that senior clinicians were slightly more sceptical about the realities of learning disabilities becoming a priority in the face of competing demands.

... just skilling the whole team up...so it raises people's confidence, but, the 'but' part of this is there are so many competing... and when it comes to deciding how to carve up the time... there are always items that get dropped (Ben: 'Eligibility, Access').

#### 3.3 Phase two: Implementation

Through the discussions with participants, the IAPT service's Clinical Leads and CLDT Psychologists, it became clear that recommendations for improvement fell broadly into 'training' or 'non-training' related areas. For the training related recommendations, a training plan was made in collaboration with service user and clinician participants', the service's LD Champions, and local CLDT Psychologists (Appendix 22). This was reviewed and agreed to with the service's Clinical Leads before being implemented. For the non-training related recommendations, a further table highlighting suggested improvements was completed with the support of service user and clinician participants, the service's LD Champions and CLDT Psychologists. This was also reviewed with the service's Clinical Leads, where it was agreed which actions could be implemented, by whom and when (Appendix 23). What follows, provides an overview of the actions taken within the six-month time-frame (July- December 2015).

### 3.3.1 Implementation of training related recommendations

Three half-day training events delivered in collaboration with clinicians within the IAPT service and local CLDT occurred. As depicted in the training overview (Appendix 22), the training events aimed to reflect suggestions made by service user and clinician participants in phase one. All events additionally, and more implicitly, aimed to increase clinician's confidence and promote the idea that IAPT can work with people with learning disabilities. The first event was designed for and attended by PWPs, HI's and senior HI's and employment support staff. Administration staff were invited, but were unable to attend. This training aimed to provide an introduction to working with people learning disabilities in IAPT. It covered areas such as: 'What is a learning disability?', 'How to ask questions that might suggest that someone has a learning disability', 'Who is suitable for IAPT?' 'Who are the CLDT and what do they do?' and 'Safeguarding people with learning disabilities'. As suggested by clinician participants, the next two training events were 'step-specific' clinical skills workshops, offering more practical advice on working therapeutically with people with learning disabilities. The first workshop was designed for and attended by PWPs and the second was designed for and attended by HI Therapists. These workshops covered areas such as: 'Possible obstacles and how to overcome them', 'How to make your own easy read documents', 'Case study: Working with someone with a learning disability in IAPT', and 'The evidence base so far'.

Over 40 IAPT staff, including clinicians from neighbouring boroughs attended these training events. In order to assess pre- and post-training confidence levels of those who attended, permission was provided by Dave Dagnan to administer the Therapy Confidence Scale-Intellectual Disabilities (TCS-ID; Dagnan et al., 2015) before and after each event. Quantitative data from completed TCS-ID questionnaires were not statistically analysed, although measures showed consistent overall improvements in attendees reported confidence levels post-training. Post-training confidence is discussed further in phase three of the results section. Further anonymised feedback was sought after each training event through an e-survey. As shown in Appendix 24, feedback was largely positive. Recommendations for improvements to the training from each event were implemented in the following event, such as making the training more interactive and ensuring more time for discussions.

#### 3.3.2 Implementation of non-training related recommendations

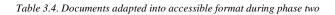
A major action point under this category was the adaptation of 20 key documents used within the service into a more accessible format. As shown in Table 3.4. these included marketing materials, assessment documents, IAPT approved clinical measures, risk documents and therapeutic materials (see also Appendix 25 for a selection of adapted documents). People involved in adapting these materials included service user and clinician participants, non-participant clinicians as well as a psychologist from the CLDT.

Feedback on all adapted documents was sought from service user and clinician participants not involved in their creation, a local speech and language therapist and CLDT Psychologists (appendix 26). Further refinements were then made before the adapted documents were disseminated within the service and shared electronically with two other London IAPT services. Adapted promotional materials were distributed by service user and clinician participants to local services including GP surgeries, the CLDT, third sector LD services and a local college. An easy read overview of what the service offered was also added to the service's website.

In addition to the 'in-house' adaptions, the service's Clinical Leads approved service funding to purchase published easy read CBT materials and documents on mental health which were disseminated within the service. A 'quick reference guide' to working with people with learning disabilities in IAPT, produced by an LD Champion, based on the training events and LD-PPG (2015) was similarly disseminated within the service and to other local IAPT services. To further raise awareness within the service, the Lead Researcher presented an overview the action research project

in a bi-monthly 'whole team' meeting; it was further agreed that a bi-annual slot would be dedicated to this to maintain awareness within the service.

PROMOTIONAL MATERIALS	THERAPUETIC MATERIALS
Service Poster	Hot cross bun/ Five Area Model
Service Leaflet	Thought record
Service Website	Graded Hierarchy
ASSESSMENT MATERIALS	• What is CBT?
Triage Script	FEEDBACK DOCUMENTS
Therapy Contract	Patient Experience Questionnaire –post assessment
MEASURES	Patient Experience Questionnaire- post treatment
• Minimum Data Set (IAPT, 2011)	RISK/ SAFEGUARDING
• Social Phobia Inventory (Connor, Davidson, Churchill et al, 2000)	Risk Assessment
• Penn State Worry Questionnaire (Meyer, Miller, Metzger & Borkovec, 1990)	Safety Plan
• Impact of Events Scale- Revised (Weiss & Marmar, 1997)	Emergency Contact Card
• Health Anxiety Inventory (Salkovskis, Rimes, Warwick & Clark, 2002)	



Further non-training related actions included the production of bigger, clearer signs (e.g. '*waiting room*', '*way out*') to make navigation of the main IAPT services building easier. With a view to better support friends, families and carers, a 'Carers of People with Learning Disabilities' workshop was also established by non-participant clinicians. A specific 'learning disability safeguarding pathway' and an 'LD Safeguarding Lead' were also established. Recruitment advertisements were also adapted

to highlight a desire for those with a specialist interest in working with people with learning disabilities.

## 3.3.2.1 Working Together

With regards to improving joint working with other agencies, meetings were held with the IAPT service's in-house employment support team to discuss how they could best support people with learning disabilities. This led to improved links (via a clear referral pathway) between the IAPT service's employment support team and third sector learning disability training and employment services. Furthermore, quarterly meetings for three IAPT services LD Champions, and their associated CLDT-IAPT Leads were set up with a view to share ideas about implementing good practice according to LD-PPG (2015) and GLTK (2013). Also as a result of this project, a referral pathway was established with the local Higher Functioning Autism service and plans were made for further training to be carried out on working with people with higher functioning autism in IAPT within the service.

# 3.4 Phase three: Evaluation

## 3.4.1 Phase three: Services users' results

As shown in Table 3.5, service users' post-implementation GLTK (2013) ratings indicated that most domains had been improved upon as indicated by a slight increase in the number of green ratings given to the different domains, and associated mean scores, and decrease in the number of red ratings given when compared to ratings givens pre-implementation. The third domain that showed a decrease mean score was 'Friends and Family'. One participant gave a red score for this as they did not feel the 'Carers of People with Learning Disabilities' had been adequately advertised.

As depicted in Table 3.6 analysis of service users' transcripts from phase three revealed two higherorder themes: 'Better', with the associated subthemes of 'Adaptations' and 'Staff Attitudes', and 'More work', with the associated subthemes of 'Recommendations for clinicians' and 'Recommendations for the service'.

		S	ervic	e use	Phase one mean	Phase three mean								
Domain					Plann herin		Pha	ase th	ree-					
Eligibility and Access	?												4	3.8
Safeguarding							?						3.6	4
Assessment													3.3	3.8
Equalities							?						3.3	4
Staff Attitudes													3.8	3.8
Accessible information							?						3.3	3.8
Research							?						3.3	4
Local plans	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Skilled workforce	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Service user involvement							?						4	4
Psychological Therapies													3.1	3.8
Working together	?												3.8	4
Buildings and environments													3.3	3.6
Leadership	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Friends and family													3.6	3.5
Employment support	?												3	3.6
Checking services	/	/	/	/	/	/	/	/	/	/	/	/	/	/
Monitoring	/	/	/	/	/	/	/	/	/	/	/	/	/	/

Table 3.5. Service users pre and post phase two (implementation) GLTK ratings, means scores.

Key:		
Response	Meaning	Numerical value used to calculate mean
_		score
?	Unsure of answer	0
Grey	'In the garage, not yet started'	1
Red	'On the journey, but stuck at red'	2
Amber	'Ready for more'	3
Green	'Continuous progress'	4
/	Domain was not asked about	/

Higher Order Themes	Subthemes
1. 'Better'	1. Adaptations
	2. Staff attitudes
2. 'More work'	1. Recommendations for clinicians
	2. Recommendations for service

Table 3.6. Phase three service user higher order themes and subthemes

## 3.4.1.1 Service user theme one: 'Better'

All service user participants indicated that they felt the service had improved since phase one, one service user observed:

*It's doing well, the service is better...much better, it's improving a lot.* (Clara: 'Service-user Involvement')

Areas of improvement noted by service users were varied, and inevitability linked to actions taken during phase two and GLTK (2013) domains. As depicted in Table 3.5, improvements were most notable in the domains 'Psychological Therapies', 'Working Together' and 'Employment Support'. Indications of approval, or recognition of progress also occurred several times with reference to training, service-user involvement and friends and family support.

### 3.4.1.1.1 Subtheme one: Adaptations

Three service users indicated their approval of the actions taken to adapt existing documents used within the service.

...like the resources, like so the sheets are important, like the worksheets are really good, easy read stuff is really good (Jade: 'Accessible Information')

Service users also seemed appreciative of the changes that had taken place with a view to increase access to the in-house employment service.

... it's good that you're doing like supporting people with learning disabilities get into jobs... (Jade: 'Employment Support')

Two participants spoke favourably of the changes that were taking place regarding service user involvement to help improve the service for them, one noted:

...because, what you, you, you requested, you aware, what was outstanding, and you let people make, let people make, aware, with everything (Sally: 'Eligibility, Access')

There were further encouraging references to the IAPT services increased endeavours to work with local LD services. When asked whether she thought the IAPT service worked well with other services, one service user, who had attended a series of accessible assertiveness workshops offered by IAPT in collaboration with a local LD service after phase two, commented:

I believe so, from what I seen when I go to the [assertiveness] workshops. I think they work together, cause we have a laugh as well. Cause last time, when we did the workshop about assertiveness... (Kayleigh: 'Service-user Involvement')

# 3.4.1.1.2 Subtheme two: Staff attitudes

Three service users referred to what they felt might be a positive shift in staff attitudes and ability to understand people with learning disabilities as a result of the training in phase two:

... because now with the training for the staff here the therapists to support, also the lovely people at reception too, how they talk to people if they have a learning disability, they are always welcome here...you actually now know the way you can talk to people with disabilities (Jade: 'Staff Attitudes')

As depicted above and below, this positivity was also extended to administration staff:

I say 'I'm here', I can't get my word out, 'I have an appointment', and they say 'come in', and they give me the questionnaire, and they say 'here you go', and all that, and they, they know it's the easy read one, think they have a list or something, and they don't seem nervous...I think, they treat me well. (Kayleigh: 'Staff Attitudes')

A further two service users stated that they felt staff attitudes had improved as a consequence of this project, but did not greatly elaborate on why they thought this was.

...yeah, because you're doing everything, understanding, the staff know how to behave with people (Sally: 'Staff Attitudes')

This may be attributed to the structure of the interview schedule as guided by the GLTK (2013) which did not allow much scope for responses to be expanded upon. Alternatively, this might have been because some service users were not fully aware of the ways in which staff attitudes might have changed. Another explanation for why some service users did not elaborate in their responses on how staff attitudes had, or might improve further, could be that they were unsure what to say about this

following the summary that had been provided to them of what had occurred in phase two. When asked how staff attitudes might be improved, one service user responded:

You basically said all of it. (Alan: 'Staff Attitudes')

# 3.4.1.2 Service user theme two: 'More work'

As in phase one, suggested improvements could be subcategorised into further recommendations for clinicians, which included increasing their awareness of learning disabilities broadly, learning more about individuals, and consideration of their attitudes towards them, and further recommendations for the service, such as additional reasonable adjustments and extending service promotion.

3.4.1.2.1 Subtheme one: Recommendations for clinicians

One stream under recommendations for clinicians could be term 'improving awareness', be it on a practical level with regards to learning more about learning disabilities, as noted by three service users, for example:

...probably have a bit more, like, understanding....like, what the disability is, and like research on like, how, if there's anything that you can improve with them? (Alan: 'Assessment')

Or on a personal level as noted by two service users:

I think, what they need to do, I mean, all therapists, they need to, umm, get to know us better... Like get to know us, like, know us more. (Dena: 'Staff Attitudes')

Erm, ask people questions about their disability... to know them more...What sort of disability do we have? Erm, is it like a mental disability, learning disability, asking like, questions! (Clara: 'Assessment')

Equally indicating a need for clinicians to be aware of an individual's needs in terms of planning for sessions, one service user suggested clinicians prepare administration staff better with the adapted version of the MDS:

Give them the names...which one is the learning difficulties (Dena: 'Assessment')

These suggestions may have been proposed because service users felt that this area had not been adequately addressed during phase two, or perhaps because of previous experiences, where they had perceived 'learning disabilities' was not well understood by mainstream clinicians. Another explanation for this might be that better awareness and understanding of individuals could positively influence idiosyncratic treatment plans, which may then be shared with other services:

...make an action plan for people with disabilities, which they can actually use within the youth service and then follow it through, and understand a bit more what that persons going through and what they don't, like, do and do not like... (Jade: 'Working Together')

In keeping with the suggestion to share what is known with other services, further recommendations for clinicians included ongoing joint working with other services:

... you could get all the staff together so they could help you know a little bit more around people with learning disabilities...like go over to [LD service X] or [LD service Y] and do the same thing with both of them and if there's young people there that are mentally not able to cope and get really stressed out and like anxious and you've got and they can learn a technique and way of dealing with it (Jade: 'Working Together')

One service-user also appeared to indicate that joint working may aid the sustainability of the project:

...to improve it again, I think you should, um, talk to, work together...all the different teams, the doctors, everyone...That's to improve it long period. You know, you're all doing same work. (Sally: 'Working Together')

As in phase one, increasing awareness of learning disabilities also often overlapped with a requirement for clinicians to acknowledge individual differences. One service user indicated how training on working with people with learning disabilities may aid this awareness:

*Just training and understanding people...Training, yeah. Cause everybody got different needs* (Sally: 'Equalities')

At times, increasing staff awareness coincided with improving staff attitudes. There were two key areas regarding improving staff attitudes; patience and confidence. Three service users implied a need for clinicians to be more patient with them.

Yeah, be aware, people with learning disabilities because they got, can get mood swings...and the staff have to be aware and patient (Sally: 'Accessible Information')

# 3.4.1.2.2 Subtheme two: Recommendations for the service

Three service-users recommended that the service disseminate promotional materials more widely in the community. Perhaps suggesting a desire for access to IAPT be made more obvious and simpler,

two highlighted this with reference to the services openness to people with disabilities, as well as how to refer.

Hand out leaflets...On the streets, to let, so they know if they have anyone disabled or anything, let them know there is a place they can go to...or stick them up like on some walls...people see about it... Erm, maybe basically, or in [the borough] you know on the lampposts and stuff...coz then people see the leaflets, call that number and stuff (Clara: 'Eligibility, Access')

Although acknowledging the progress made regarding promotion of the service, one service user proposed additional alternate visual modalities of advertising that may be more accessible and appealing to people with learning disabilities.

...you've done booklets and that but also you could probably as well do a little like film as well about [IAPT]...basically a film of like what the service provided for, and basically much more visual stuff like that for people with disabilities. (Jade: 'Equalities')

Another service user indicated a need to make further adaptations to the adapted MDS. Her comments highlighted one of the potential barriers to IAPT being the requirement to complete this measure before each session.

*P*: ...there's one [questionnaire] that says 'in the past two weeks' and I can't remember what happened, like yesterday! So that's hard to remember what happened two weeks ago!

I: So what could we do to improve?

P: Put 'in the past week' (Kayleigh: 'Accessible Information')

Similar reasonable adjustments noted in phase one were proposed, including flexibility with sessions, as one service user suggested:

...if people need more sessions, they can have more sessions, if they want to be like that, because, I know, some people wants sessions and less sessions. (Dena: 'Equalities')

Alternative forms of communication, were also noted by four service users, including "sign language" (Dena: 'Accessibility').

One of the few recommendations made in phase one by service users that was not implemented during phase two was making the main IAPT service's base fully accessible to wheelchair users. It was explained to service users that this request was not carried out because there were clinic spaces downstairs. Nonetheless, four service users continued to insist that the entire building be made accessible.

...make sure they put the lift in there...somehow...with the, what if the erm rooms are full downstairs? ...because they could like, you could eventually see someone in a wheelchair and like, you know...and the rooms are full downstairs and can't get in there, you need to, like get in somehow. (Clara: Buildings, Environments)

It was interesting to see this strongly insisted upon by four service users, none of whom had difficulties with stairs. The ongoing request for a lift or 'chair lift', perhaps reflected service users desire for equal access for those with physical disabilities, as well as learning disabilities, and the refusal to make the upstairs of the building fully accessible was perhaps reflected a concrete, visible example of how this had not been achieved.

Some service users also requested that they and their supporters be helped by the service, and kept involved with and informed of service developments. Suggestions included "A talking group" (Dena: 'Research') and "Leaflets" (Sally: 'Friends and Family'). One service user suggested that their supporters being included in their care.

...not just only one person to speak and then the others. ... I mean, I know, some people don't want to umm, to talk with learning difficulties but, that that be helpful, for us and for them, to speak (Dena: 'Staff Attitudes')

# **3.4.2 Phase three: Clinicians' results**

As can be seen from the higher number of 'green' or 'amber' GLTK (2013) ratings and mean scores in phase three, comparable to the initial data gathering in phase one (Table 3.7), the improvement in clinician ratings post implementation was more noticeable than service users'. In terms of statistical increase, the greatest improvements occurred in the domains of 'Assessment', 'Accessible Information', 'Skilled Workforce', 'Service user involvement', 'Buildings and environment', Friends and Family' and 'Employment Support'. Interestingly, the only domain that saw a slight decrease in mean score was 'Research'. This may be due to some participants becoming more conscious of the need for further work in this area and the importance of it being appropriately disseminated.

...we need to do more audits....have up-to-date literature for recommendations regarding its application. (Nancy: 'Research')

The greater increase in pre-post scores from clinicians compared to service users may be a due to the comparably lower ratings clinicians gave in phase one. This might also be due to clinicians being more aware of the changes that had occurred during phase two as a result of working within the service, thus witnessing the changes 'first hand'. The reduction in '?' (i.e. unsure the answer) suggests

an increase in awareness of how the service fared in relation to the GLTK (2013), whilst the lack of grey scores suggests that no clinicians thought that no progress had occurred in any of the domains.

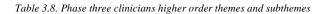
Domain	Clinicians pre and post implementation GLTK scores																			
		Phase one- Planning and data gathering										P	has	se t	hre	n	Phase one	Phase three		
Eligibility and			8																3.2	3.5
Access																				
Safeguarding																			3.3	3.6
Assessment	?																		2.3	3.7
Equalities																			3	3.5
Staff Attitudes																			3.2	3.3
Accessible information	?																		2.4	3.4
Research																			3.5	3.2
Local plans	?																		3	3.6
Skilled workforce	?											?							2.1	3.6
Service user involvement	?	?																	2	3
Psychological Therapies	?											?							2.2	3.6
Working together	?											?	?						2.2	3.7
Buildings and environments	?											?							1.6	3.2
ership																			3.1	3.8
Friends and family																			1.8	3.4
Employment support	?	?	?																2.2	3
Checking services	?																		2.5	3.2
Monitoring	?																		2.6	3.2

Table 3.7: Clinicians pre and post phase two (implementation) GLTK scores

Response	Meaning	Numerical value used to calculate mean score
?	Unsure of answer	0
Grey	'In the garage, not yet started'	1
Red	'On the journey, but stuck at red'	2
Amber	'Ready for more'	3
Green	'Continuous progress'	4
/	Domain was not asked about	/

As shown in Table 3.8, three higher-order themes were identified from the analysis of clinician's transcripts in phase three. It is worth noting that the structure of these interviews were weighted toward eliciting further suggestions (rather than reflecting on progress made), hence more was discussed in terms of moving the project forward compared to actions that had been implemented. The first two higher-order themes closely mirrored those identified by service users during phase three. The third theme encompassed uncertainties about how realistic it was for IAPT services to effectively adapt.

Higher Order Themes	Subthemes
1. Making progress	1
2. Auxiliary recommendations	1. Ongoing commitment
	2. Better involvement
	3. Better working together
	4. Further need for clarity
	5. Increase exposure to increase confidence
3. Can IAPT Adapt?	1. Limits to flexibility
	2. Need for a 'cultural shift'



### 3.4.2.1 Clinician theme one: Making progress

Nine clinicians remarked on the overall progress made with the project. Specific praise was given for the manner in which it had been carried out, and in terms of the increase in clinician's confidence that had occurred as a result:

I think it's an amazing piece of work, in terms of thoroughness...I think the rigor with which you're going through this is really important, in terms of prospectus. I'm really impressed- I think it's useful that we're doing it this way, because then we'll have direct comparison with models like [NHS LD service] (Harriet: 'Monitoring')

There is definitely an increase in awareness... beforehand, it was like walking on egg shells...I didn't know how to approach this and I didn't want to offend anyone, I feel now it's

okay to say "I'm not sure how to ask"...for me, that's been really good. (Amy: 'Eligibility, Access')

Six clinicians indicated training had aided awareness on a practical level, for example by understanding how to make and use, thus feeling more confident with easy read documents, and also in terms of feeling better equipped to assess and manage safeguarding concerns. Furthermore, the training appeared to have lessened some clinicians concerns about making errors and accountability:

There has been a big shift, I feel more supported around this now...I feel less concerned about saying the wrong thing, I feel there is a lot less of a blame culture now... (Amy: 'Safeguarding')

Eight clinicians spoke favourably about having more clearly identified 'LD Leads'.

I think now we've got named people and that's important, because you can't hold everything in your head all of the time, as long as there is a clear pathway of where to get more information... (Anthony: 'Safeguarding')

Potentially, increased awareness of the service points of contact for learning disability related issues positively correlated with the clinicians increased confidence levels; knowing with whom to speak perhaps decreased a possible sense of isolation when working with this client group and thereby, the risk of getting things wrong and being "blamed" for doing so. Additional developments concerned better and clearer reasonable adjustments, joined up working with other services, and the inclusion of friends and family within the service. Eight clinicians commented on the service working better with the CLDT. For many, comments represented a sense of their simply being more familiar with this team.

It feels good in terms of them making themselves aware, they came to the training... (Joe: 'Working Together')

## 3.4.2.2. Clinician theme two: Auxiliary recommendations

Clinicians unanimously asserted further developments could be made to improve the service for people with learning disabilities. Responses to questions about how the service could improve further particularly reflected ideas about maintaining and continuing progress. In some cases, this was a broad need for an ongoing commitment through sustaining awareness of this project within the team. Overlapping sustainability but warranting separate subtheme status, were proposals regarding: enhanced joint working, better involvement for service users and their supporters, further clarity surrounding service policies, and a continued need to increase "exposure" to people with learning disabilities to increase clinician's confidence levels.

#### 3.4.2.2.1 Subtheme one: Ongoing commitment

Every clinician suggested ongoing commitment was required to maintain and continue progress and most means of achieving these reflected areas highlighted by service users. For example, four clinicians indicated promotion could be further improved. Examples of this included ensuring referrers were aware of the changes that had occurred through this project.

...[we should be] highlighting what we have done to make the service more accessible (Priya: 'Service-User Involvement')

Also echoing service user's suggestions were many references to adapted materials being more widely available by putting them online, and to "…look into the possibility of obtaining audio materials" (Ben: 'Accessible Information'). Six clinicians suggested further documents be adapted, including "appointment letters" (Tanya: 'Assessment'). Another suggestion akin to service-users' recommendation was making adaptations beyond easy read.

[adaptations] needs to be at every level of the service, including accessible voicemail messages. (Nancy: 'Accessible Information')

Nine clinicians inferred a need for ongoing training to aid the project's sustainability.

We can't just offer the training once, things change. (Anthony: 'Skilled Workforce')

Frequent suggestions regarding training included making this mandatory and more experiential. Most clinicians highlighted providing further support for non-clinicians, namely the administration team.

*...training for admin...make them aware of what they can do at first contact* (Emma: 'Buildings, Environment')

This was possibly a result of the clinicians seeing the comments made by service users in phase one during the 'member checking' about their experiences with the administration team.

Six clinicians stated that the changes that had occurred during phase two needed to "stay in people's mind" (Jasmine: 'Working Together'). Six clinicians put forward specific suggestions reflecting this, including "email updates" (Tayna: 'Friends and Family') on further progressions and "reminders to use labels and easy read materials" (Priya: 'Monitoring'). As highlighted below, many also referred to the importance of having several clinicians involved to aid sustainability.

...think making sure that that leadership role is sustainable within the team, so it's not just one person, and then if that one person leaves...so kind of continual training up of individuals. (Harriet: 'Leadership') These comments perhaps reflect concern that the progress that had occurred might not be upheld once this study was completed. Six clinicians also suggested a need for ongoing progress reviews in the form of auditing, dissemination of findings and their applicability to practice. Also in regards to monitoring progress, four clinicians highlighted the importance of having a space to discuss and feedback on their experiences of working with people with learning disabilities:

...we need a mechanism for feeding back how people are feeling, confidence-wise, (Harriet: 'Psychological Therapies')

When considering further improvements to the in-house employment service, six clinicians alluded to the developing and supporting this to improve the service they are able to provide for people with learning disabilities.

...check in with [employment support] about how they are doing with this. (Tanya: 'Employment Support)

The above comments could reflect some of the uncertainties noted in phase one, and/or an increase in clinicians' awareness of the intricacies involved in developing IAPT for people with learning disabilities and how this may effect staff going forward.

## 3.4.2.2.2 Subtheme two: Better involvement

Almost every clinician spoke of how more could be achieved to include service users and their supporters. Alluding to and expanding on the concept of monitoring progress to better the service, as noted above, the majority of clinicians spoke about enhancing service user involvement, such as through their inclusion with the auditing process, or with provision of feedback:

...get general feedback from service users about their experience of the service, like, how we deliver the service maybe, particular forums. (Emma: 'Checking Services')

However, perhaps suggesting doubts about how inclusive the service may be going forward, or awareness of power struggles faced by this client group, four clinicians expressed uncertainty as to whether people with learning disabilities ought to be included in the service's existing service user forum, as illustrated below:

...maybe a service user forum for 'minority' groups...when I think about power in conversations with the mainstream, they might not get their voices heard. (Ben: 'Equalities').

Possibly suggesting some further uncertainty about how best to adapt to meet the needs of people with learning disabilities, three clinicians suggested eliciting service user feedback to improve in the domain of 'Buildings and Environment', for example:

# *I suppose one of the key things would be to ask the service users directly.* (Harriet: 'Buildings, Environment')

The other strand of 'involvement' and elaborating on suggestions made by service users and clinicians in phase one regarding offering support for carers of people with learning disabilities, three clinicians proposed further developing this, for example, by finding out about "services for carers of people with learning disabilities in the borough." (Tanya: 'Friends and Family'). This perhaps indicates an increased recognition of the importance of supporting carers of people with learning disabilities beyond a one off 'Carers Group'.

## 3.4.2.2.3 Subtheme three: Better working together

Continuing with the idea of acknowledging and involving wider systems, every clinician suggested ways in which the service could enhance joint working. These suggestions broadly fell into three categories: better communication with the CLDT, working with services beyond the CLDT, and forming local strategies. Regarding the CLDT, three clinicians commented it would be helpful for contact with the CLDT to be simpler:

I think we need to have names of key [CLDT] people in common areas...like an A4 page with key links and contact details on it (Emma: 'Working Together').

This comment is somewhat reminiscent of a comment made by anther clinician in phase one pertaining to the difficulties she experienced trying to make a referral to the CLDT. Both comments are indicative of a desire for joint working to be particularly convenient, perhaps due to the limited time IAPT clinicians may have.

Although most clinicians commended the progress that had occurred regarding joint working between the IAPT service and CLDT, two noted that this had not necessarily extended to other local services:

I don't think the same is true of the links with CMHT, and how they might work with people with a learning disability. (Harriet: 'Working Together')

Accordingly, seven clinicians suggested further joined up working could be achieved with other local mental health and learning disability services. Again, possibly for reasons of convenience and ease due to time constraints, suggestions such as "getting more people from the outside to come in" (Jasmine: 'Skilled Workforce') were put forward by four clinicians. However, two clinicians inferred joint working could be enhanced by clinicians from the IAPT service going into other services to talk about the changes that had occurred through this project, suggesting a willingness to 'reach out' as well. Propositions included giving "promotional service talks to the LD team" (Priya: 'Eligibility,

Access') and speaking to GPs and other professionals, "just letting them know what we have been doing" (Nancy: 'Eligibility, Access').

Also under the umbrella of better working together, two clinicians suggested further improvements could be made within the domain of employment support.

Joined up care between [employment support] and LD employment services. Have a list of accessible employment services...and have this on shared drive. (Priya: 'Employment Support')

Finally, and overlapping ideas regarding enhanced 'Working Together', five clinicians indicated that the service could improve further by strategising with local services, "In terms of where you want to go locally with the developments" (Harriet: 'Local Plans'). This perhaps also underscored earlier mentioned notions of sustainability.

### 3.4.2.2.4 Subtheme four: Clarity

Two reoccurring areas that clinicians reported ongoing uncertainty about, and need for clarity on, were the 'LD label', and the duration and number of sessions that they could offer people with learning disabilities.

Despite efforts to clarify what the 'LD label' represented in the whole team training, and a subsequent email reiterating when and how to use this, five clinicians continued to indicate uncertainty about this.

Auditing is really important...this will require clarity around LD diagnoses and label (Jasmine: 'Research')

With the LD label, I think we need to be clear about what this means. (Priya: 'Checking Services')

Potentially, this reflected fears of making errors of using this label as were alluded to in phase one by clinicians. As has already been stated, four clinicians highlighted concerns about the label being used incorrectly, and the implications that this could have on data collection and the effective monitoring of progress.

... for logistical reasons in terms of checking services because of the label. If we don't have any accurate valid data, we can't, check what we're doing, so it's kind of the step before that needs to be clarity... we don't have this label undoubtedly, so actual, kind of statistical checking isn't possible. (Harriet: 'Checking Services') The other major area of ongoing uncertainty concerned the number of sessions clinicians could offer people with learning disabilities. Four clinicians spoke about their desire for more precision on this:

...we need clearer guidance on the upper limit of session numbers. (Nancy: 'Psychological Therapies')

However, most clinicians who spoke about this did so with reference to a need to individualise reasonable adjustments, seemingly appreciating there could not be any 'hard and fast' rules about the number and duration of therapy sessions:

...it needs to be on a case by case basis – some may need longer appointments; other people need shorter appointments due to a lower attention span. (Jasmine: 'Equalities')

This perhaps suggests an increase in awareness of the heterogeneity within this client group.

3.4.2.2.5. Subtheme five: Increase exposure to increase confidence

Resonating with the cycle (Figure 2) described in phase one: clinician results, four clinicians explicitly stated that increased confidence would require increased 'exposure' to people with learning disabilities.

Because of this lack of exposure and lack of practice, there's still this uncertainty. (Harriet: 'Staff Attitudes')

Also as mentioned in phase one, some clinicians expressed doubts about increased exposure becoming a reality in IAPT.

More exposure and more experience...I don't really know how you can force that to happen, I guess the more referrals we have, we will naturally get more exposure... but I don't know how realistic that is. (Anthony: 'Equalities')

Such comments thus reiterated the tautological nature of the issues and the cycle described in phase one; clinicians felt they were unlikely to feel confident working with people with learning disabilities until they had gained experience in this. As detailed in theme three below, many clinicians perceived attaining this exposure was dependent on service leads and commissioners prioritising learning disabilities and allowing appropriate adjustments.

#### 3.4.2.3 Theme three: Can the IAPT model adapt?

The final theme, sub-categorised into 'limits to flexibility' and a "cultural shift" reflected clinician's uncertainties about whether IAPT, as a model, could sufficiently adapt to effectively meet the needs of people with learning disabilities.

#### 3.4.2.3.1 Subtheme one: Limits to flexibility

Although never explicitly asked about, every clinician spoke of what appeared to be their perceptions of the IAPT model itself posing a barrier to working with people with learning disabilities. Under this sphere were frequent discourses regarding limitations to IAPT's flexibility and associated concerns about how realistic it was for IAPT clinicians to work with people with learning disabilities within the existing framework.

I don't know how far we can do flexibility. Flexibility doesn't, as much as you want to say or pretend, it doesn't fit that well in an IAPT model, you can be flexible a bit, but there's a limit. (Anthony, 'Equalities')

Specific concerns spanned several areas including: buildings, "In terms of realistic adjustments, that's trickier." (Harriet: 'Buildings, Environment') and cancellation policies. One clinician noted:

*I think IAPT is indirectly discriminating with the DNA cancellation policy* (Tanya: 'Eligibility, Access')

IAPTs reliance on written materials was also identified by several clinicians as another possible practical barrier, for example:

It's quite a big project, isn't it? Make everything that we do accessible to that level. We do quite a lot (Joe: 'Accessible Information')

Although how you deliver the audio is a problem... I mean it's a lovely idea but practically not sure it'll work (Anthony: 'Accessible Information')

Echoing service users' concerns regarding the MDS, three clinicians expressed apprehensions about IAPT's insistence on using this standard, upadapted or adapted, unvalidated measure at every clinical contact:

... it's quite shocking that they haven't standardized measures for people with a learning disability (Harriet: 'Research')

Concerns about the limits within IAPT also extended to a sense of unrealistic expectations clinicians felt were placed upon them to work in ways beyond their capabilities.

Most PWPs feel under trained anyway- so once qualified, you're just expected to know how to work with people with learning disabilities. That's not feasible (Tanya: 'Skilled Workforce')

Appreciatively, six clinicians indicated unease about such expectations without corresponding means or adjustments in place to support these, and accordingly made references to a need for 'top-down' recognition and flexibility to carry out this work.

[commissioners] need to think about this population and not just the recovery rate. They need to let us make adjustments and think about how that might work... (Tanya: 'Skilled Workforce')

I think it's about head space and time... I think there's a healthy level of cynicism... It's not as though we have this spare time kicking around...I think it's more just uncertainty around what that would look like in practice... It certainly feels like more IAPT continues, the more it tries to take on but within the same level of resourcing. To make extra time for something would be nice but something else has got to give. There has not been much evidence or a proactive attitude from the top about, okay we're going to do more of that and do less of this. It doesn't seem to work like that, it just says, "Do more of that" (Joe: 'Staff Attitudes')

# 3.4.2.3.2 Subtheme two: 'Cultural shift'

Overlapping with perceived unrealistic expectations, many clinicians frequently alluded to a need for a "cultural shift" (Tanya, Eligibility, Access). Four clinicians proposed learning disabilities ought to be included in the IAPT training courses, "....it needs to be on the PWP curriculum" (Priya: 'Skilled Workforce'). Many also highlighted a need to validate adapted measures, and to improve communication with commissioners.

Discuss the impact of changes with the commissioners, so make sure that they understand the potential impact, and then for clinicians to have a quota of people with learning disabilities on their caseload and adjust the job plans accordingly so that it's spread evenly (Harriet: 'Equalities')

At the end of her interview, one clinician seemed to sum up the tensions felt and expressed amongst many clinicians during phase three:

I don't think it's an easy thing to do, I think we are a machine of sorts, that is expecting to have some kind of leeway ...it's not been happening as much as it should in practice, it's good...it sounds fantastic, the training was fantastic and that's all brilliant, but it's just making sure that in practice that it's done and kept that way going forward so they're not shaving off bits as we go along, it needs to be truly meeting the need... just thinking, umm, will IAPT, or can it adapt? Is it feasible? (Jasmine: 'Monitoring')

#### **CHAPTER FOUR: DISCUSSION**

#### 4.1 Overview

This study aimed to find out how well IAPT service users with learning disabilities and IAPT clinicians thought one IAPT service fared in relation to the GLTK (2013), what could be done to improve this, implement these suggestions, and then evaluate them. The following begins with a summary of findings and then considers in a successive fashion, the theoretical, clinical, policy and commissioning implications of these. There is then an overview of the studies applicability and dissemination to date. This is followed by critical review, including the study's key limitations and strengths and ends with a brief conclusion.

## 4.2 Summary of findings

The main findings in phase one were that both service users and clinician participants already felt that the service was 'Doing Well'. Within this theme, both sets of participants indicated that the service was 'Inclusive' in terms of offering talking therapies to people with learning disabilities. Service users, but not clinician spoke of 'Helpful Clinicians'. Clinicians, but not service users, emphasised some success the service 'Working Together', internally and externally. Service users and clinicians put forward recommendations for 'How clinicians could improve' and 'How the service could improve'. Whilst for service users, these subthemes were represented by the higher order theme 'Recommendations', for clinicians', these subthemes were represented by the higher-order theme 'Clinician uncertainty'. Phase one highlighted an additional two clinician-only sub-themes that also seemed to interplay with their uncertainty about working with people with learning disabilities in IAPT, these were feeling 'Ill-equipped' and 'LD' is not our core business'.

As highlighted in the results chapter, phase two saw the collaborative implementation of suggestions made in phase one that aimed to improve the service for people with learning disabilities. Following this six-month implementation period, phase three saw service users and clinicians indicate that the service was 'Better', or 'Making progress'. Both groups highlighted this with reference to the training that had taken place. For service users, progress represented 'Adaptations' and 'Staff attitudes'. In light of AR's formula of a repetitive cycle of planning, action, and evaluation, both service users and clinicians put forward further suggestions for improvements as indicated by the higher order themes 'More work' and 'Auxiliary recommendations', respectively. Both groups recommended ongoing training for clinicians. Service users highlighted this with specific reference to staff increasing their awareness of the nature of learning disabilities. Both advocated better promotion of the service, with service users especially referring to wider dissemination of promotional material and provision of

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information about self-referrals. Both also recommended improving reasonable adjustments, especially in terms of session number and duration. Service users, but not clinicians, stressed the importance of IAPT buildings being wholly accessible for wheelchair users and accentuated a desire to be kept informed in matters relevant to them, such as employment support and 'LD Carer's Workshops'.

Suggested improvements proposed by clinicians, but not service users, included better working with services beyond the CLDT, better involvement of service users, and their carers. Clinicians continued to stress a need for clarity on the services policies, protocols and remit regarding people with learning disabilities, and a need to increase exposure to working with this client group to further increase their confidence levels. A further theme amongst clinicians only, were ongoing concerns about whether the IAPT model could sufficiently adapt to meet the needs of this client group. Regarding this, references to IAPT's limited flexibility and a need for a "cultural shift" in attitudes, led by commissioners and IAPT training courses, were repeatedly highlighted.

## 4.3 Theoretical implications

# **4.3.1** The value of involving people with learning disabilities in research and service development

Whilst there are no discernible proposals to exclude people with learning disabilities from research, their exclusion is apparent in the deficit of literature and research seeking to elicit their views on, and recommendations for, psychological services (Brown et al., 2011). Although not explicitly investigated in this study, the findings add weight to arguments that given the opportunity, service users with learning disabilities can offer rich insights and recommendations for psychological services (Melville et al, 2006). Pleasingly, this concept is currently being acknowledged in a scheme to include people with learning disabilities in the design of quality checks for NHS services, including mental health services (NHS, 2016), and arguably contrasts proposals that people with learning disabilities experience difficulties communicating their needs in mainstream services (Chinn et al, 2014).

### 4.3.2 IAPT can and does offer psychological support to people with learning disabilities

The findings of this study suggest that IAPT services may be able to provide psychological support to some people with learning disabilities. Prior to phase two, all clinicians, and, appreciatively by virtue of being involved in this study, all service users, recognised that the service in which the study took place could be accessed by people with learning disabilities. Furthermore, service users and clinicians were able to provide rich examples of clinicians actively engaging with recommendations from phase

one, for example, by forging positive therapeutic alliances and clinicians sensitively modifying their communication to facilitate assessment and treatment. This supports the assumption that IAPT clinicians [already] have the skills to work with people with learning disabilities (PPG-LD; Dagnan et al., 2015) and furthermore, have qualities considered desirable to service users with learning disabilities such as the ability to adapt communication styles (Stenfert-Kroese et al., 2013).

Service users also provided examples of how they felt therapy within IAPT had positively impacted their emotional wellbeing, supporting Pert et al's. (2012) findings that service users with learning disabilities self-reports of talking therapy being helpful. Although many clinicians expressed concerns about working with people with learning disabilities, not one suggested people with learning disabilities should be excluded from IAPT. This supports earlier findings that most mainstream clinicians feel this client group should be able to access mainstream psychological services (Chinn et al., 2014; Dagan et al., 2015).

# **4.3.3 IAPT** clinicians feel ill-equipped to work with people with learning disabilities due to a lack of training and guidance.

Despite positive examples of IAPT supporting people with learning disabilities, every clinician in this study referred to feeling ill-equipped to work with this client group at least once. This is in contrast to Chinn et al's. (2014) finding that 72% of IAPT clinicians reported feeling 'somewhat' or 'very' confident working with this population. The discrepancy may be due to different means of data collection and analysis. Chinn et al.'s (2014) statistic was taken from the quantitative component of their study. It could be that given multiple choice responses, the majority of IAPT clinicians may self-report feeling 'somewhat' confident ('somewhat' and 'very' confident were collapsed into one group and no breakdown of this statistic was provided in their report). Although the current study did not specifically investigate confidence levels, the transcript analyses highlighted that all clinicians experienced some uncertainty or even "fear" about working with people with learning disabilities. A possible explanation for this may be that use of a qualitative design enabled a richer understanding from clinicians of the complexity of feeling 'somewhat' able to offer this service, as noted through clinicians (and service users') references to positive therapeutic experiences, whilst simultaneously holding a contrasting perspective of feeling 'ill-equipped'. This inconsistency possibly highlights ambivalence IAPT clinicians may have regarding their own competence working with this population.

The current study's findings that clinicians felt ill-equipped or "underprepared" to work with people with learning disabilities echoes existing studies that suggest mainstream clinicians feel inadequately trained to work therapeutically with this population (e.g. Bouras & Holt, 2004; Rose et al., 2007). This finding also supports more recent studies that suggested IAPT clinicians specifically lack confidence in this area (Marwood, 2015; Shankland & Dagnan, 2015). For some clinicians in the

current study, perceived inadequacies led to a reluctance to work with people with learning disabilities. This quite starkly corroborates suggestions that low confidence in IAPT clinicians may present barriers in the delivery of therapy to people with learning disabilities in IAPT (LD-PPG, 2015).

Parallels can be drawn with this study's findings regarding clinician's resistance to work with this population and Bender's (1993) account of 'therapeutic disdain'. However, unlike Bender (1993), who insinuated resistance arose from concerns about the intensity and intimacy required for therapeutic relationships, the current study suggests clinicians' reservations were underpinned by perceived deficits in knowledge, experience, and confidence (which, by extension, activated fears of error, be it in terms of offending people with learning disabilities, or by contravening service policies). This difference in reason for not wanting to work with people with learning disabilities may reflect changes in services, and perhaps dominant therapeutic modalities, since Bender (1993) wrote of the 'unoffered chair'. This difference may also reflect differing lenses used to view data. The current study employed an empathic, semantic approach, that stayed with, rather than 'dug below' what was presented, whilst Bender's (1993) article alludes to therapist's possible unconscious biases (i.e. use of a more latent lens) about working with this population.

The majority of clinicians in the current study were not, at least consciously, opposed to working with people with learning disabilities; rather, their sense of feeling ill-equipped were strengthened by the pressures of working within a high-volume therapy service, service constraints, and not knowing how to 'do' CBT with this group. Many clinicians expressed a would-be welcoming attitude *if* they felt more equipped to do so, through training, and *if* clarity about reasonable adjustments existed. Results of this study thus suggest that IAPT clinicians' reluctance to work with people with learning disabilities stem from personal anxieties of feeling ill-equipped to work with this population in IAPT, rather than Benders (1993) description of therapeutic distain, or any prejudicial assumptions that those with a lower IQ would not have the necessary 'psychological mindedness' to be able to engage and benefit in therapy, as has also been noted (Whitehouse et al., 2006).

In this study, there appeared to be a negative correlation between optimism about IAPT's adaptability, and seniority among clinicians. PWP's suggestions overall seemed less caveated than HI and senior HI Therapists, strengthening Chinn et al's. (2014) claim that PWPs may be more optimistic about IAPT's ability to adapt. This may be due to more senior clinicians being privy to the service's priorities, budgets and targets. However, it is important to note that this interpretation is based on findings from a sample of just 12 clinicians, thus is particularly tentative.

With further reference to possible variations in staff confidence, unlike Marwood's (2015) finding that Clinical Psychologists reported greater confidence than non-Clinical Psychologists in working with people with learning disabilities, the current study found no marked differences in confidence

levels in relation to job title or clinical background levels. However, it is again noteworthy that the current study did not specifically investigate confidence levels, hence this interpretation is also cautionary. Similar levels of uncertainty across clinical backgrounds in the current study suggests all clinicians, regardless of core profession, may benefit from training and clearer guidance regarding working with this group within IAPT. Nonetheless, as is now discussed, service users appeared to feel that clinicians did well enough to adapt their individual practices, although further acknowledgement of their individual differences and increased needs was also welcomed.

#### 4.4 Clinical Implications

#### 4.4.1 Acknowledge the heterogeneity and increased needs of people with learning disabilities

When explaining why they had given a domain green according to the GLTK (2013) traffic light system, or how the service might improve, service users frequently highlighted the importance of recognising "different needs" and considering additional support for people with learning disabilities. Clinicians similarly highlighted a need to adjust communicative approaches to best meet the needs of this group, which supports Stenfert-Kroese et al's. (2013) findings regarding the importance of clinicians adapting communication styles when interacting. Suggestions about acknowledging the increased needs of people with learning disabilities also fits well with legislations regarding reasonable adjustments (e.g. Disability Discrimination Act, 2005; Disability Equality Duty, 2006; Equality Act 2010). However, recent research has highlighted that IAPT is at risk of breaching these requirements (Chinn et al., 2014; Marwood, 2015; Stenfert-Kroese et al., 2013). Suggestions to acknowledge individual differences may be common-sensical, as people with learning disabilities are of course a heterogeneous group. Yet, despite clinicians in the current study referring to a need to be "sensitive" to individual needs, their references to this were proportionally much less than services users. There also seemed to be a simultaneous, arguably contradictory, desire among clinicians for a 'one-size fits all' training, as seen through repeated requests for "practical" training on "how to" treat people with learning disabilities. This could be indicative of a slight lack of appreciation of the heterogeneity within this population among IAPT clinicians, and a consequential need for training to emphasise this. It could also highlight the possible tensions between the need for clinicians to be more flexible and creative when working with people with learning disabilities, and, the time constraints and emphasis on adherence to evidence-based protocols within IAPT.

#### 4.4.2 Keep people with learning disabilities involved: Provide information and ask questions

Service users regularly made reference to the importance of being kept involved in relation to why the service was successful, and how it might be further improved. Examples of positive references to

being provided with information were especially found in relation to safeguarding in phase one, and further requests to be kept involved were found in relation to the 'LD Carers Workshop' in phase three. References to being kept involved also occurred frequently in relation to the importance of clinicians asking them questions. Service users' suggestions to "get to know us" and find out more about their home life potentially provides additional support for Sternfert-Kroese et al's. (2013) findings that highlighted the importance of clinicians acknowledging how past history and specific life events may impact an individual's mental health. More explicitly were service users requests to be kept involved in service development "to give you a little bit more feedback". Given the scarcity of research that has sought to elicit the view of mental health service users with learning disabilities, it is difficult ascertain how well such suggestions fit with the existing literature. Emphasising the importance of their involvement may support Pert et al.'s (2012) findings which denoted service users with learning disabilities appreciated their difficulties taken seriously and understood, and may also map onto existing findings of service users with learning disabilities' desires to be treated as equal, and for clinicians to demonstrate their interest in them (Sternfert-Kroese et al, 2013; Pert et al, 2012).

#### 4.4.3 Need for, and clarity on reasonable adjustments

A need for better reasonable adjustments was emphasised by service users and clinicians during phase one and three. One commonly requested reasonable adjustment made by both was to have more accessible, or easy read materials. This fits with proposals that IAPT clinicians require access to adapted materials (LD-PPG, 2015), and literature that purports that many of the written materials in IAPT are inaccessible (e.g. Chinn et al., 2014, Salmon et al., 2013). Following in-house adaptions of key documents, and training on creating easy read materials during phase two, many service users and clinicians reported in phase three that this area had been adequately addressed. This supports the notion that whilst CBT requires alterations to support people with learning disabilities, it does not necessarily require extensive adaptation (Haddock & Jones, 2006), and is thus one potential barrier that may be relatively easily overcome.

Consistent with literature (Marwood, 2015; LD-PPG, 2015), another oft noted reasonable adjustment suggested by both service users and clinicians concerned the length of therapy sessions. Clinicians in this study noted that whilst theoretically permitted, in reality, additional time in and out of sessions may be problematic to obtain. Marwood (2015) similarly found that IAPT clinicians struggled to have additional time authorised, suggesting that this finding may not be unique to any IAPT service in particular. Further key reasonable adjustments frequently referred to by service users and clinicians were those required pre-access. Both groups suggested making self-referrals easier, supporting the LD-PPG (2015) recommendation to allow a range of referral pathways for people with learning disabilities. Clinicians also suggested having a specific question on referral forms to 'flag' if someone

has a learning disability. It was also noted that this could ensure that the 'LD label' was used at the earliest possible point in the process to help them to prepare by having accessible resources in place. Both ideas fit with the LD-PPG (2015) recommendations of introducing referral forms that allow referrers to indicate if someone has a learning disability, and using a screening tool at, or prior to assessment to identify those that may require reasonable adjustments. No-one proposed introducing questions to assess for suitability for CBT as recommended in the literature (e.g. Hatton, 2002), perhaps highlighting how "far removed" IAPT clinicians may be in terms of best practice for this group.

With further regards to reasonable adjustments, an intriguing finding was that all service users (and no clinicians) declared in phases one and three that the upstairs of the IAPT service's main building be made fully accessible. It was hypothesised that this may have been at the forefront of service users' minds as the physical accessibility of a building is a very visual and concrete representation of a service's commitment to make reasonable adjustments to support those with disabilities. The Equality Act (2010) code of practice attempts to define what is 'acceptable' in terms of ensuring access. It proposes that as long as a service is not disadvantaging disabled individuals with access, the Act is not contravened. Thus, considering that a service could be provided in rooms on the ground floor, it's unlikely that the Act was breached in this respect, perhaps explaining why this was not emphasised by clinicians.

Finally, clinicians in the current study frequently highlighted a need for better clarity on adjustments. This clearly supports Chinn et al's (2014) comments that unelaborated assumptions regarding reasonable adjustments is an unrealistic way to address equity of access. It further implies that careful consideration and clarification of what constitutes reasonable adjustments in IAPT is needed to ensure clinicians feel confident offering therapy to people with learning disabilities.

#### 4.4.4 Need for, and clarity on service policies, protocols and remit

In addition to clarity on reasonable adjustments, clinicians also frequently insinuated a need for clarity on the service's 'official' standpoint on working with people with learning disabilities (e.g. safeguarding policies, inclusion/exclusion criteria, LD label). This fits with Marwood's (2015) assertion that IAPT is not providing clinicians with adequate guidance regarding people with learning disabilities. The current study postulated that clinicians lack of awareness of service policies intensified their uncertainty and perhaps made them warier of working with this group. Combining this with existing research suggests inexperienced IAPT clinicians risk offering a poor service to people with learning disabilities (Marwood, 2015), and may mean that many IAPT clinicians are faced with a dilemma regarding inclusiveness. They could be 'inclusive', and risk making errors and

possible negative managerial appraisals, or be 'exclusive', but safe in the knowledge that errors were not made. This calls for services to provide clarity on their specific polices and protocols.

#### 4.4.5 Working better with other services

The finding that many IAPT clinicians were unsure of, and subsequently desired to know more about learning disability services reaffirmed similar results of existing literature (Chinn et al, 2014; Dagnan et al., 2013; Goodey & Stirk, 2014; Marwood, 2015, Salmon et al., 2013). The advantages of specialist and mainstream services working in partnership highlighted in this study, such as clarity on referral pathways, joint assessments, specialist supervision, and sharing of accessible resources, are also consistent with the literature (Chinn et al., 2014; LD-PPG, 2015). Perhaps more novel was the finding that service users also felt IAPT would do well to forge better relationships with local learning disability services. However, consistent with Chinn et al's. (2014) comments that the formulation of mental health needs expressed by CLDTs does not always 'mesh well' with IAPT's approach, phases one and three of the current study saw clinician's express concerns about the practicalities of such joint working. This was predominantly based on clinicians' awareness of the different models adopted by IAPT and CLDTs (with the former adopting a high volume, short-term approach, and the latter, a comparably lower volume and more flexible approach). It might also be explained by, as speculated by Marwood (2015), IAPT clinicians considering additional liaison-work with systems outside of therapy to be additional unrecognised work, which may be unappealing if already overstretched and/or struggling to meet their targets. Nevertheless, phase three also saw many clinicians suggesting "reciprocal arrangements", for example, suggestions that IAPT clinicians visited the CLDTs to inform them what IAPT offered, perhaps in an effort to 'mesh' better. This suggestion is in line with Chinn et al's, (2014) proposal that the role of CLDTs in supporting people with learning disabilities into IAPT services may be enhanced by their having a better awareness IAPT's eligibility criteria, treatment modalities and working practices. This is an area that will require further attention and clarity at local levels, especially when considering that people with mental health problems and a learning disability are often 'batted' between services because of unclear boundaries (Chinn et al., 2014; Rose et al., 2007).

#### 4.4.6 Increase involvement of supporters

Involvement of service users and their supporters was indicated to be both an area of success and for improvement by both participant groups. In contrast to Stenfert-Kroese et al's (2013) findings that staff, but not service users, highlighted the importance of a 'family-centred' approach, the current study found service users, not staff, were more inclined to speak of carer involvement in their therapy.

That is, service users tended towards references to their supporters being involved in their care, whilst clinicians tended towards references to offering supporters of people with learning disabilities standalone support. The discrepancy between staff in Stenfert-Kroese et al's (2013) study and those in the current study may be that those in the former derived from specialist services, where systemic interventions may be more commonplace, whilst those in the current study, derived from mainstream primary care psychology, where individualist therapy is more commonplace. Minimal references from clinicians to include service users wider-network in their treatment could also be due to the IAPT model making this problematic due to time constraints as alluded to in the above section 4.5.5. In light of the importance of incorporating service user's systems in their therapy, this perhaps reiterates a need for IAPT clinicians working with this population to have their weekly targets appropriately adjusted to reflect this, as suggested in the LD-PPG (2015).

#### 4.4.7 Understanding the evidence-base

Arguably coinciding with desires to alleviate anxieties, most clinicians implied a need for better awareness of evidence-based interventions/tools and protocols for people with learning disabilities. Whilst it was occasionally acknowledged, in line with literature, that the complexity and diversity amongst this population required a degree of flexibility (LD-PPG, 2015, Whitehouse et al 2006), such entreaties fit with proposals that IAPT clinicians could benefit from having a better awareness of the evidence-base (Chinn et al., 2014). Clinicians' desire to be familiar with specific evidence might also suggest that they are either unaware of, or uncomfortable with the proposal to assume that existing evidence applies to this group until proven otherwise (LD-PPG (2015). The possible discomfort with this suggestion may be because equivocal suggestions to 'be flexible' conflicts with clinicians' mindfulness of IAPT's need to use NICE approved protocols. Hesitancy to be flexible and adapt existing practice may reflect IAPT clinicians fears of entering 'therapist drift' (Waller, 2009), which is heavily cautioned against in IAPT training programmes. If this hypothesis is true, it supports the proposal that strict adherence to evidence-based protocols presents barriers to IAPT for people with learning disabilities (Chinn et al., 2014). In addition to a need for an evidence-based adapted practice, this also calls for IAPT clinicians to be supported in modifying their current practice within the parameters of the existing evidence in light of individual needs. This may be facilitated by greater guidance and support from learning disability specialists as suggested by Salmon et al. (2013).

#### 4.5 Policy Implications

4.5.1 IAPT clinicians require training on working with people with learning disabilities

Training was by far the most common recommendation made by clinicians. Perhaps supporting findings that mainstream clinicians feel at ease relationally, but were unsure of the technical aspects of delivering CBT to people with learning disabilities (Dagnan et al., 2014), all 10 clinicians in phase one requested training be "practical". Clinicians also frequently reported that a deficit in training on working with people with learning disabilities rendered them feeling ill-equipped to carry out this work, which is consistent with existing findings (e.g. Chinn et al, 2014; Marwood, 2015). Accordingly, several clinicians believed training would increase their confidence in working therapeutically with people with learning disabilities, in line with findings from much existing, related research (Dagnan et al., 2014; Chinn et al, 2014; Marwood, 2015; Shankland & Dagnan, 2014).

In contrast to Chinn et al's. (2014) finding that 68.2% of IAPT staff felt training should be for all, all clinicians in the current study advocated training for everyone. This may be due to the clinicians in the current study, aware of its design and purpose, sensed that working with people with learning disabilities was more imminent to them (compared to those who participated in Chinn et al's., 2014, study, who may have answered the question on a more hypothetical basis). A key reason given for training being mandatory was a perceived mismatch between what they felt IAPT training had prepared them for and what they felt was expected of them, echoing Marwood's (2015) findings of a similar nature.

The omission of 'learning disabilities' from the IAPT curriculum has also been suggested to contradict the aim of inclusivity within IAPT (Marwood, 2015) and in line with Rose et al's. (2007) findings, may lead IAPT clinicians to feel such work was not "part of their core job". Therefore, in addition to enabling clinicians to feel better equipped, inclusion of working with people with learning disabilities on the IAPT curricula may normalise such work within their roles. It may also further enhance some of the elements of candidacy as described by Chinn et al. (2014). They highlight that judgements about likely therapeutic successes made by IAPT services, and arguably, by extension, clinicians, may determine persistence to work with someone. Formal training in this area may be beneficial when clinicians are weighing up how successful therapy may be, versus the demands it will make on their limited time. At the time of writing, this is an area that continues to need addressing within the IAPT curricular.

#### 4.6 Commissioning Implications

# **4.6.1** Widely promote that IAPT can and does offer support for people with learning disabilities and increase the number of people with learning disabilities accessing IAPT.

In phases one and three, service users and clinicians highlighted a need for IAPT to better promote that it can offer support to people with learning disabilities. This is consistent with the LD- PPGs

(2015) emphasis on publicising IAPT's inclusivity to enhance access. Promotion may be particularly important given Chinn et al's. (2014) reference to candidacy (Dixon-Woods et al., 2006), which proposes that people with learning disabilities may not see themselves, nor be viewed by the systems around them, as candidates for IAPT. Better and wider promotion of clear statements of inclusion may enable people with learning disabilities experiencing anxiety and/or depression (and those around them), to identify them as candidates for IAPT. This in turn may lead to increased numbers of people with learning disabilities accessing psychological support, which may not only be advantageous for them, but would also lead to greater 'exposure', experience and confidence amongst IAPT clinicians.

As well as a lack of training, clinicians frequently referred to feeling ill-equipped to work with this population due minimal 'exposure'. Both factors are conceivably a consequence of the low numbers of people with learning disabilities entering IAPT, causing a self-perpetuating cycle as highlighted in Figure 2 (section 3.2.2.2.1), where low numbers mean a lack of 'exposure', and this group not being seen as a priority, warranting allocation of funding for training. Supportively, several clinicians implied in phase three that low numbers of people with learning disabilities accessing IAPT limited the opportunities to practice what they learned in phase two, echoing issues raised in previous studies (Bouras & Holt, 2004; Marwood, 2015). Rose et al. (2007) similarly found that while training was considered important, numerous staff participants in their study felt that much of the expertise in this field could only be gained from learning 'on the job'. Relatedly, the LD-PPG (2015) states that access to treatment in IAPT will improve the competencies of IAPT clinicians. Training combined with experience and permission to work flexibly may also minimise premature drop-outs from this group, which may unhelpfully reinforce the idea that this client group are unable to benefit from mainstream psychology services (Chinn et al., 2014). This underscores the importance of increasing the numbers of people with learning disabilities within IAPT.

#### 4.6.2 Conflicts with IAPT ideologies: Limits to flexibility in a high-volume, high-pressure service

Many clinicians made unprompted remarks highlighting their uncertainty regarding the 'achievability' of effectively working with people with learning disabilities within the current IAPT framework. IAPT clinicians often spoke of the pressures of working within IAPT generally, echoing Stenfert-Kroese et al's. (2013) reference to staff participants utilizing interviews as opportunities to describe the challenges their jobs entailed. Clinicians in the current study expanded on this by stating that there were unrealistic expectations on them to incorporate a learning disability population, and provide best practice, whilst working within a "high-volume, high-pressure service". As alluded to in section 4.4.5 and 4.5.6, practical concerns about adapting materials, joint working and consideration of systemic interventions when already struggling with heavy workloads were also mentioned. This provides further support for existing suggestions that mainstream clinicians may not be in a position to provide

the time necessary to support people with learning disabilities (e.g. Bouras & Holt, 2004; Chinn et al., 2014; Marwood, 2015; Rose et al., 2007). Sparse time and heavy caseloads, have been linked with emotional exhaustion for IAPT workers in particular (Steel, Macdonald, Schröder & Mellor-Clark, 2015). Accordingly, commissioners and senior management need to set more realistic targets for IAPT clinicians working with this population, not only to enable them to be able to support this group on a practical level, but also to minimise the risk of emotional exhaustion.

Some clinicians insinuated that IAPT was inadvertently "discriminating" against people with learning disabilities through stringent adherence to existing polices, supporting existing studies that similarly indicate that the rigidity of IAPT service protocol places people with learning disabilities at an unfair disadvantage (Chinn et al., 2014; Marwood, 2015). Clinicians in the current study acknowledged that commissioners set targets that needed to be met to ensure continued funding. Intertwined with this, many noted that change and clarity from "the top" was required to prevent "*things get[ting] messy on the ground*". Perhaps due to unclear guidance, many clinicians directly or indirectly implied that people with learning disabilities were not IAPT's "core business". Many commented that IAPT was not set up to meet their needs and therefore felt that working with this population was beyond what could realistically be expected of them. This adds further support to proposals that from clinicians' perspectives, IAPT is neglecting to acknowledge and implement policies and legislations pertaining to equal access to health services for people with learning disabilities (Marwood, 2015), and implies clear access targets and guidelines regarding flexibility set by commissioners is required facilitate people with learning disabilities' access to IAPT.

#### 4.6.3 Prioritising and competing demands

Several clinicians expressed belligerence towards IAPT's efforts to offer 'specialist' support to an increasing array of groups not covered in the IAPT training, such as to those with long-term health conditions, carers, as well as perinatal individuals. This supports existing findings that some clinicians feel frustrated by IAPT's expanding nature (Marwood, 2015). Awareness of these "competing demands" led several clinicians to suggest that learning disabilities needed to be prioritised by services and commissioners via specific learning disability policies and targets in order for inclusion to be truly successful. This could be encouraged by making it a requirement for IAPT to 'flag' people with learning disabilities on their data systems and commissioners setting and monitoring clear access targets, as noted in the LD-PPG (2015). Relatedly, whilst we saw that service users and clinicians recommended various reasonable adjustments to improve IAPT, we also saw clinicians doubting the workability of such adjustments within the current IAPT model, and implying managers were more keenly aware of meeting existing targets. This could be rectified by commissioners making reasonable adjustments a clear requirement of services and ensuring they have sufficient flexibility in terms of

meeting targets to allow sufficient time for clinicians to meet the needs of people with learning disabilities.

Through commissioners setting access targets, IAPT services may see an increase in the numbers of people with learning disabilities, which may increase clinicians' confidence and competencies in working with this client group. However, as noted by service users and clinicians, ongoing training and access to funding for this will be necessary. This corresponds with Chinn et al's. (2014) recommendation, and suggestions made within this chapter, that commissioners set clear access targets for people with learning disabilities and ensure support within IAPT is funded appropriately, and the LD-PPG (2015) suggestion that commissioners adjust funding and data collection requirements to enable effective engagement. The ongoing commitment many clinicians spoke of may more specifically be achieved via the LD-PPG's (2015) proposal that commissioners incentivise inclusion through Commissioning for Quality and Innovation (CQUIN) payment frameworks. Since the LD-PPG (2015) publication, 'Learning Disabilities' has been listed among seven priority areas on the CQUIN Menu for 2016/17 (NHS England, 2016). Whilst the longer term implications of this for IAPT are currently unknown, it has the potential of allowing IAPT to allocate appropriate funding for this area.

#### 4.7 Recommendations for future research

Whilst this study demonstrated that service users with learning disabilities and clinicians are capable of participating in the research process, further research could consider a more PAR approach, involving participants more in the design, delivery and analysis of such research. Ensuring that the focus begins with and remains on topics most pertinent to participants, it is likely to increase its validity and this may be achieved through utilising the approach adopted by Chinn et al. (2014) whereby stakeholders met to design interview questions. Involvement of service user participants as interviewers may also improve the quality of data, as service users with learning disabilities may have felt more comfortable discussing their experiences with those who had encountered similar experiences (Schneider, 2012).

Although the data analysis phase endeavoured to include participants as much as was feasible within the confines of this project, greater involvement with this warrants further attention in future research. One method of including co-researchers with learning disabilities in the process of thematic analysis that could be considered in the future is described by O'Brien, McConkey and Garcia-Iriarte (2014). In their feasibility of inclusive research with adults with learning disabilities, O'Brien et al. (2014) used a two stage process where focus group transcripts were thematically analysed by university coresearchers, then presented to co-researchers with learning disabilities who had facilitated those focus groups. Co-researchers then rated the theme's significance by placing those they recalled to be of most importance closest to a square on a large piece of paper.

Whilst Stenfert-Krose et al. (2013) have already qualitatively investigated service user views of CBT within specialist services, and larger scale studies have quantitatively studied the delivery of manualised CBT (e.g. Hassiotis, et al 2013), there remains a need for closer investigation of therapeutic mechanisms of change from service users with learning disabilities perspectives within IAPT. Therefore, another area for future research may be an in-depth exploration of the elements of therapy within IAPT service users found most helpful. This could be facilitated through a retrospective video reviewing process, which Burford and Jahoda (2012) found to be effective in enabling people with learning disabilities to describe their experiences of CBT. As the current study was confined to one IAPT services. Furthermore, despite often being highlighted as key to developing mainstream services for people with learning disabilities, commissioner's views seem to be missing from the research on this area. Therefore, future research could also endeavour to elicit their views regarding requirements, challenges and dilemmas of commissioning in this area.

Perhaps one of the most significant areas warranting future research is the MDS. Whilst collective efforts were made to adapt this in phase two of the current study, and many service users commented favourably on it, some difficulties persisted. As noted in the introduction, the MDS consists of standardised questionnaires and is used routinely by all IAPT services nationally as routine assessment and sessional outcome measurement. The current study's findings regarding its inaccessibility, contradicted the LD-PPG (2015) proposal that the MDS in its current form is *"entirely suitable for people with learning disabilities"* (p. 18). It instead corroborated suggestions that the MDS can be problematic for some people with learning disabilities (Chinn et al., 2014), and that even adapted versions can pose difficulties in completion (Marwood, 2015). For example, comments made in this study suggested that even with additional time, some service users may struggle with aspects of MDS. As one service user noted: "that's hard to remember what happened two weeks ago". This implies that further research is needed to investigate the validity of the scales in the MDS specifically with people with learning disabilities.

As 'success' in IAPT is closely monitored via the MDS, the importance of having a standardised and psychometrically validated version of it has far wider implications in terms of accurately establishing the effectiveness of therapy for this group in IAPT (Chinn et al., 2014), and consequential commissioning of services for this group. This is of critical importance when considering IAPT's requirement to reach established targets derived from key performance indicators (KPIs), including, as noted in the introduction, 'recovery' and employment rates. It has been suggested that the use of existing KPIs to measure therapy outcomes may not be appropriate for people with learning

disabilities (Kirk, Sehmi, Hazeldine, Palmer, & Ruddle, 2013). Given that IAPT services and clinicians within them, are assessed on 'recovery' as determined by the MDS, it is not unthinkable that they may be reluctant to work with this population as the inaccuracy of these measures may reflect badly on them. The idea that there is little to incentivise IAPT to commit to improving services for those less likely to achieve high recovery levels has not gone unnoticed (Price, 2011), nor has the idea that people with learning disabilities are less likely to meet the employment KPI. This has led to suggestions that the existing emphasis on outcome monitoring may present access barriers to those with learning disabilities (Chinn et al., 2014). Critics of IAPT may also see this as further evidence that prioritizing targets and outcomes over attention to individuals needs disregards the 'emotional realities' of their suffering (Rizq, 2012). Therefore, given the possible limitations of the MDS for people with learning disabilities, further research into its validity is greatly welcomed, as is a comprehensive assessment of the psychometric properties of an accessible version of the MDS.

#### 4.8 Applicability and Dissemination

Counselling Psychologists are particularly interested in addressing 'real-world' challenges encountered by professionals in Counselling Psychology and beyond (Kasket, 2012). The current study sought to address an existing challenge (how IAPT might adapt to meet the needs of people with learning disabilities) by highlighting suggested improvements and implementing and evaluating those recommendations. It aimed to do this within a relatively brief timeframe, without additional funding or resources to enhance its applicability to other IAPT and mainstream psychological services. In addition to this strength, this study demonstrated the feasibility of service users with learning disabilities participation, together with IAPT clinicians, in the implementation and evaluation of action research within IAPT.

Relevant literature and findings from the literature review were initially disseminated to the service at the point of recruitment to the study and then team presentations. This subsequently occurred though the team training and dissemination of easy read materials, safeguarding tutorials and sharing of other resources that took place during phase two. Wider dissemination of the study occurred through training delivered to IAPT staff and services in different local boroughs, and sharing of resources with other local services. As a result of this project, there are now quarterly meetings involving service user representatives, 'LD Champions' from local IAPT services and their associated CLDTs, which ensure ongoing dissemination of best practice. This approach is now being rolled out to related groups, namely developing a care pathway and improving joint working between IAPT and the specialist services for people with high functioning autism.

Elements of the study were more widely disseminated through presentations at a National Learning Disability Conference in September 2015, and the Intellectual Disability Research Conference in

December 2015. Both presentations were shared on the IAPT service's social media platform and Trusts intranet to further raise awareness of the topic and its findings. Also, the research carried out as part of this project has contributed to an article published in the '*Bulletin of the Faculty for People with Intellectual Disabilities*' (Theodore et al., 2015). There are further plans to publish this study in the '*Journal of Intellectual Disabilities*', present the full study at a national conference, and to put together an accessible summary for people with learning disabilities. In line with the recommendations noted above, the current project has also directly contributed to a further research study now underway that is investigating the validity and psychometric properties of the adapted MDS.

#### 4.9 Critical review

#### 4.9.1 Limitations

#### 4.9.1.1 Limitations to an Action Research framework

A key limitation of this research was the lower than ideal level of inclusion of participants in its design and execution. Greater inclusivity may have been achieved by ensuring participants were more involved in decisions regarding research questions, methodological design, as well as data analysis and write up. Unfortunately, greater inclusion would have required time and resources beyond the scope of this doctoral level research project (e.g. requirement of accessible research design and data analysis 'training' sessions for participants). Nonetheless, the neglect to include participants, particularly service users, in every aspect of this research's design, delivery and dissemination, leaves this study open to criticism. As discussed in the ensuing reflexivity section, these findings may have been influenced by my own biases rather than a collective group of participants. Criticisms of this study's design may be particularly strong from AR researchers at the emancipatory end of the AR continuum, who may consider it to be evidence of further systematic exclusion of people with learning disabilities. From this perspective, AR is believed to reinforce existing power structures, rather than confront or change them, simply allowing previously excluded groups to participate in the research "game" (Oliver, 1997, p12). However, Oliver (1997) also notes it is not possible to 'do' emancipatory research-researchers can only engage with those already seeking to emancipate themselves. Therefore, a more emancipatory research design would prove particularly challenging for doctoral level research.

#### 4.9.1.2 Sampling and generalisability of findings

Another means in which the study's design may have influenced the findings is through the sampling method. As highlighted by authors of similar research (Chinn et al., 2014; Marwood, 2015), using a self-selected method may have meant clinician participants who feel more strongly about either inclusion or exclusion of people with learning disabilities in IAPT were more inclined to participate. For the current study, this may have instigated more extreme views regarding either acceptance of, or anxieties about working with this client group, as well as more extreme scepticism or optimism about the feasibility of suggested improvements. As this study sought to elicit a range of clinicians' views, it included those who had and had not worked with service users with learning disabilities within IAPT. It is possible that those who had not, felt comparably greater optimism, or anxiety, than those who had, and that this skewed the overall findings. Accordingly, findings may not be generalisable to IAPT clinicians who regularly see people with learning disabilities within IAPT.

Service user participants were also self-selected. It is also possible that those who participated were those who felt positively about the service, given their willingness to participate and their typically positive responses in interviews. It is also acknowledged that whilst low numbers of people with learning disabilities currently accessing IAPT meant it would be challenging to recruit more service users in this study, the small number of service users who participated means that the findings cannot be representative of the experiences and ideas of all service users who have accessed IAPT, nor those who may have been (unintentionally) 'excluded' from IAPT due to the uncertainty about the service's remit at the point of referral to IAPT. It is also noteworthy that participants in the current study were those with mild-borderline learning disabilities, thus findings cannot be generalised to those with moderate-severe learning disabilities. However, it is also of note that IAPT is less likely to be appropriate for this group as they are more likely to require specialist support (LD-PPG, 2015).

Some of these sampling biases could be addressed through alternative sampling methods. For example, a broader array of clinicians could have been incentivised to participate by being offered a fee for their time, or by offering to conduct interviews through secure video conferencing platforms 'out of hours' so that time was not taken from their working day. Greater numbers of participants might have been recruited through a national, online recruitment campaign. A larger sample may have added support for identified themes, enabled additional conceptual generalisations and permitted data that may have contradicted or modified the final analysis (Mays & Pope, 2000). However, a larger sample would have made an AR design extremely challenging within the allocated timeframe.

All interviewers came from the IAPT service in which the study took place, and whilst efforts were made to stress confidentially of the interviews, it is acknowledged that being interviewed by colleagues may have led to social desirability biases. A suggestion to overcome this may be offering interviews via anonymous online instant messaging conversations. Service users were also interviewed by IAPT clinicians. Whilst it was stressed that their responses would not affect future

support within the service, as some literature concerning acquiescence in interviews with people with learning disabilities notes (Sigelman, Budd, Spanhel & Schoenrock, 1981), it is possible that service users felt under pressure to provide more positive responses to questions about how well the service was faring. It is noteworthy that service users in the current study provided much less detailed responses than clinicians. This may suggest that questions were understood less well, and/or that service users were less sure of the answers. When coupled with more positive responses, this again could suggest acquiescence in their responses. In line with the principles of inclusive research, this could be addressed in future by ensuring service users play a greater role in the creation of research questions and by interviewing participants themselves (Rose, 2001).

Another limitation to this study was the use of revised copies of the GLTK (2013) to guide interviews. This provided a very structured interview schedule, unlike a more unstructured / open interview schedule that would typically be used for a qualitative project. This meant that is was at times difficult to interpret transcripts beyond a quite superficial level. A related further limitation arose through a need to 'scaffold' service users' participation, particularly in phase three. For service users, this phase involved, per domain, a summary of phase one responses, pseudo themes noted by clinicians and a description of the actions taken before asking service users to provide a new GLTK rating and further recommendations for improvement. This may have caused confusion, made interview questions more difficult to understand, meant that responses were biasedly led, and increased acquiescence. Had time permitted, an alternative format may have been for phase three with service users' to have taken place over a series of shorter interviews. The first could have used a less verbal, more pictorial, accessible overview of participant's responses from phase one, per domain, where service users could state what they felt the themes were per domain. A second interview could have used a pictorial format to illustrate the changes that had occurred during phase two, and service users could then be asked to think about and rate how well the service now fared considering the changes that had occurred. A third interview could, per domain, recap on themes and actions, and then asked service users for further suggestions.

Regarding generalisability, it is possible that the findings are unique to the particular IAPT service in which the study took place, thus not generalisable to IAPT services nationally. Recruiting participants from multiple IAPT services may have enabled a more representative overview of service user's and clinician's experiences and ideas. However, the desire to deliver recommended improvements as part of this AR study combined with time constraints meant that it was only feasible to conduct the study within one IAPT service. Efforts were made to ensure a plurality of perspectives of IAPT clinicians by not restricting anyone based on clinical experience. Furthermore, the results generally closely echo similar existing studies (Chinn et al., 2014; Marwood, 2015), suggesting its findings may be representative of IAPT services more broadly.

#### 4.9.2 Quality and strengths in research design

Various means of assessing validity and overall quality within qualitative research have been proposed. What follows includes a reflection of the current studies strengths in the quality of the research design and further aims to consider this with reference to Spencer and Richie's (2012) guidelines for assessing quality, including its contribution, credibility and rigour.

#### 4.9.2.1 Contributory

The current study provides further support for existing research that sought to elicit the view and experiences of IAPT clinicians regarding working with people with learning disabilities (e.g. Chinn et al., 2014; Marwood, 2015; Shankland & Dagnan, 2015). In line with these studies, the results of this research paints a mixed picture regarding the feasibility of IAPT adapting to meet the needs of this client group. It supports existing recommendations that IAPT clinicians receive training to improve their knowledge and confidence levels in working with this group. It further adds to concerns that unclear reasonable adjustments and guidelines within IAPT, as well as limited flexibility and arguably unrealistic expectations may hinder clinician's abilities to effectively meet the need of this client group. As such, this topic requires attention and prioritisation from service leads and commissioners to avoid IAPT from being in breach of legislation, such as the *Equality Act* 2010.

The current study expanded on existing studies that sought to offer a largely quantitative account of IAPT staff perspectives (Chinn et al., 2014), or a purely qualitative account of HI clinicians' experiences who had worked with this client group (Marwood, 2015) by offering an in-depth exploration of the views of both PWP and HI clinicians with and without experience of working with people with learning disabilities. It also expanded on existing research by offering a novel insight into the views of service users with learning disabilities who had received talking therapy within IAPT, with regards to how well they felt IAPT fared in relation to meeting their needs, and what might be done to improve it. Critically, it further built on limitations to existing studies by using an AR framework in order to include people with direct experience of IAPT in the collaborative implementation and evaluation of service user and clinician recommendations for improvement.

#### 4.9.2.2 Defensible in design and analysis

AR seemed a fitting framework to investigate the current study's research questions, particularly in light of the 'nothing about us without us' ethos of including those affected by decisions and policies in their development. This study did well considering Tolbert, McLean and Myers (2002) proposal that

AR strives to gain knowledge through action in a cyclical fashion. However, as highlighted in the methods section, tensions exist concerning where AR places greatest emphasis. This can be predominantly driven by researcher's agendas, actions and organisational transformation, or, by stakeholder's agendas, equality in power over research decisions, and efforts to address the relationship between social and material relations of research production. On the continuum of AR, this study leaned toward the Lewinian approach with an emphasis on action, and although it did not profess to be toward the emancipatory end of the AR continuum, a better balance could have been struck between inclusion and action. However, the involvement of both service users and clinicians as partners and not just participants in the research, is a strength of the project overall.

Qualitative data collection and analysis are understood to suit AR approaches, thus was appropriate for the current design. When faced with complex social situations, we convey both contradictions and dilemmas linked to different processes and lines of thought (Billig, Condor, Edwards et al., 1988). A qualitative approach advantageously allowed space for nuances and contradictions, as well as explanations for responses and real life examples. This, in turn, allowed for scope to actively and creatively engage with the data beyond a descriptive level that would have resulted from a quantitative approach. Whilst use of semi-structured interviews based on a standardised tool might contradict this intention, it is hoped that the reader acknowledges that findings from this study were solely based on the thematic analysis of the interviews as opposed to the colours awarded using the GLTK traffic light system. Although qualitative and quantitative research methods share 'publishability guidelines', such as explicit scientific context, purpose, and contribution to knowledge, many have argued that qualitative research represents a distinctive paradigm that cannot be measured using the same criteria applied to quantitative research, such as validity, generalisability and reliability (e.g Elliot et al, 1999). Mays and Pope (2000) argue that qualitative methods can be more effectively evaluated based on two overarching criteria: relevance and validity. It is hoped that the introduction chapter and the sections on applicability, dissemination and contribution within this chapter highlight this studies relevance, whilst the methods and results chapters, as well as the ensuing two sections highlight its validity.

#### 4.9.2.3 Credible in claim

The methods chapter offered the rationales for the chosen research design, method and sampling strategies, and their relevance to the study's aims. From an AR perspective, all researchers approach research with subjective values that invariably shape their research (Schneider, 2012), thus AR cannot be entirely free from contamination and biases. However, action researchers also believe involving those directly affected by a 'problem' is an important knowledge source, offering an effective means of enhancing quality, validity and relevance (e.g. Davidson et al., 2009). The 'member checking'

procedures enabled the current study's analysis to incorporate a fuller observation of the data, and increased the validity of the concepts and categories developed regarding participant's accounts' and processes. Credibility is further seen through the detailed accounts of data collection and analysis, as well as raw data extracts in the results chapter. The table of coded excerpts and early thematic development map within the appendices support the auditability of this research.

#### 4.10 Researcher reflexivity

As noted in the methods chapter, reflexivity is the attempt to explore ways in which a researcher's involvement with a particular study influences, acts upon and informs such research (Nightingale & Cromby, 1999), and is considered imperative in assessing research rigour (Spencer & Ritchie, 2012). Woolfe & Dryden (1996) argue that Counselling Psychologists should aim to strike a balance between being a non-practicing researcher and a non-researching practitioner. Throughout this project, I was able use my experiences as an IAPT clinician to research a phenomenon that Counselling Psychologists in IAPT will inevitably face (providing talking therapies for people with learning disabilities) and through this study's findings, I was also able to adapt my own clinical practice. As noted in the method chapter, the impetus for this project stemmed from my experiences as an IAPT clinician involved with the Foundation for People with Learning Disabilities (2013) project. This experience left me with mixed feelings about the suitability of IAPT for this population, and concerned that poorly thought out attempts to increase access to IAPT for people with learning disabilities would be detrimental to them, as well as to IAPT clinicians. I also felt moved to offer research in this area as someone affiliated with IAPT, to include views of service users with learning disabilities who had received support within IAPT, and attempt to take action as part of the research, as these elements all seemed to be lacking within the existing literature. The topic and design of this study were thus clearly influenced by these factors, and I was very conscious of the possibility of this impacting the way I interpreted the findings. To redress the prospective leaning toward positive confirmation, I knew I needed to pay specific attention to 'negatives' and disconfirmation of my existing biases. This was greatly facilitated through supervision.

I can retrospectively appreciate that I doubted IAPT's ability to effectively adapt to meet the needs of people with learning disabilities at the outset of this project. This view was chipped away at by unexpected findings regarding how well service users and clinicians felt the service was faring in relation to the GLTK in phase one, and their commitment to make changes in phase two. I was consequently increasingly swayed toward the belief that IAPT services could adapt to meet the needs of this group, if given sufficient time and attention. I thus moved to a position aligned in many was with that of the LD-PGG (2015). It is acknowledged and accepted that my personal biases may have influenced the interpretation of the data. That is, it is possible that I was hyper-vigilant toward service

users and clinician's views that fitted my own and neglected of those that did not at the different stages of analysis. I was extremely conscious of this when analysing the data and hoped to achieve a more valid interpretation through regular supervision and 'member checking'. Both of these processes helped me to better appreciate the more positive and optimistic views of the participants within this study.

With reference to methodological reflexivity, one of the most challenging aspects of this project was managing the power relations between myself and the participants. I was conscious that many decisions, including the research topic, method, and dissemination were made by me alone. I was particularly conscious of the fact that one group of participants, the clinicians, were also my colleagues, with whom I could often identify with. Although I strived to stay mindful of over-identification, I recognised that there was nonetheless a high probability of this happening and sought to manage this through supervision. I do not identify myself as someone with a learning disability and I remained acutely aware of the difficulties I had genuinely identifying with this group, and my fear of misinterpreting their responses. Frequent consultations with a Clinical Psychologist who specialises in learning disabilities and 'member checking' greatly facilitated this aspect of the study.

I strove to involve service users and clinicians and relinquish power wherever possible, and although decisions were regularly discussed, this was not always the case. Key decisions remained largely under my control and on occasions, were made without consultation. Had it been more participatory, control would have been more evenly distributed. There would have been a better balance regarding when and where actions during phase two occurred. It is also worth noting that few disagreements occurred during these discussions and consultations, suggesting that either participants were generally in agreement, or the power balance was skewed in favour of majority opinion and those in the minority were reluctant to vocalise disagreements.

Perhaps in line with this, Schneider (2012) notes, one cannot simply 'give' people power, willingness to take the power and participate is required. The lack of service user participants in the delivery of the training events and conference presentations illuminates this concept. Although service user participants were invited to collaborate with this element, no-one took up this offer. Schneider (2012) further notes processes of sharing control in collaborative research projects often evolves over many years, and again, could be seen to be beyond the time constraints of this doctoral level research project. It is hoped that a similar project could be undertaken in the near future with a more evenly distributed power balance.

#### 4.11 Conclusion

The study merits Chinn et al's. (2014) use of the concept of candidacy, which describes a dynamic, multi-dimensional and contingent process whereby eligibility for medical attention and intervention is jointly negotiated by individuals and health professionals. This study hoped to offer an insight into the complexities of increasing access to mainstream psychological services for people with learning disabilities, and avoid giving the impression that 'barriers' to access can be easily be removed by commissioners alone. It is hoped that this was evident in the portrayal of the mixed picture that is IAPT's current 'successes' in meeting the needs of people with learning disabilities. Evidence of inclusiveness among IAPT staff, and good examples of joint working were found. Overall, the key implications from clinicians in phase one may be that if IAPT clinicians implement changes on the ground, for example, better working together, familiarisation of evidence base, and changes occurring 'from above', such as through the introduction of training, and provision of adapted materials, then clinicians will feel more confident and the service will fare better in relation to the GLTK (2013). However, uncertainty may persist in terms of the longevity of such changes until 'learning disabilities' becomes seen as a more core part of IAPT.

This study aimed to enable both IAPT service users with learning disabilities and IAPT clinicians the opportunity to offer their insights into how IAPT fared in relation to offering a service to people with learning disabilities; and how it might improve; to participate in the implementation of suggested improvement, and then evaluate their effectiveness and offer further suggestions for improvement. In participating, individuals contributed not only the development of knowledge, but also held a small but important role in the promotion health equality and social justice. This is perhaps most crucial for participants with learning disabilities who, despite recognition of the contributions that they can make, are all too often overlooked due to time and resource constraints. Whilst this study aimed to avoid a tokenistic involvement, its success in service user and clinician involvement will inevitably depend on the perspective of the reader. In line with the philosophy of AR, this project continues to move forward with the latest recommendations that emerged from this research and aims to continue in this reflective cycle, with structures in place to do so.

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### Appendix 1

Official Green Light Toolkit (2013) example excerpt

### The Basic Green Light 2013 Audit

LD means learning disabilities and MH means mental health.

Basic Audit	In the garage, not yet started	On the journey, but stuck at Red	Ready for more – Amber	Continuous progress – Green	Score
1. Physical health	1D. We are doing nothing locally to correct for the health inequalities suffered by people with a combination of autism, LD and MH needs		1B. Specific actions are taken by MH services to help people with autism or LD engage with routine health screening in primary care	1A. In addition to supporting people to access routine health screening our local MH service is taking action to encourage healthy lifestyles and people with autism and LD are engaged	
2. Eligibility and Access	2D. Autism or LD is used as a diagnosis of exclusion to shut people out of MH services	2C. Some people with autism or LD may receive support from MH services, but this is not part of a deliberate and systematic approach	2B. Eligibility criteria include a clear expectation that MH services should serve people with autism or LD, but they may not actually be doing so	2A. People with autism or LD are found in all parts of the MH service	

Green Light Toolkit 2013: A guide to auditing and improving your mental health service so that it is effective in supporting people with autism and people with learning disabilities. November 2013.

Appendix 2

Accessible information sheet

## IMPROVING ACCESS TO PSYCHOLOGICAL THERAPY (IAPT) FOR PEOPLE WITH LEARNING DISABILITIES

## **INFORMATION SHEET**

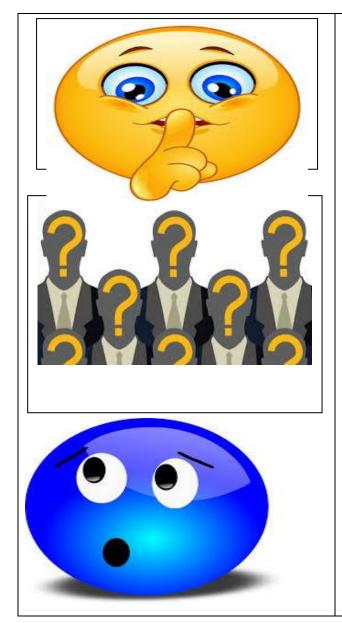
Contraction of the second seco	This sheet tells you about an IAPT for people with learning disabilities project. It will help you choose if you want to take part or not.
i, j	What is it about? We are interested in how well people think psychological therapy services like this are doing for people with learning disabilities.
	Why me? You are being asked because you have had some support in this service.

?	Do I have to do it? You <b>do not</b> have to take part in the project. If you decide to take part in the interview or not, it will not change the way services work with you.
<image/>	<ul> <li>What happens if I take part?</li> <li>You will be asked: <ul> <li>How well you think the service is doing.</li> <li>Why you might think that.</li> <li>Your ideas on how we can make it better.</li> </ul> </li> <li>We would like to use a sound recorder to record what you say</li> <li>The interview would last around 1 hour.</li> </ul>

	<ul> <li>We will also be asking some of therapists in this service for their ideas on:</li> <li>How well they think the service is doing</li> <li>What they think could be done to make it better for people with learning disabilities.</li> </ul>
	After we have finished the project, all of the answers we get from the interviews will be gathered together. We will tell you what the research showed too, if you want.
CHANGES	We will use everyone's ideas to make positive changes in the therapy service over the next six months.

	After we have tried to make to positive changes in the service, we would like to meet with you again. We would tell you about the changes made to the service and then ask you about how helpful you think the changes have been.			
EIO Bank or Ingland	Payments			
	<ul> <li>We will pay you £10 per interview to say thank you for your help.</li> </ul>			
	<ul> <li>We will also give you the money you might spend on getting to the interview</li> </ul>			

	There might be good things and bad things about taking part.
	Talking about therapy service might be hard or confusing.
YYY	But it might be good to talk to someone about things that will make the service better.
files	If the project has to stop, all of your answers will be destroyed



# Keeping things private

We will **not** tell anyone your name or who you are.

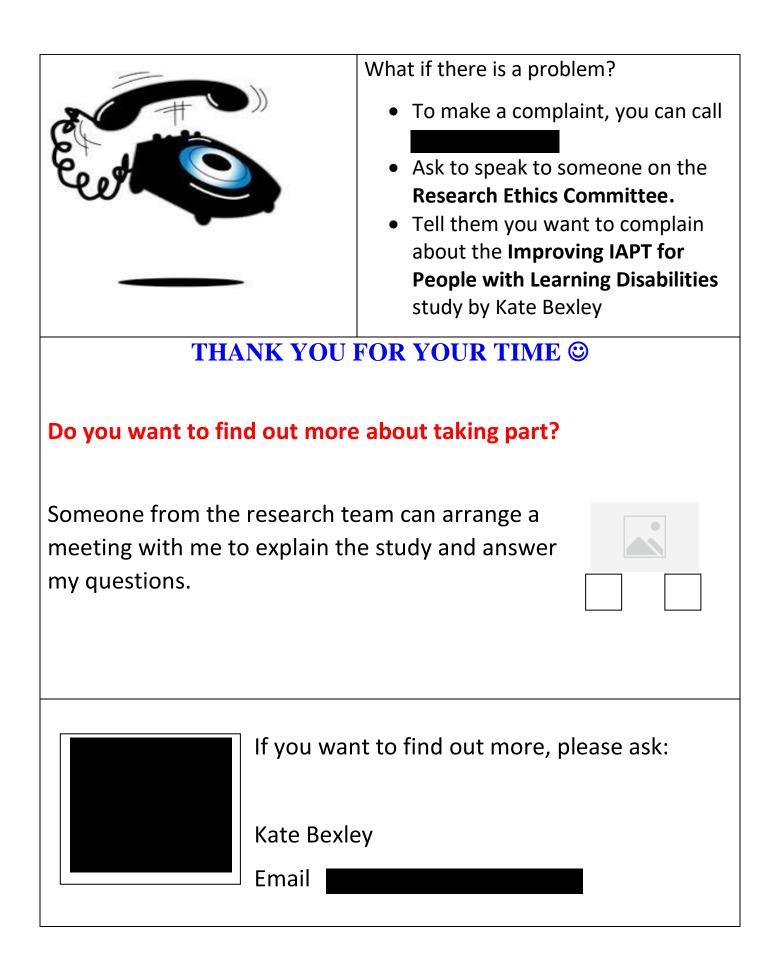
The things you tell us will be kept

- Private
- •In a safe place
- and will not have your name on.

If you tell us something that makes us worried that you or someone else might be at risk, we may need to speak to someone else about it.

We will let you know if we need to do this.

After the project is finished, I will write about it, to let more people know what we found out.
This might include some of the things you say, but <b>not</b> your name. We hope this will help make this service
and other services better for people with learning disabilities in the future
What if I change my mind?
It's your choice
<ul> <li>You do not have to take part in the interview.</li> </ul>
<ul><li>interview.</li><li>You choose what you want to</li></ul>
interview.
<ul><li>interview.</li><li>You choose what you want to say.</li></ul>
<ul> <li>interview.</li> <li>You choose what you want to say.</li> <li>You can stop the interview at any time. It is ok to change your</li> </ul>



Non adapted information sheet

# **Information Sheet for IAPT Clinicians**

**Title of study:** Improving IAPT for People with Learning Disabilities from the perspective of Service Users and Clinicians: An Action Research Approach using

I would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Please ask me if there is anything that is not clear or if you would like more information.

# What is the purpose of the study?

**Overview:** The purpose of this study is to find out how well service users with learning disabilities who have received therapy in IAPT, and IAPT clinicians think IAPT currently fairs in relation to the Greenlight Toolkit audit tool (2013). Results will be analysed and used to guide the implementation of changes within the service over the subsequent six month period. It then hopes to re-evaluate the effectiveness of these changes, again from the perspectives of service users with learning disabilities who have received therapy in IAPT, and IAPT clinicians.

**Background**: IAPT intended reverse inequalities that existed in terms of those receiving treatment. The NHS Confederation, on behalf of the DoH, commissioned the NDiT to report on reasonable adjustments made in made in mental health services to for people with learning disabilities and autism. The resulting report *'Reasonably Adjusted?'* (NDiT, 2012) highlighted few mental health services comprehensively and systematically audited their practice and redesigned accordingly. The NDiT went on to update the Greenlight Toolkit (GLTK, 2013) audit. This is an audit tool which aims to support mental health services measure how successful they are in making adjustments to accommodate the needs of people with learning disabilities and autism within their services. An accessible version was made so that service users could also have their say on how well services faired in relation to the GLTK. At present, little seems to have been done to include the views of service users and the mental health clinicians who work with them in this process.

# Aims:

- To assess how people with learning disabilities and IAPT clinicians think IAPT currently fairs in relation to the GLTK, and obtain their views on what changes might be made to improve the service's rating on the GLTK and experience of people with learning disabilities within IAPT.
- After applying thematic analysis to the data, the study, to implement proposed changes within the IAPT service over a six-month period.
- Reassess how effective the service users and clinicians think the changes have been.

This study is being undertaken as part of my Professional Doctorate in Counselling Psychology. It is expected to last approximately two years in total.

# Why have I been invited?

You have been approached because you are a clinician working within an IAPT service and I am very interested in your views on this topic. I will also be speaking to service users with learning disabilities who have received therapy within IAPT. It is hoped that I will speak to four to eight clinicians and four to eight service users.

# Do I have to take part?

Participation in the project is entirely voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way. It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason.

# What will happen if I take part?

Your involvement in the study will only last the duration of the initial interview in the first instance. To 'check' my assessment of the interview, that is, to validate my analysis, I will ask you at the end of it, if I can speak to you again briefly a few weeks after the interview. I will also ask if you would be interested in being interviewed again after the six-month implementation period for a re-evaluation interview. If you agree to this, I will approach you again in six months, explain the changes which have been made since the first interview and ask if we can arrange a 'follow-up' interview. This would involve asking you the similar questions asked in the first interview. I will again ask if I can meet you again soon after the second interview, again to validate my analysis of our discussion. All meetings are entirely your choice. Hence, you may meet with me once, or more depending on your decisions.

All interviews will be face-to-face, last 30-60 minutes and carried out in the IAPT services main hub, unless agreed otherwise. They will be audio recorded and notes will be made during the interviews to allow me to acknowledge any factors that may be influencing me at the time.

This is a qualitative study using a method known as Action Research in Organisational Development. This method has three main phases. The first involves the interview where I aim to collect your ideas on how well you think the IAPT service is doing in relation to the GLTK and your ideas about what changes might be made to improve it for people with learning disabilities. The second aims to implement the changes suggested by you and other participants. The third aims to review the changes made during the second phase.

The study is expected to last no more than two years. Your involvement will begin with the first interview and end with the review interview six months to one year later, but you may withdraw before this if you choose to.

# What do I have to do?

During the interview, you will be provided with a printed copy of the GLTK which I will talk you through. I will ask you to give each domain a rating. After offering your rating, I will ask you tell me a bit more about why you have given it this rating. I will then ask you for you for your views and suggestions about how the service might improve in this area. If you agree to the follow-up interview, this procedure will be repeated.

# What are the possible disadvantages and risks of taking part?

There are no anticipated risks of harm for participants in this study as it will only be enquiring about views on how well you think IAPT is currently fairing in relation to the GLTK and suggestions about how it better. You are under no obligation to answer any questions. If at any point you feel uncomfortable and/or wish to discontinue the interview, please do let me know and we will stop immediately. All information will be anonymous, your name, nor any other identifiable information will be included in the report.

# What are the possible benefits of taking part?

Participation in this project will provide you with an opportunity to offer your honest views on how well you think IAPT is doing in relation to working with PwLDs, to explain why you think that, and to give your ideas about how things might be improved. It is hoped that you will find the idea that your views and suggestions will be used to make positive changes for current and future PwLDs within the service, during the six-month implementation phase, and the opportunity to be involved with its re-evaluation, a rewarding aspect of participating. It is further hoped that your participation in this study will not only help PwLDs in this IAPT service, but subsequently many other mainstream psychology services. Your participation will also contribute to the knowledge base on this currently under researched area.

# What will happen if the research study stops?

In the unlikely event that the research stops, your anonymized data will be destroyed either by me or by a member of the research supervisory team.

# Will my taking part in the study be kept confidential?

It is of upmost importance that your responses are kept confidential and anonymized. The only reason confidentiality would be broken would be if it was felt that you, or someone else was at risk of harm. In this case, the interviewer will speak to you about what actions they intend to take in order to minimize any potential future harm to yourself or others. I will be the only person aware of your un-anonymized responses. All interviews will be recorded on a digital recording device and then copied onto a password protected disc. Only I will have access to this. The interview will then be deleted from the digital recording device. The interview will be transcribed verbatim and any identifying information will be anonymized to protect confidentiality. The anonymized interview transcript may be read by the research supervisors or by the examiners who assess this thesis project. Following examination, all recordings will be destroyed. Written transcripts will be kept on a password protected computer file for five years, and quotes may be used for additional articles or publications.

# What will happen to the results of the research study?

The results from the first phase of the study will be used to guide the changes in the second (implementation) phase with a view to improve the service with which it relates to for PwLDs. The results from the third phase will be used to further refine adjustments where possible. The completed research project will be written up and submitted in the form of a thesis to examiners at City University, London. It is possible that this research may be submitted for publication. It may also be offered to other IAPT and mainstream psychology services with a view that they may use the results to enhance their practice. Please be assured that all data with remain completely anonymised at all stages post interview. Should you wish to receive a summary of the results and/or copy of the final thesis, please let me know after your interview.

# What will happen if I don't want to carry on with the study?

You have the right to withdraw from this study at any stage without the need to offer an explanation (should you decide to withdraw, the principle investigator reserves the right to use you anonymized data in the writeup of this study and any further analysis that may be conducted by the principle investigator)

### What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is 'Service Users and Clinicians Perspectives on Improving IAPT for People with Learning Disabilities: An Action Research Approach'.

You could also write to the Secretary at: Anna Ramberg



# Who has reviewed the study?

This study has been approved by City University London Psychology Department Research Ethics Committee, and WLMHT

### Further information and contact details

Principle Investigator:

Kate Bexley, Counselling Psychologist Trainee, City University, London.

Email:

Supervisory Team:

Dr Jessica Nielson-Jones, Course Director and Research Supervisor at City University, London, Professional Doctorate in Counselling Psychology programme.

Dr Kate Theodore, Clinical Tutor, Lecturer and Research Supervisor at Royal Holloway, Clinical Psychology Doctorate programme

### Thank you for taking the time to read this information sheet.

### Service user interview schedule

Interview Schedule –Service-users with Learning Disabilities.

#### Introduction

• Thank you very much for coming to talk to me today.

How do you feel about talking to me today?

- Do you have any questions about anything on here (information sheet)?
- Will you let me know if you want to stop the interview at any time? How will you do that?
- If you want a break to go to the bathroom or get a drink or if you get tired will you let me know? How will you do that?

#### **Confidentiality**

Before we start talking today it's important for me to tell you something. As it says here on this information sheet everything we talk about will be kept private. Can you tell me what private means?

I will not tell anyone about anything that we talk about today. But if you tell me something that makes me worry about you or worry about someone else that you know – that could be that you are in danger or someone else is – then I might need to talk to someone else. I will tell you if I need to do this. Do you have any questions about this?

#### Introduction to the questions

I'm going to ask you some questions about this therapy service. It might be difficult to remember some things, and you might not know the answers to some things. That's ok, just tell me as best you can and don't worry if you don't know the answer, some of the questions are very hard! Remember it's your choice. If you don't want to answer a question just tell me. If you want to stop the interview at any time, just tell me.

To help mental health services do better, something called an audit tool was written. An audit is something you can use to check how services are doing. It is important that people with learning disabilities are part of checking how services are doing. To help this happen an easy read version of the audit was written- *point to hard copy of Easy Read GLTK* 

- For all the questions I'm about to ask you, I would like you to give me a rating from D (not very good) to A (very good). –point to traffic light system on Easy Read GLTK.
- You need to choose the description that fits the service best. We can talk a bit about it first if that is helpful for you. If you really can't do this, put a ? in the last row but try not to do this unless you have to.
- Some of the words are a bit difficult. Please ask me if you are unsure what anything means.
- 1. (2) You might know already, this service is called an IAPT service. The first area I would like to ask you about is what you think this IAPT service says about who can use it- *point to hard copy of GLTK*
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?

- What do you think would be helpful to improve the services rating in this area?
- (4). The next area is asking you to think about how well you think this service is able to keep people safe point to hard copy of GLTK
- How would you rate the service which those four answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 3. (5) The next question is asking you about what happens the first few times you met with someone from this service. This is sometimes called an assessment–*point to hard copy of GLTK*
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 4. (6) The next question is asking you what changes you think have been made in IAPT to meet people's needs *point to hard copy* of *GLTK*
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 5. (8) The next question is asking about how you think Staff in IAPT think and behave point to hard copy of GLTK
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- (9) The next question is asking you about the use of Accessible Information in IAPT. This is the same as easy read reading things.
    *point to hard copy of GLTK*
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 7. (10) The next area is Research *point to hard copy of GLTK* This means finding out more about things.
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 8. (16) The next domain is User Involvement in the Governance of the Service *point to hard copy of GLTK*. This means how much you think you were or are involved with making this service better.
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?

- 9. (17) The next domain is Psychological Therapies– *point to hard copy of GLTK* This means the therapy that you had to help you with your mood.
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area
- 10. (18) The next domain is Working Together *point to hard copy of GLTK* This means how well you think IAPT is working with other services like the learning disability service.
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 11. (21) The next area is asking about what you think about the IAPT building and what is like inside point to hard copy of GLTK
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 12. (23) The next area is asking you how you think your Family and Friends found your being seen in IAPT *point to hard copy of GLTK*
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?
- 13. (24) The last domain is Employment Support point to hard copy of GLTK
- How would you rate the service which those answers in mind?
- Can you tell me a bit about why you have given it this rating? Do you have an example?
- What do you think would be helpful to improve the services rating in this area?

### De-briefing

- How did you find talking me to today?
- Do you have any questions?

#### Explain what will happen now.

Now I am going to listen to the tape of what we talked about today. I am going to type it onto a computer. After I do that I will delete this interview from here (show recording device). The file on the computer will not have your name on it. I will do the same thing for all the other people I talk to. Then I am going to write a paper that links all of the things I heard together. I will write about the things we have talked about. I will not use your name anywhere. Do you have any questions about that?

Would you like me to give you more information about what I found out when I have it?

I have a piece of paper which explains some of this on for you- offer debrief sheet. If you do have any questions in the future, you can email me on this email address.

Thank you very much for your time today

### Clinician interview schedule

### Interview Schedule- Participants who are IAPT Clinicians

#### Introduction

- Thank you very much for coming to speak to me today.
- Do you have any questions about anything at all on the information sheet?
- How are you feeling about talking to me today?
- Is there anything I can do to make it feel more comfortable?
- If you want to stop the interview at any time, please let me know.
- If you want to take a break for any reason at any point, please let me know and we can do that.

#### Confidentiality

As explained in the information sheet, everything that we discuss today is completely confidential between us. The only reason I would need to break confidentially would be if I thought you, or anyone else was at risk of harm. If that did happen, I would discuss it with you before talking to anyone else. I would also like to let you know that in the write-up of this research, some quotes may be extracted from the interviews I carry out, all of these will be completely anonymised. Do you have any questions?

#### Introduction to the questions.

As you may know, the purpose of this study is to find out how well service users and clinicians in IAPT think IAPT is doing in relation to the Greenlight Toolkit, and to find out what suggestions people may have about how it might be improved. I will only be asking for your views on element of the Greenlight Toolkit which are relevant for IAPT.

The first part of each of the following questions will be multiple choice. The GLTK uses a traffic light system where respondents can suggest a rating of D (stuck in the garage -not yet started), C (on the journey but stuck at red), B (Amber, Ready for more) or A (Green, which reflects Continuous progress). I will start by describing a domain, and then go through the four possible answers you can give, which reflect to D to A rating. I will then ask you to offer me your rating of this particular domain. After this, I will ask you for your thoughts on how this domain may be improved. If you are really unsure of the answer, please just let me know and we can move on to the next one. Does that make sense? Do you have any questions about this?

(2) The first domain is Eligibility and Access - point to hard copy of GLTK

How would you rate the service which those answers in mind?

Can you tell me a bit about why you have given it this rating? Do you have an example?

What do you think would be helpful to improve the services rating in this area?

(4) The next domain is Safeguarding – point to hard copy of GLTK

How would you rate the service which those answers in mind?

Can you tell me a bit about why you have given it this rating? Do you have an example?

What do you think would be helpful to improve the services rating in this area?

(5) The next domain is Assessment – point to hard copy of GLTK

How would you rate the service which those answers in mind?

Can you tell me a bit about why you have given it this rating? Do you have an example? What do you think would be helpful to improve the services rating in this area?

(6) The next domain is Equalities – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(8) The next domain is Staff Attitudes and Values – *point to hard copy of GLTK*How would you rate the service which those answers in mind?
Can you tell me a bit about why you have given it this rating? Do you have an example?
What do you think would be helpful to improve the services rating in this area?

(9) The next domain is Accessible Information – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(10) The next domain is Research – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area

(12) The next domain is Local Plans – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(14) The next domain is Skilled Workforce – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(16) The next domain is User Involvement in the Governance of the Service – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(17) The next domain is Psychological Therapies – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(18) The next domain is Working Together – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(21) The next domain is Building and Environments – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(22) The next domain is Leadership – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(23) The next domain is Family and Friends – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(24) The next domain is Employment Support – *point to hard copy of GLTK*How would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(25) The next domain is Checking Services – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

(26) The next domain is Monitoring – *point to hard copy of GLTK*How would you rate the service which those answers in mind?

Can you tell me a bit about why you have given it this rating? Do you have an example? What do you think would be helpful to improve the services rating in this area?

(27) The final domain is Challenging Behaviour – point to hard copy of GLTKHow would you rate the service which those answers in mind?Can you tell me a bit about why you have given it this rating? Do you have an example?What do you think would be helpful to improve the services rating in this area?

Debrief:

- How did you find talking to me today?
- Is there anything that we have not covered that you think is important or that you would like to tell me about?
- Do you have any questions about anything that we have talked about or the study in general?

Explain what will happen next – as outlined on the debrief form, I will be talking to a number of other people and asking them similar questions. I will listen to each interview recording and transcribe them. After I've done that, each recording will be deleted. The transcribed file will not have your name on it. I will analyse all of the written interviews, looking for themes and links. Would you like more information about what I have found when I have it?

I will write then try to implement some of the changes suggested through these interviews over a 6 month period. After this, I will try to reevaluate how effective these changes have been. Would you be interested in being part of this re-evaluation?

I will then submit a write up of what has happened and submit it to my university in the form of a Thesis.

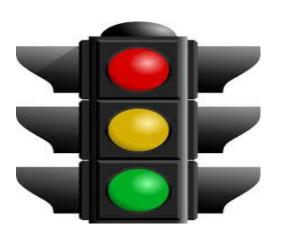
• My contact details are outlined on the debrief sheet. Please do contact me if you have any questions or concerns about the research after today.

Accessible version of GLTK

# Service-users Greenlight Toolkit Interview Questions

# EASY READ AUDIT

The audit works on a traffic light system but another colour has been put in



Grey means nothing is being done

Red means lots of work needs to happen before things are better

Amber means some work has been done but more is needed

Green means that things are going well

# The Basic Green Light 2013 Audit



	Nothing has been done about this	There is a lot to do to make things better	Some work has been done but more is needed	Things are going well	?	Score
What services say about who can use them	This IAPT service says they don't work with People with learning disabilities.	Some people with learning disabilities get support for their mental health problems in mental health services, but nothing is written down about this.	This IAPT service says they will work with people with learning disabilities but not all services do so yet	This IAPT service works with people with learning disabilities.		

Keeping people safe	I did not think my IAPT therapist knew how to keep me safe.	hink my APT/my therapist could tell if there are problems with keeping people with learning disabilities safe		This IAPT service/ my therapist felt they can say if things are wrong. They think the organisation learns from mistakes		
	Nothing has been done about this	There is a lot to do to make things better	Some work has been done but more is needed	Things are going well	?	Score
Assessment	People with mental health problems and learning disabilities can't get a good assessment of needs	People with mental health problems can get checked to see if they have learning disabilities	There are good assessments for people with learning disabilities using mental health services	There are good assessment for people with learning disabilities using mental health services. This is used to give people good services.		

Non-adapted version of GLTK

Clinician Participant Interview Greenlight Toolkit

Rating -> Domain	In the garage, not yet started- Grey	On the journey, but stuck at Red	Ready for more- Amber	Continuous Progress- Green	Rating
Eligibility and Access	LD is used as a diagnosis of exclusion to shut people out of MH services	Some people with LD may receive support from MH services, but this is not part of a deliberate and systematic approach	Eligibility criteria include a clear expectation that MH services should serve people with LD, but they may not actually be doing so	People with LD are found in all parts of the mental health service	
Safeguarding	We have no evidence to demonstrate the safety record of MH services in relation to people with LD	The MH service tracking system for untoward incidents includes a specific facility for tracking incidents involving people with LD	There is evidence that the MH service is learning and changing its practice in response to local incidents involving people with LD	Frontline MH staff report feeling supported when raising safeguarding concerns – they feel that they work in a healthy learning culture rather than a blame culture	

List of all GLTK (2013) domains included and omitted from current study

From the Basic Audit:

- 1. Physical health
- 2. Eligibility and access
- 3. Secure settings –
- 4. Safeguarding
- 5. Assessment
- 6. Equalities
- 7. Personalisation
- 8. Staff attitudes and values
- 9. Accessible information

From the Better Audit:

- 10. Research
- 11. Careplans
- 12. Local plans \*
- 13. How specialist services relate to local provision
- 14. Skilled workforce \*
- 15. People needing personal care
- 16. User involvement in governance of service
- 17. Psychological therapies
- 18. Working together

From the Best Audit:

- 19. Advocacy
- 20. Commissioning
- 21. Buildings and environments
- 22. Leadership \*
- 23. Friends and family
- 24. Employment support
- 25. Checking services \*
- 26. Monitoring \*
- 27. Challenging behaviours

\*Domains only clinicians were asked about

Verbatim phase one responses table excerpt

	Verbatim responses from participants in phase one to the question 'What can we do to improve SAFE-GUARDING?'
	1-'havingwe have a flowchart for [safeguarding] children, do we have a flowchat for adults?' 'More simplevisual, what to do, very simplistic- something on the shared drive, and what kind of things constitute vulnerable adult safeguarding issues'
	2- 'It would be good to have someone that maybe is like a safeguarder, with particular focus on LD because I'm guessing there might be different things'.
Total number of traffic light	3- 'be good to track specifically people with LD and thinking about if we are having incidents about similar things'. 'I'm thinking about what things we could put in what we could change specifically around that client group'.
colours allocated in response to the question 'how well	4. I wouldn't be inclined to ask any more questions if someone has a learning disability around safeguarding safeguarding might need to be assessed differently with people with learning disabilitiesshould there be a bit more about how they're being assessed, if they're in treatment how this is coming across, if they're actually in a relationship does that sound like a healthy relationship?, are they having difficulties with that, or are there children?' 'We don't have any training on I don't think there's anything separate as far as I'm aware'. (re: moving away from blame culture). 'Acknowledging that these kind of things do go wrong sometimes, and sometimes there's nothing we can really do about it, and not give the responsibility back to people' 'if you did have a safeguarding concern about somebody that you felt you haven't quite picked up on, possibly because you thought you haven't fully understood something, [to think about] how a clinician might feel in terms of taking that information further, if they feel that [other] people are going to be like, 'er, why didn't you pick up on that earlier'?
are we doing at the	5. There's lots of different points of view on that about [sexual] consentsome further training on those issues.
moment?'	6- 'Making it clear when we talk about vulnerable adults what sorts of vulnerabilities there arethings that you need to listen out for a little bit more, noticing bad relationshipsgenerally raising awareness of what means.
Grey-0 Red-1	7. 'different recording strategies from our general safeguarding adults reporting'
Amber-7	8. 'Specifying it in guarding guidelines'. 'sort of training or at least awareness raising it could be incorporated into that,'
Green-8 ? 0	9-[re: non blame culture] 'has to come from the clinical leads to start with and from the senior teamjust repeating that message that it really, really is about not blamingmore work to be done in communicating that it is a no blame culture'.

	10- learning disability teams are within local government and I don't have a clue about those structures and social services and supported living and the types of benefitsI just sort of think understanding that and how those systems work will help people navigate safeguarding as well
	11- 'no, you're doing it all well'
	12- 'A helpline to call, give them a helpline number what they can call on and then that way if they, they felt not safe, they could talk on the phone, they could call that line and talk about it'.[tell them] if someone's unsafe on the streets, they feel like they're gonna get mugged or something, call the police'.
	13. ' to ask them questions probably if they have any problems, or if they don't keep it safe and ask them if they have any problems, ask them questions and then they will answer you'
	14- 'Ummm, I'm not really too sure about that'
	15- 'a bit moreadvice on things, like how to keep safe', 'maybe have a contact number for a police officer or something, maybe they come in and have a chat with them and keep them feeling more secure and safe'
	16- to get in touch with people who can look after youFamily, friendsthat person you worrying tell him to get in touch with family and friends either the policeDoctors, speak to the social worker if they got a social worker tell them they can't keep themselves safe'.
Themes:	Suggestions:

	Verbatim responses from participants in phase one to the question 'What can we do to improve EQUALITIES?'							
	1. We could have more specific materials available', 'people that don't have a specific diagnosis, you sometimes don't want tojump to conclusions with them' 'a lot more difficult when someone doesn't have a diagnosis, and you have to adjust your sessions, but not in an explicit way where you agree together' 'you've maybe got some kind of queries along the way, so your sessions kinda have to be adjusted, but not to the extent of using specific [LD] materials//what we were saying in the assessment stages, so getting training, knowing what materials are available and how to work with them/I might be a bit kind of hesitant with some of the materials[knowing] which is the bestway and howto work with it, and so againties in with training.							
	2-'basic stuff likeground floor or yellow paper if they have difficulty readingrolled out in terms of training' 'knowingexclusion criteria, what would it bewhen severe, then its that's understandable, but when it's the mild to moderate let's say?', 'clarity around that would be helpful'.							
	3-' kind of recording the impacts and seeing with a specific LD and different LD diagnoses, if there is a trend and changes that need to be made' 'tracking'.							
	4- 'recording the impact of reasonable adjustments', but in order for us to get to that we need to be, we need a second one, so having an awareness of what a reasonable adjustment is'.							
	5- I think if the team are all trained up a bit more' '[more] flexibility with triages'							
Total number of traffic light	6- Make sure there's willingness to be flexiblefrom management andcommissioners ultimately commissioners set targets and we have to meet targets otherwise we risk fundingwe need an understanding at the higher levels otherwise things get messy on the groundmaybe build in LD into targets'.							
colours allocated in	7-'general things about making it accessible in terms of what our posters look like for, for workshops whether we provide specific workshops for people who struggle with their learning, or try to make all groups more accessible?'							
response to the question 'how	8- 'I don't know what else you can do'.							
well are we doing at the	9- 'a practical, "This would be a good way to work with this group of people," and to offer some practical advice', 'open dialogues about the fears, that might come up for peoplepeople's personal experiences of itso people could be quite openabout any misgivings or concernsan open forum, where people could share their experiences of working with differences'.							
moment?	10- website have the consultation forums and like we were going to have the service user forum but make sure it's kind of well represented and not a homogenous sample of our clients we do try and keep it varied and if its not appropriatehave a seperate one but ideally you want to be integrating where you can							
Grey-0	11- After some of the sessions with my therapist, I think I need a bit longer with herbecause the problems that I had a home she helped me withbut I need a bit more extra help on top							
Red-3	15 or 20 minutes longer sessions, or more than once a week.							
Amber-7	12-don't know							
Green-6	13- 'nah'							
	14- 'There's a little step down there, you could maybe get a little ramp for people who are in a wheelchair, or where there's the buzzer you could press the button, and the door could open automatically. Um. the front desk just press the buzzer and adored open automatically for someone who is in a wheelchair.							
	15- appointments sometimes need, they should have a little bit longer appointments because, if you like, if someone with learning disabilities cant always talk like properly, they need time to try to get the words out and it's not, like fair,							

16- make it better for people who may be got severe learning difficulties to put it on bright paper make it more stand out' 'Make it easier to read, not long words. I know it's like when your child to break it down it makes it easier teaching that I think is really good I find when you broke the word it makes it so simple read and that.							
Suggestions:							

Domain	Pseudo- themes identified from the first phase by lead researcher	Pseudo -themes	seudo -themes identified from the first phase by participant clinicians							Pseudo-themes identified from the first phase by CLDT clinical psychologist	
		Nancy	Priya	Harriet	Anthony	Joe	Tanya	Ben	Emma	Jasmine	
Eligibility and Access	-Need to increase awareness amongst LD population and professionals (GPs, LD services) that we can/do work with PwLD -Need to increase clinician confidence/ experience/ training – see 'training plan'	-Awareness in terms of publicity and Reasonable Adjustments. -Training- for staff and other professionals.	-Training. Increase access. -Promotion of service. Improve links with other services	-Training, -Advertising -Improving adapted materials	-Training [for]- internal [professionals e.g. IAPT staff] and external [e.g. GPs professionals]. Make changes to the materials	-Awareness raising. Training	-Promotion -Training clinicians	-Training for the team on working with LD. Increasing awareness with stakeholders that we can work with LD. Marketing – specific to our work with LD. Connecting with other organisations in Borough who work with LD groups	-Need to increase access and accessibility. Training for staff and what that would look like	-Training. Confidence levels of work with pwld. -Links to other services	Raising awareness in other professionals / advertising in services that IAPT can work with PwLD Increasing accessibility in the service Training for IAPT staff and increasing staff confidence Improving links between LD service and IAPT

Safeguarding	-Uncertainty around difference in procedures for assessing and managing safeguarding issues amongst PwLD/ -Need to raise awareness of different risk factors and how to approach and manage. -Need to reiterate non- blame culture	<ol> <li>Need for training/ awareness of specific LD safeguarding problems.</li> <li>Tips for safety.</li> <li>Specific LD safeguarder</li> </ol>	2. Separate safeguarding lead. Differences with LD population.	3. Improve intersystem communication. Training on what to look out for Improve no blame culture.	4. Easy access info – flow chart. Training – specific information on how to ask, 'how to keep safe' and who to tell.	5. Complexity. Need for guidelines and guidance	6. Separate LD safeguarding person Training	7. Lack of clarity and consensus on safeguarding issues for people with LD Need for 'no blame culture'.	<ul> <li>8.</li> <li>Need key LD safeguarding lead person.</li> <li>Lack of confidence, who to approach.</li> <li>Not knowing the right thing to do.</li> </ul>	9. Is there something more specific we should be doing for PwLD? Need for more advice and information on PwLD	Clarifying procedures for Safeguarding PwLD Managing clinician anxiety / increasing clinician confidence in raising / managing Safeguarding concerns for PwLD (linked to non-blame culture?) Accessible contacts sheet / advice for service users re keeping safe
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City Ethics Approval Letter



Psychology Research Ethics Committee School of Social Sciences City University London London EC1R 0JD

9 December 2014

Dear Kate Anne Bexley

# Reference: PSYCH(P/F) 14/15 58

**Project title:** Improving IAPT for People with Learning Disabilities from Service Users' and Clinicians' Perspectives: An Action Research Approach

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

# Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

### Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

### Adverse events

Kind regards

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee (<u>anna.ramberg.1@city.ac.uk</u>), in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and vulnerable adults
- (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Erika Suchanova	Katy Tapper
Departmental Administrator	Chair
Email:	Email:

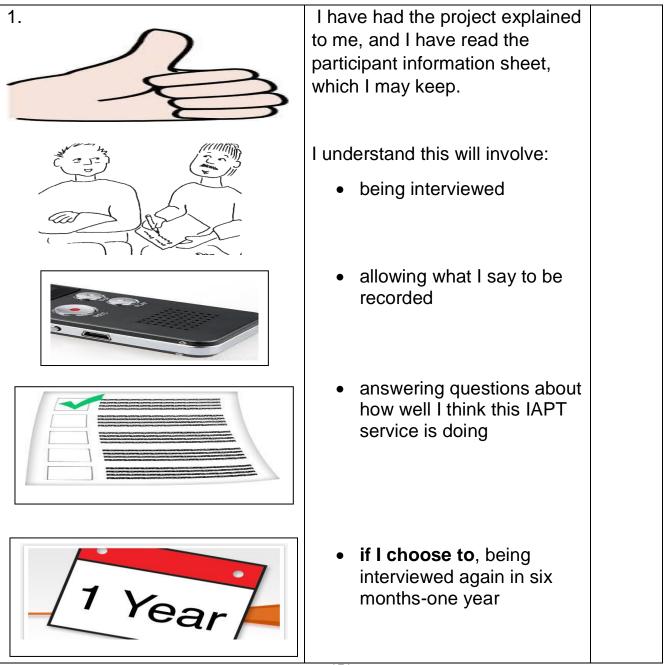
Services users-accessible consent form

# Service User Participant's Consent Form

# Title of Study: Improving IAPT for People with Learning Disabilities from Service Users' and Clinicians' Perspectives: An Action Research Approach

Ethics: Reference: PSYCH(P/F) 14/15 58

Please initial box



It <b>will not</b> have my name on it No-one except the person asking me questions and main researcher will know I said what I said
I understand <b>I do not</b> have to take part in the project. If I decide to take part in the interview or not, it will not change the way services work with me.
ree to City University London bing this information about derstand: This information will only be used for the reasons explained to me My agreement is only there if the University keep its promise to keep this information private.

5.	I agree to take study.	part in the above
Name of Interviewer	Signature	Date
Name of Participant	Signature	Date

When completed, 1 copy for participant; 1 copy for researcher file.

Clinicians (non-adapted) content form

# Clinician Participant's Consent Form

Title of Study: Improving IAPT for People with Learning Disabilities from Service Users' and Clinicians' Perspectives: An Action Research Approach

# Ethics Reference: PSYCH(P/F) 14/15 58

Please initial box

1.	I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.	
	I understand this will involve	
	being interviewed by the researcher	
	<ul> <li>allowing the interview to be audiotaped</li> </ul>	
	<ul> <li>completing the Greenlight Toolkit Audit asking me about how well I think this IAPT service is doing</li> </ul>	
	• if I choose to do so, making myself available for a further interview in six months-one year	
2.	This information will be held and processed for the following purpose(s):	
	I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.	
3.	I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalized or disadvantaged in any way.	
4.	I agree to City University London recording and processing this information about me. I understand	
	that this information will be used only for the purpose(s) set out in this statement and my consent is	
	conditional on the University complying with its duties and obligations under the Data Protection Act 1998.	
5.	I agree to take part in the above study.	

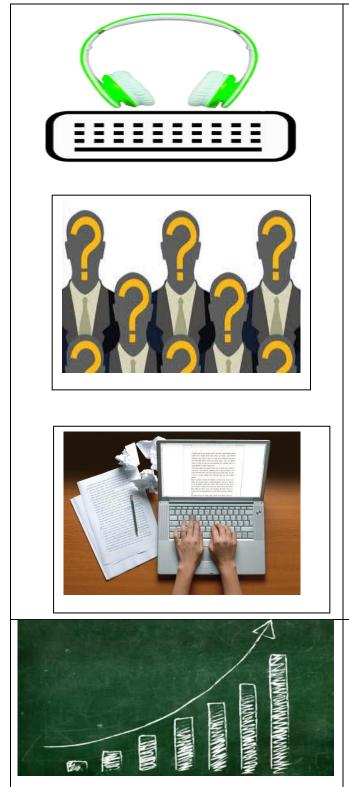
Name of Researcher	Signature	Date
Name of Participant	Signature	Date

Services users-accessible debrief form

# After Interview Information Sheet for Service Users

About the Improving IAPT for People with Learning Disabilities Project

# What happens now?



The recording of our interview will be listened to and typed onto a computer.

The recording be deleted from the recorder.

The file on the computer will not have your name on it. I will do the same thing for all the other people I talk to.

Then a paper is going to be written that links all of the things heard together. Things we have talked about will be written about. Your name will not be used anywhere.

Would you like me to give you more information about what I found out when I have it?

We will then try and make some changes in this IAPT service over the next six months to make things better for people with learning disabilities who also have mental health problems

E Z R	If you have stated that you would consider being part of this, you will be contacted shortly, if you want to be part of the re-evaluation, you will be contacted over the next 6 months to one year
O See	If you do have any questions in the future, you can email me on this email address: or call me on:
	<ul> <li>What if there is a problem?</li> <li>To make a complaint, you can call</li> <li>Ask to speak to someone on the Research Ethics Committee.</li> <li>Tell them you want to complain about the Improving IAPT for People with Learning Disabilities study by Kate Bexley</li> </ul>

# Thank you again for your time!

Clinicians (non-adapted) debrief form

# **After Interview Information Sheet for Clinicians**

# About the Improving IAPT for People with Learning Disabilities Project

# What happens now?

- I will be talking to a number of other people and asking them similar questions. I will listen to each interview recording and transcribe them. After this, each recording will be deleted. The transcribed file will not have your name on it. I will analyse all of the written interviews, looking for themes and links. Please do contact me on the details outlined below of you would you like more information about what I have found out when I have it
- I will write then try to implement some of the changes suggested through these interviews over a 6-month period. After this, I will try to re-evaluate how effective these changes have been. If you have stated that you would consider being in part of the implementation phase, you will be contacted shortly. If you have indicated that you would like to participate in the re-evaluation, I will be in contact with you over the next 6 months to one year.
- Following the re-evaluation, I will write up of what has happened and submit it to my university in the form of a Thesis.

If you do have any questions, comments of feedback about this study, please do not hesitate to contact me

# What if there is a problem?

If you would like to complain about any aspect of the study, City University London has established a complaints procedure via the Secretary to the University's Senate Research Ethics Committee. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is 'Service Users and Clinicians Perspectives on Improving IAPT for People with Learning Disabilities: An Action Research Approach'.

You could also write to the Secretary at: Anna Ramberg



Principle Investigator: Kate Bexley, Counselling Psychologist Trainee, City University, London.

Email:

Supervisory Team:

Dr Jessica Nielson-Jones, Course Director and Research Supervisor at City University, London, Professional Doctorate in Counselling Psychology programme.

Dr Kate Theodore, Clinical Tutor, Lecturer and Research Supervisor at Royal Holloway, Clinical Psychology Doctorate programme

# Thank you again for your time.

Excerpt of annotated transcript (clinician 'Amy', phase one)

I: Okay, so the next domain is equalities, again, if you just want to have a read through and... let me know what you think. P: (pause-reads answers) So, do you mean sort of adjustments to, erm, kind of be quite flexible with the way that we work? Erm I: Yep P: Yeah, then in that case it would be green seure 5 I: Okay, can you... P: I think, well, there's, you know it definitely something we work with and we can be guite flexible, urm...can I just see ... (looks over answers again) so it think its erm, in terms of working with people, although I think its really positive in this service, I think, um, oh, maybe that's more kinda me. So, we could have more specific materials available, I know they are available, but how readily used they are. I suppose I'm thinking about people that don't have a specific diagnosis, you sometimes don't 1 pm me for a gating diagrass worg? want to....jump to conclusions with them materi CO H I: Yeah P: Ummm, so if someone does have a diagnosis, it's kinda, it's quite clear how you are going to work and quite clear how you adjust things. It's a lot more difficult when someone doesn't have a mana diagnosis, and you have to adjust your sessions, but not in an explicit way where you agree together, OKOC does that make sense? So you're kind of working with somebody, and you've maybe go some kind of (1)m queries along the way, so your sessions kinda have to be adjusted, but not to the extent of using n daa Untre how mon/ specific materials and that kind of thing. I: Okay, P: but, I do think it's definitely a good service for having those adjustments available, um and the flexibility to work with people, erm, yeah, creatively. I: So, it sounds as though the green rating is kinda a reflection of the fact that we will make adjustments, but in terms of perhaps what we could do to improve this area...? P: Sorry, I really wasn't clear I: No, no no! it sounds kinda like being more collaborative with the client in the session to figure out...and again it's a tricky area, it not always black and white P: Yeah, I think it really depends on, it really ties into what we were saying in the assessment stages, so getting training, knowing what materials are available and how to work with them. So, I think, I might be a bit kind of hesitant with some of the materials, purely because I have never worked with documpt them before and I don't know which is the best, kind of way and how and all of that to work with it, and so again, that ties in with some of the training. Errm. But I do think it is a good, flexible service. Loch OF EXPENSIO Trang to noteose considere? motoriau I: Thank you. So the next domain is staff values and attitudes. Erm , again if you want to have a read through and let me know how you'd rate the service with those answers in mind. P: [reads through]. Yeah, it would be green

I: Green?

P: Yep I: And...can you say a bit more about ... P: Erm... it seems like people have a really positive attitude here. Umm, kind of, it's quite hard to CR QP ma explain, like really open to accepting people and being very, erm, you know, a good sense of equality. If you assess people, it's not kind of, there's no stigma, and we're, it seems like we're happy  $P_{i'}$ to work with people, all different kinds of people, so .. I: It sounds like there's no kind of prejudice or stereotyping that we're quite open? NON P: Yeah, so people work with people with LD and seem happy and confident to do so. I certainly think that that's a really good area. I: Okay, and what do you think could help improve even more in this area? In terms of staff values SW? lipsod to recrease and attitudes of staff working with LD? P: Erm... I think if there were more people referred and we worked with more people, then, that kind NUTRES 4 AMD of ties back to what we were saying at the beginning about improving access, so by seeing more OLCOSTIC LE people, we'd all kind of ... I: Feel a bit more experienced? Jordn le Incresse P: Yeah, yeah I: So, it sounds like feeling a bit more experience of PwLD, we'd have perhaps a more, erm, positive attitude? P: Yeah, definitely. ]WRAAD I: ...and that links back in with improving access? numbers P: Yes, yeah. I think so far, its excellent, but I think by getting more people in, more people would 100000 feel more confident and it would improve even further experience IMACHED I: Okay, great, thank you. So the next area is 'accessible information', so thinking about easy-read, Confident and the language that we use. P: Umhm, so I think that would be green LOCK OF and I: Uh huh, great. P: Er, possibly an amber ... [laughs]. So, I think, I think it's really good. The problem is that I haven't worked specifically with all the whole range of materials so I don't know. So it would be more a kind , nonan of a question mark, than a definite, purely because I haven't worked with all the materials myself Erm, but, as far as I am aware, there is a lot of materials, umm, people kinda are flexible to adapt the sessions and um, you know , adapt language and communication styles based on who they are working with. But then, I can only speak for myself, so, but as far as in know, it is really positive. tope Flexible Thingtue 60 Befoxide/

## Initial codes list

#### Codes:

- 1. Clinician anxiety/uncertainty
- 2. -little confidence
- 3. -lack of knowledge
- 4. -lack experience/ awareness
- 5. need for training/ clarity
- 6. -Same or different
- 7. -fear of offending
- 8. About 'achievableness' in IAPT
- 9. Need for exposure to pwld/ increasing access
- 10. -access to protocols
- 11. Desire for this to simple/convenient
- 12. Promotion/dissemination- advertising what we do
- 13. Externally
- 14. Internally
- 15. Training:
- 16. awareness raising within the team
- 17. for the whole team/ everyone
- 18. for specialists and supervisors
- 19. -step specific
- 20. to be practical-broad, basic 'how to'
- 21. -on materials
- 22. -on risk
- 23. -on other services
- 24. -experienced based
- 25. -mandatory
- 26. -protocols and policies
- 27. To increase comfort /confidence

## 28. Evidence base

- 29. Application of research
- 30. Treatment of LD
- 31. Standardised tools and protocols

## 32. Joint working/working

- 33. Clarity- who are they and what do they do?
- 34. -CLDT
- 35. -CMHT
- 36. -Third sector
- 37. Employment
- 38. -referral pathways
- 39. -sharing expertise
- 40. -consultations/ liaisons
- 41. Make it simple/ obvious

## 42. Constraints of IAPT

- 43. time pressures
- 44. needs to be Top down / manager and commissioner led
- 45. competing demands

## 46. SU involvement

- 47. Need to increase
- 48. To help us develop
- 49. To keep them informed
- 50. PEQ 51. Validity of
- Consent / confidentiality Empowerment –what can SU's do (risk)

## 53. F/F involvement

- 54. Involvement
- 55. Helping them

## 56. Reasonable Adjustment's

- 57. RAs: easy read materials
- 58. RA's; multi-model communication
- 59. RAs: session duration, number and time
- 60. RAs: building
- 61. RA's: clarity on
- 62. RA's: permission 'from above'
- 63. RA's; Flexibility
- 64. RA's: monitoring the effects of

## 65. Ongoing service commitment

- 66. Needs to be a priority
- 67. monitoring -dx
- 68. -reflective practice -implementing what we learn
- 69. -adjustments to policies
- 70. -recruitment of specialists
- 71. -training

#### 72. Championing

- 73. More than one expert
- 74. Transparency / approachability

#### 75. Individual differences

#### 76. Preparedness

- 77. pre access reasonable adjustments communication
- 78. fairness –
- 79. LD label-clarity on- role of/need for LD Diagnosis
- 80. Permission to get it wrong-blame culture-fear of erroropenness

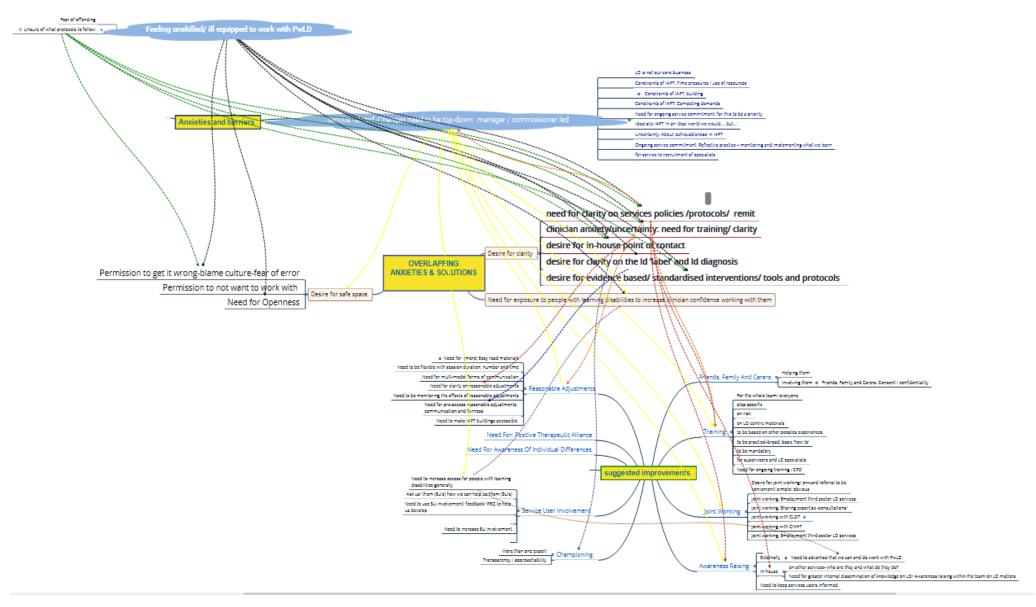
ment I pathways g expertise

Coded extract table excerpt- clinicians phase one

Participant /Domain	Extract	Coded for
'Amy' PWP		
Eligibility, Access	P:thinking in terms of my experience, there's you know, from screening, it's definitely not something you'd, I'd exclude at screening and then triage people, we see people at step two, I'm sure I've seen people who have then gone on to step three	We are doing well: Inclusive of PwLD
Eligibility, Access	P:well, I suppose because there are people, it doesn't mean its representative, I certainly think that there could be more that could be done. I'm not sure whatthe national proportion is of people with LD but, I haven't come across loads of people, in this service, but I have come across people	<ul> <li>We are doing well: but could do better</li> <li>Need to increase access for people with learning disabilities generally</li> </ul>
Eligibility, Access	P:I suppose just numbers, and kinda I'm sure we come on to it, but barriers at earlier stages, soyeah, at the kinda later stages, when they get to see somebody I think it's fine. I think it's more about getting people in	<ul> <li>Need to increase access for people with learning disabilities generally</li> <li>Need for pre-access reasonable adjustments, communication and fairness</li> </ul>
Eligibility, Access	P:kinda, increasing awareness of our kinda service and the fact that we <i>do</i> work with people, you know, all different kinds of people. Maybe kinda targeting areas where people with learning disabilities might be, I don't know what that might be, erm, I suppose kinda thinking about the distinguishing between a more specialist service and our service and whether other kinda professionals know that we do have the scope to work with peopleso they don't have to go to a specialised service, so maybe there's increasing awareness amongst other professionals as well.	<ul> <li>Need to advertise that we can and do work with PwLD</li> <li>Joint working: Sharing expertise -consultations/ liaisons</li> <li>Need to develop referral pathways between services</li> </ul>
Safeguarding	P: I have never raised a safeguarding issue with a vulnerable adult here, but I know that if that were to arise, I would feel comfortable, um, raising it and I would feel supported in the decision of what to do and I feel that people have, people working here have a lot of knowledge in terms of what to do in those kinds of situations, so that's, that would be, yeah, green	<ul> <li>We are doing well: Supportive/ sharing skills</li> <li>We are doing well: Safeguarding</li> </ul>
Safeguarding	P: maybe havingwe have a flow chart for children, do we have a flow chat for adults? More simple kinda, erm just visual, what to do, very simplistic, that you can kinda follow it and then know exactly what to do and take things a bit more in depth, umm, , there are all sort of things that can come up	<ul> <li>We are doing well: Supportive/ sharing skills</li> <li>Clinician desire for simplicity /convenience</li> <li>Clinician anxiety/uncertainty: Unsure of what protocols to follow</li> <li>Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD</li> <li>Training: To be practical-broad, basic 'how to'</li> <li>Clinician anxiety/uncertainty: Need for training/ clarity</li> </ul>
Assessment	P: often we don't have people who don't have a diagnosis, and then sometimes it can be quite tricky to assess if you get a referral and it doesn't have a diagnosis or any kind of indication on it, sometimes it can be quite difficult to assess and know what we're meant to be assessing and I haven't had any training in sort of LD, oh, actually, I think I probably have (laughs) I remember that now very vividly (jokingly), but I mean in terms of assessing it, what sort of questions to ask and how to assess it thoroughly, erm, when working with it and what sort of level to be working with it, that sort of thing, er, so the clinician working with the patient, what they would need to know at assessment, erm, so I think they could be improvements there, but whether there's something, I think there's just a difficulty in there being a lack of diagnosis generally,	<ul> <li>UNCERTAINTY for clarity on the LD 'label' and LD diagnosis</li> <li>Need for pre-access reasonable adjustments, communication and fairness</li> <li>Clinician anxiety/uncertainty: Need for training/ clarity</li> <li>Need for training: to be practical-broad, basic 'how to'</li> </ul>

Equalities	P: there's, you know it definitely something we work with and we	We are doing well: Making adaptations
	can be quite flexible, urmcan I just see ( <i>look over answers again</i> ) so it think it's erm, in terms of working with people, although I think it's really positive in this service, I think, um, oh, maybe that's more kinda me. So, we could have more specific materials available, I know they are available, but how readily used they areI suppose I'm thinking about people that don't have a specific diagnosis, you sometimes don't want tojump to conclusions with them	<ul> <li>Need for greater internal dissemination of knowledge on LD/ Awareness raising within the team on LD matters</li> <li>Reasonable Adjustments: Need for (more) easy read materials</li> <li>Clinician anxiety/uncertainty: Fear of offending</li> </ul>
Equalities	P: It's a lot more difficult when someone doesn't have a diagnosis, and you have to adjust your sessions, but not in an explicit way where you agree together, does that make sense? So you're kind of working with somebody, and you've maybe got some kind of queries along the way, so your session ns kinda have to be adjusted, but not to the extent of using specific materials and that kind of thing.	<ul> <li>Desire for clarity on the LD 'label' and LD diagnosis</li> <li>Need for clarity on reasonable adjustments</li> <li>Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD</li> </ul>
Equalities	P: but I do think it's definitely a good service for having those adjustments available, um and the N to work with people, erm, yeah, creatively.	We are doing well: Making adaptations
Equalities	P: so getting training, knowing what materials are available and how to work with them. So, I think I might be a bit kind of hesitant with some of the materials, purely because I have never worked with them before and I don't know which is the best, kind of way and how and all of that to work with it, and so again, that ties in with some of the training. Errm. But I do think it is a good, flexible service.	<ul> <li>Need for training on LD centric materials</li> <li>Need for training to be practical-broad, basic 'how to'</li> <li>Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD</li> <li>Clinician anxiety/uncertainty: Need for training/ clarity</li> </ul>
Staff Attitudes	P: it seems like people have a really positive attitude here. Umm, kind of, it's quite hard to explain, like really open to accepting people and being very, erm, you know, a good sense of equality. If you assess people, it's not kind of, there's no stigma, and we're, it seems like we're happy to work with people, all different kinds of people so people work with people with LD and seem happy and confident to do so. I certainly think that that's a really good area	<ul> <li>We are doing well: Making adaptations</li> <li>We are doing well: positive staff attitude to working with PwLD</li> <li>We are doing well: Inclusive of PwLD</li> </ul>
Staff Attitudes	<ul> <li>P: I think if there were more people referred and we worked with more people, then, that kind of ties back to what we were saying at the beginning about improving access, so by seeing more people, we'd all kind of</li> <li>I: Feel a bit more experienced?</li> <li>P: Yeah, yeah I think by getting more people in, more people would feel more confident and it would improve even further</li> </ul>	<ul> <li>Need for exposure to people with learning disabilities to increase clinician confidence working with them</li> <li>Need to increase access for people with learning disabilities generally</li> <li>Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD</li> </ul>
Accessible Information	P: The problem is that I haven't worked specifically with all the whole range of materials so I don't know. So it would be more a kind of a question mark, than a definite, purely because I haven't worked with all the materials myself. Erm, but, as far as I am aware, there is <i>a lot</i> of materials, umm, people kinda are flexible to adapt the sessions and um, you know, adapt language and communication styles based on who they are working with. But then, I can only speak for myself, so, but as far as in know, it is really positive.	<ul> <li>Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD</li> <li>Need for greater internal dissemination of knowledge on LD/ Awareness raising within the team on LD matters</li> <li>Unsure of answer</li> <li>We are doing well: Making adaptations</li> <li>We are doing well: Aware of individual differences</li> <li>We are doing well: probably</li> </ul>
Accessible Information	P: if all supervisors and triage supervisors were really really familiar with all the materials and things like that, to then work, perhaps, you know, if I were seeing somebody, um, taking it to supervision and using that supervision time to think about things, so if my supervisor had a lot of knowledge and experience of everything that was available, that would be really helpful I think.	<ul> <li>Need for training: for specialists and supervisors</li> <li>Need for training: on LD centric materials</li> <li>Need for greater internal dissemination of knowledge on LD/ Awareness raising within the team on LD matters</li> <li>Clinician desire for simplicity /convenience</li> </ul>

Early thematic mind map example- clinicians phase one



# Code frequency table example- clinicians phase one

Frequency Codes Table: Clinicians Phase One

Chief code	Sub code	Number of parti to this-	cipants who referred	TOTAL OCCURANCES		
We are doing well		CLINICIANS	SERVICE USERS	CLINICIANS	SERVICE USERS	
	We are doing well: Accountability, elicitation of and responsiveness to feedback	5	2	14	2	
	We are doing well: positive staff attitude to working with PwLD	6	3	7	4	
	We are doing well: Helping people improve lives	0	3	0	3	
	We are doing well: Aware of individual differences /increased needs	2	3	2	4	
	We are doing well: Helping through talking therapies	0	2	0	3	
	We are doing well: Helping through information giving	0	3	0	6	
	We are doing well: Safeguarding	9	4	11	6	
	We are doing well: Collaborative safeguarding	0	2	0	2	
	We are doing well: Supportive/ sharing skills	8	0	21	0	
	We are doing well: Accessible building	1	1	1	1	
	We are doing well: Inclusive of PwLD	10	5	20	13	
	We are doing well: Services working together	6	3	12	6	
	We are doing well: We are considered helpful- we care to make a difference?	0	5	0	7	
	We are doing well: Making adaptations	4	5	6	11	
	We are doing well: Friends and family are involved	2	3	2	5	
	We are doing well: Positive therapeutic alliance	0	3	0	5	
	We are doing well: Point of contact/ LD lead(s)	8	0	18	0	
	Need for: Positive therapeutic alliance	0	1	0	1	

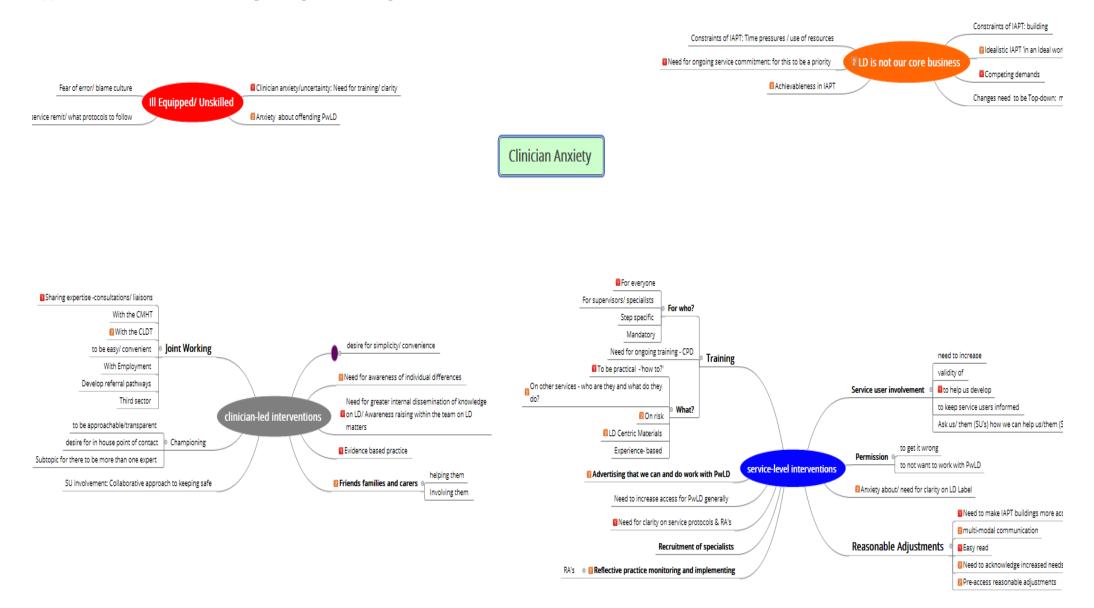
	•	•			
	Need for awareness of individual differences	6	3	11	10
	Need to acknowledge the increased needs of PwLD / need for flexibility	6	4	10	10
	Give us information	0	6	0	9
Clinician anxiety/uncert ainty	Clinician desire for simplicity /convenience	4	0	10	0
	Clinician anxiety/uncertainty: Need for training/ clarity	9	0	31	0
	Clinician anxiety/ uncertainty- feeling unskilled/ ill equipped to work with PwLD	10	0	41	0
	Clinician anxiety/uncertainty: Unsure of what protocols to follow	8	0	16	0
	Clinician anxiety/uncertainty: Fear of offending	6	0	9	0
	Clinician anxiety/uncertainty: About 'achievableness' in IAPT	5	0	6	0
	Clinician anxiety/uncertainty: Permission to get it wrong-blame culture-fear of error	4	0	10	0
	Permission to not want to work with PwLD	4	0	4	0
	Need for Openness	2	0	5	0
Training –who, why, what?	Need for training to be step specific	4	0	5	0
	Need for training for LD specialists and supervisors	4	0	5	0
	Need for greater internal dissemination of knowledge on LD/ Awareness raising within the team on LD matters	10	0	48	0
	Training: For the whole team/ everyone	10	3	26	5
	Need for training to be mandatory	1	0	2	0
	Need for training to be based on peoples experiences	2	0	2	0
	Need for awareness raising / training to include details on other services- who are they and what do they do?	7	0	14	0
	Need for training on risk	7	0	6	0
	Need for training on LD centric materials	5	0	9	0

	Need for training: to be practical- broad, basic 'how to'	10	1	36	1
Increasing access					
	Need for exposure to people with learning disabilities to increase clinician confidence working with them	4	0	7	0
	Need to increase access for people with learning disabilities generally	4	0	8	0
Promotion/ dissemination advertising what we do					
	Need to advertise that we can and do work with PwLD	5	3	10	3
Evidence base					
	Desire for evidence based/ standardised interventions/ tools and protocols	8	0	9	0
Joint working					
	Need to develop referral pathways between services	4	1	9	2
	Joint working: Sharing expertise - consultations/ liaisons	9	2	26	3
	Joint working: Employment	2	2	3	2
	Desire for joint working/ onward referral to be convenient/ simple/ obvious	4	0	5	0
	Need to develop joint working with CLDT	7	0	12	0
	Need to develop joint working with third sector LD services	1	0	1	0
	Need to develop joint working with the CMHT	3	0	3	0
Constraints of IAPT					
(Barriers)?	Idealistic IAPT 'in an Ideal world we would, but'	6	0	10	0
	Constraints of IAPT: Competing demands	8	0	15	0
	Changes need to be Top-down: manager / commissioner led	5	0	10	0
	Constraints of IAPT: Time pressures / use of resources	4-	0	11	0
	Constraints of IAPT: building		0	10	0
	LD is not our core business	5	0		

SU involvement					
	Need to increase SU involvement	3	1	3	1
	Need to use SU involvement/ feedback/ PEQ to help us develop	9	1	14	1
	SU involvement: Need to keep services users informed	1	3	2	3
	SU involvement: Validity of	4	0	6	0
	SU involvement: Collaborative approach to keeping safe	0	3	0	5
	Ask us/ them (SU's) how we can help us/them (SU's)	3	2	6	2
Friends, Family and Carers					
	Friends, Family and Carers: Consent / confidentiality	3	0	5	0
	Friends, Family and Carers: Helping them	5	2	5	2
	Friends, Family and Carers: Involving them	7	2	10	2
Reasonable Adjustments					
	Need for (more) Easy read materials	8	4	24	5
	Need for multi-model forms of communication	6	2	7	4
	Need to be flexible with session duration, number and time	4	2	5	3
	Need to make IAPT buildings accessible	8	4	10	4
	Need for clarity on reasonable adjustments	3	0	4	0
	Need to be monitoring the effects of reasonable adjustments	6	0	11	0
Ongoing commitment					
	Need for this to be a priority	9	0	20	0
	Ongoing service commitment: Reflective practice – monitoring and implementing what we learn	6	0	15	0
	Need for ongoing training - CPD	4	0	5	0
	Need for clarity on services policies /protocols/ remit	8	0	21	0
	Ongoing service commitment: for service to recruitment of specialists	3	0	3	0
Preparedness					

Need for pre-access reasonable adjustments, communication and fairness	7	1	13	1
Desire for clarity on the LD 'label' and LD diagnosis	7	0	15	0

## Appendix 21 Final thematic mind map (example- clinicians phase one)



Learning disabilities in IAPT- training overview

## SEEING PEOPLE WITH MILD LEARNING DISABILITES / LOWER LITERACY LEVELS IN IAPT

## TRAINING OVERVIEW

- Importance of being able to have \* open\* and confidential discussions
- Clinician confidence measure before and after

Whole team training– <i>Introduction to LD in</i> IAPT	Step 2- <i>clinical skills</i>	Step 3/ supervisorsAdvanced assessment and treatment
<ul> <li>Permission to struggle / not get it</li> <li>Introduction of LD 'leads'</li> <li>Why have IAPT for PwLD</li> <li>Assessing -being aware of 'signs' of LD what it looks like' diagnostic criteria</li> <li>What is Global Developmental Delay?</li> <li>How to ask if someone has LD</li> <li>How to communicate with PwLD</li> <li>Distinction between what we offer and what the LD Psych team offer</li> <li>Explanation of the referral pathways with LD team / AT, awareness of who and how to refer for LD assessment- availability of consultations</li> <li>What the LD label on IAPTus refers to- need to use it!</li> <li>What adjustments can we make- session duration, number of sessions</li> <li>Safeguarding amongst PwLD- awareness of different vulnerabilities Non blame culture – easy read safety plan</li> <li>Encourage PwLD to speak to friends, family, social worker and GP as well if they feel unsafe</li> <li>Employment support options</li> </ul>	<ul> <li>Working with PwLD at step 2 using GSH e.g. depression, panic, worry, relaxation, assertiveness</li> <li>S2 evidence base for PwLD</li> <li>How to engage pwLD at triage and during treatment</li> <li>Specific, common difficulties encountered and how to overcome</li> <li>Making letters more accessible, picture of building, clinical, clock for time</li> <li>Introducing existing easy read materials (where they can be found on G Drive) how to use/apply it</li> <li>Making 'mainstream' CBT materials accessible –disorder specific materials</li> <li>*lived experiences of clinicians who have worked with pwLD e.g. CR, BA.</li> </ul>	<ul> <li>Working with PwLD at step 3 using CBT- e.g. trauma, social anxiety, OCD, anger, GAD, Health Anxiety.</li> <li>CBT evidence base for PwLD</li> <li>How to engage pwLD at triage and during treatment</li> <li>Specific, common difficulties encountered and how to overcome</li> <li>Making letters more accessible, picture of building, clinical, clock for time</li> <li>Introducing existing easy read materials (where they can be found on G Drive) how to use/apply it</li> <li>Making 'mainstream' CBT materials accessible –disorder specific materials</li> <li>*lived experiences of clinicians who have worked with pwLD e.g. NET, Tree of life</li> <li>What is 'challenging behaviour' and how to manage (how to broach with SU)-what is considered manageable in primary care and when to refer on to AT or CLDT</li> </ul>

Excerpt from non-training related action plan

Domain	Proposal	Who	Deadline	Current Status	Plan	Completed
Accessibility	Make service leaflet and poster accessible – include reference that we offer adapted services for mild LD and lower lit/ num levels.	KB & HR	By end of Oct '15	Made –comms /graphics emailed re: amending and bulk printing	KB to add ref re: working with LD/ lower lit Speak to HR again in Oct SU FB	HR JC, CM, PM SALT
	Check /list locations where we can advertise – local GPs, chemists, youth clubs, LD services	KB & DS	By end of Sept '15	Pending	Speak to DS 10/9/15	DS
	Place leaflets/advertisements in places PwLD will see	All	November '15	Discussed and agreed	Speak to CLDT re disbursing?	KB, ID,
	Easy read sum of services for website	КВ	/	Completed	SU FB	JC, CM, PM SALT
	Reference that we offer adapted services for mild LD and lower lit/ num levels on website	КВ	Nov '15	In progress	Speak to HR again in Oct SU FB	JC, CM, PM SALT
Safeguarding	Send email to team stating KB (and ID?) as LD safe guarders	КВ	Oct '15	Completed	Note in whole team training	
	Flowchart – what to do when concerned about LD safeguarding issue- reference to risk/OP Pol	AoG/ KB- have discusse d and agreed	Oct '15	Discussed and agreed with AoG- AoG emailed re: this	KB to chase AoG – check her folder?	HR
	Update risk policy guidelines	KB &HR	Oct '15	To be included when policy is update in Autumn	KB – to check with HR again in Oct	HR
	Start Track LD safeguarding- liaise with OD	КВ	July '15- ongoing	Discussed with OD- child safeguarding protocol and spread sheet shared	Flag in whole team training	KT/LH JC, CM, PM SALT
	Create Easy read Safety Plan	КВ	July '15	Draft completed	SU feedback from SUs with LD and LD Team	KT/LH JC, CM, PM SALT
	Easy read card of helplines/ services to contact in emergency – LD duty (if known, police A&E, GP, bespoke)	KB/ ID/ DS	August '15	Draft completed	Get feedback from SUs with LD and LD Team	KT/LH JC, CM, PN SALT
Assessment	Adapted triage scripts	КВ	September' 15	Adapted S3 triage complete	Flag in whole team training	KT/LH JC, CM, PM

	S2	AoG				SALT
	Easy Read MDS	КВ	July '15	Draft Completed	Get feedback from SUs with LD and LD Team	KT/LH JC, CM, PM
	Easy read SPIN, PSWQ, IES-R, HAI-SW	ID	September '15	Drafts completed	Get feedback from SUs with LD and LD Team	SALT* KT/LH JC, CM, PM SALT*
	Email RD care pathway to include in operations policy	КВ	September '15		Flag in whole team and s3 training	
Equalities	Clarity re: reasonable adjustments-	КВ	July meeting with RD	Confirmed number and duration of sessions- can be extended if agreed in supervision	Flag in whole team training	
	Acquire more 'readymade' accessible easy read materials esp. S2	КВ	July meeting with RD	Order recived – added to LD folder on shared drive	Flag in whole team and s2 / s3 training	
	Adapt session forms used frequently S2 (depression, anxiety/ worry, panic, phobia, stress, sleep, assertiveness, relaxation) S3 PTSD/ Trauma, GAD (Dugas), Compassion, ACT, Social Anxiety, OCD, Mindfulness?	AoG ?DS? KB ID	By end of September '15 By end of September '15	In progress	KB to add to shared drive, get SU FB and flag in team training	KT/LH JC, CM, PN SALT
	SU representation/ involvement Make SU Forum leaflets accessible	DS?	August '15	Discussed and agreed with DS	Send reminder to DS 30/7/15	DS
	Notify GP's/ other services that we work with PwLD	KB Meeting with RD	August '15	Discussed with RD and HR- ?	KB HR	HR/KJ
Accessible information	Adapt/find- liaise with WLMHT, easy read/ braille/ audio versions of: -PEQ -Complaints procedure -Info on medication – people 1 <sup>st</sup> ? Place in waiting room (with ER BoT posters and leaflets)	DS KB- KB- KB KB	July '15 July '15 July '15 July '15 July '15	PEQ completed In progress contacted comms- Matt- awaiting response	Get feedback from SUs with LD and LD Team KB to checkin in HR Oct	KT/LH JC, CM, PM SALT
Research	Make Easy Read research on CBT summary booklet Journal club – research on CBT for PwLD- what measures, tools, protocols	KB/ID KB KB/RD	September'1 5 November '15	In progress		
Local plans	Ongoing monitoring/ auditing Find out what local plans are and disseminate – how it applies to BoT- Add to 'whole team' training	КВ	Ongoing End of October '15	In progress- plan for KB, ID and DS to attend LD open day in H&F 16/9/15	KB to speak to Roman/ GLTK attendees Flag in Team training	

	Twice yearly slot in Team meeting	KB-	September 15		KB to Arrange to	
	Twice yearly south reall meeting	check	September 13		attend in March '16	
	Brief PP presentation- what, why,	with RD-	Team		meeting	
	progress, plans.		meeting		Ŭ	
Skilled	Written 'guidelines' for working with	КВ		In progress- plan to	KB to send reminders	DS
workforce	PwLD- disseminate at Training:	AoG	All by end of	draft day of conf	to	
	Guide from whole team training	AUG	September	17/9/15	ID and DS mid-August	
		ID	·15		ib and bo mid ragast	
	Guide from S2 clin skills training				KB to liaise with KT	
	Guide from S3/ Supervisors training				and LH from CLDT	
	Specified as area of interest in person	KB to	July '15	Discussed in meeting	RD to add interest	
	specs	discuss		with RD	working with LD to	
		with RD			recruitment	
					advertisements	
SU	ID PwLD IAPTus label –gather and ?	ID	December	Discussed and agreed	Remind ID mid-Nov	
involvement	actively request feedback/ input/		'15- Jan '16	this with ID		
in service	attendance at SU forums/ attendance of					
	F2F forums – including SO's where					
	consent has been given					
	A-PEQ and PEQ to include question about	DS	End of July	Discussed and agreed	Check in with DS	
	SO's (e.g. relatives) involvement in		'15	this with DS	30/7/15	
	providing feedback					
	3 monthly SU LD Forums- including SO's	КВ	Jan '16 then		KB to discuss further	
	where consent has been given- make		every 3		with RD in Nov	
	enjoyable e.g. bingo night		months		meeting?	
	Monitoring all feedback from SUs with LD-	КВ	Jan '16 then		KB to discuss further	
	planning changes		every 3		with RD in Nov	
			months		meeting?	
	Implementation of feedback from PwLD	All	Ongoing	As arises		
	PEQ's					
	Keep PwLD and SO's (where consent has	AoG	January '16		KB to discuss further	
	been given) informed of changes to		then every 6		with RD in Nov	
	service if requested		months		meeting?	
Psychological	Training:			In progress	KB to check dates with	
therapies	Whole team Sadmin?	KB (and	October (15		everyone, email team	
	Whole team -?admin?	CLDT)	October '15		and co-ordinate	
	S2 – clinical skills		4 <sup>th</sup> Nov '15		training preparations	
		AoG and	2 d d th as			
	S3/ supervisors	ID	? 11 <sup>th</sup> Nov'	1		1

# Anonymous feedback on training event- excerpts

Question	Answers	Themes –other comments and possible changes
Which topics or aspects of the workshop did you find most	1-it was useful to consider what a diagnosis of LD means and how the definition has shifted and changed over the years. In practical terms it was helpful to think about how to ask about difficulties at triage i.e. Rather than 'do you understand written English?', to ask more generally 'do you have any difficulties with reading and writing at all?'.	What LD dx is/ change in definition
interesting or useful?	2-getting an understanding of who we could see within an IAPT setting	The LD team. Who they are, what they do, joint working
		How to phrase questions
	3-learning more about LD and how to phrase/appraise things more appropriately with these clients.	Who we see in IAPT
	4-learning more about the LD team and what they offer, knowing more about the possibility of joint working, understanding the likely prevalence of unknown LD in IAPT services	Safeguarding easy read materials available employment info
	5-overview of the stats. Normalising of my anxieties/questions	
	6- finding out about the integration of the LD team and IAPT in joint assessments and finding more out about what the LD team's role is.	
	7-all of it	
	8- historical context of definition of LD.	
	9- safeguarding easy read materials available employment info 7:52	

# Excerpts from PWP Clinical Skills 4/11/15- e-Survey Feedback

Question	Answers						
Which topics or aspects of the workshop did you find most interesting or useful?	1-Thinking about common difficulties, adaptions that we can make to sessions and thinking about working with families as well						
	2-How to phrase questions in an assessment. Talking through how it is OK to adjust treatment structure etc. How it's OK to focus on to get them to understand it better. Use of visual aids - some ideas around that.						
Knowledge and information gained from this event: Met your expectations?	1 A bit 2 Yes, I haven't had any specific training on LD in a therapeutic setting so found it extremely helpful. Gained info on how to structure a						
	session - small details involved such as having a clock in the room, pens & paper, visual aids. How it's OK to adapt sessions e.g. focus on one component, repeat components and/or adjust timings of sessions.						
Knowledge and information gained: Will be useful/applicable in my work?	1-definitely, good to be more aware of easy read materials and where they are - will be using these straight away!						
	2-Found it useful how to work with family and social workers etc. in assessment and treatment. Helped me understand the boundaries.						
How do you think the workshop could have been made more effective?	1-would have been good to have some input from step 2 team as to what reasonable adjustments we are able to make. eg. how many extra sessions is reasonable, what a piece of work might look like.						
	2- It was helpful hearing short snippets of cases where something had been useful or not useful - made it easier to apply and gave an opportunity to learn more about techniques that could help or what to watch out for / what not to do. So perhaps a few more of those throughout would be helpful.						

Selection of excerpts from adapted documents

Excerpt from the adapted minimum dataset (MDS)

YOUR INITIALS.....TODAYS DATE

PHQ 9

SUNDAY Playsh 31	MONDAY	TUESDAY	WEDNESDAY April 3	THURSDAY	FRIDAY	SATURDAY
Service Res	Anthonia	conversion inc.	Teacher Inc.	mentity	man want by	To fair the
SUNDAY April 7	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY

# In the last 2 weeks.....



1. -Have you felt less interested in doing things as you used to?

Have you felt this way... Please tick one:

.....

SUNDAY Forch 26	MONDAY	TUESONY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY Participal	MONDAY	TUESONY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SURDAY North In	MONDAY	TUESONY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY Name In	MONDAY	TUESONY Auril 2	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY
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							34	*			W,			26	300		30	Wr		+	24	300		×	W,	2	+
							196	34			$\mathcal{A}_{0}^{\ell}$			196	36		inte	$\mathcal{A}_{0}^{\ell}$		×	196	36		+	$\mathcal{A}_{0}^{\ell}$	$\approx$	×
Farty Turnity	Artholity	CONTRACTOR INC.	Facelity	theority	NUMBER	Turke Rea	- Internation	arterita		- Teartes	merris	-	tore be	Test Sold	arturna		- Tanata	metria	-	1010100	100 York	artista		lares	mercia	-	tuncite.
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY	NUNDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDA
Aprel	Apr2 0	4,075	April 15	April 11	April 13	April 13	1	4941	100	April	49-931	April 12	5ge0.53	X		4	2	Carl I	1	X	×	×	$\sim$	X	×	*	×
									34			_		×		26	×		×	30	$\times$	$\approx$	34	×	1	×	×
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days?

half the days? every day?

. . . . . . . . . . . . . . . . . . . .

. . . . . . . . . . . . . . . . . . .

Excerpt from the adapted patient experience questionnaire (PEQ)

# 1. Did staff listen to you and treat your concerns seriously? Please tick one: At all times Most of the time Sometimes Not very often Not very often Never Sometimes 2. Do you feel that the service has helped you to feel better? Please tick one: 2. Do you feel that the service has helped you to feel better?

# **Treatment Patient Experience Questionnaire**

			•				
At all times	Most of the time	Sometin	nes	Not very often	Never		
			<b>cho</b> trea	d you help in making oices about your atment? ease tick one:			
			•				
At all times	Most of the time	Sometin	nes	Not very often	Never		
	2		nee	you get th eded? e <b>ase tick o</b>	e <b>help</b> you <b>ne:</b>		

At all times	Most of the time	Sometimes	Not very often	Never

Excerpt from adapted CBT Information Sheet 'What is CBT?'

# What is CBT?



CBT means Cognitive Behavioural Therapy

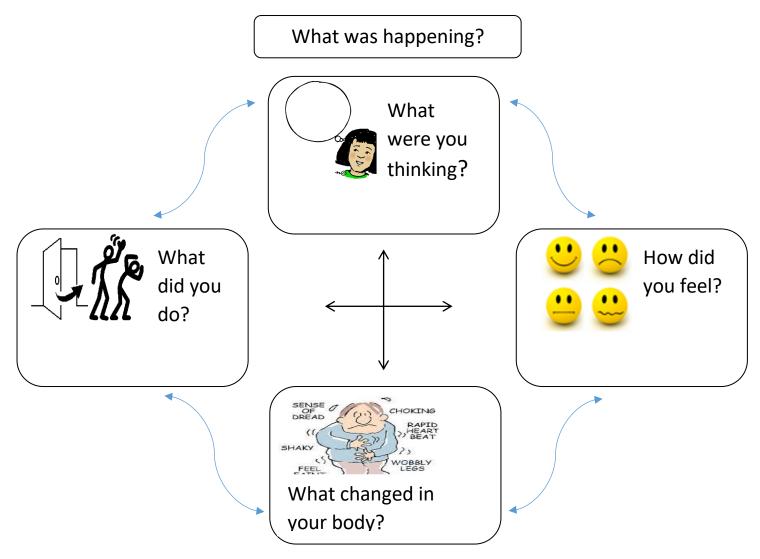
The '*Cognitive*' part looks into the way you *think* and the

*'Behavioural'* part looks in to what you do

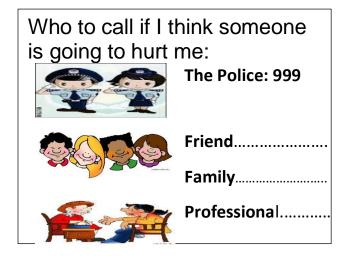
This can then affect how you *feel*.

CBT looks at how you are thinking, how you are feeling and what you are doing in the moment. Your therapist will try to understand your current situation.

Your therapist will look at the different areas with you like in this cycle below.



Easy read wallet sized emergency contact card template





# Anything or anyone else?

- •
- •
- •
- .

Add to the back of each card above

# Appendix 26 Excerpt from amalgamated feedback on adapted documents

ADVERTISEMENTS	Respondent	Suggestions
Poster	SU 1	Its good- I like it- like the pictures
	SU 2	I like it, it's good, it's better than the other one cause it's easier to understand
	SALT	
	CLIN PSYCH-LD	Not sure if this document is a predecessor of the BoT Easy Read Booklet, and if so whether the latter has taken its place now? If you still want this as an abbreviated version of the Booklet, I think it's ok – but I think the wording and images are better on the Booklet, so I think it may be better to make an abbreviated version of the Booklet using the images / wording on the booklet e.g. using pages 1 / 2 / 5 / 8 or something like that from the Booklet, to make a 2 page leaflet in addition to the longer booklet, if that makes sense?
	CLIN PSYCH-LD	could you have photos of each of the buildings that you highlight on the map and could you have photos of the 3 emotions you list rather than just one photo of sad
	HI IAPT	This is very clear
	HI IAPT	
	PWP	Add a picture of our blue sign that's outside with address on it to help locate the building as its probably one of the first things you notice walking up to the building.
Booklet	SU 1	I prefer 3 fold colour version better than the booklet
	SU 2	I really like this one- with the picture and the colour- the colour is very important
	SALT	
	CLIN PSYCH-LD	Overall think this leaflet looks really great – well done! Not sure if the one I had on the email was the most updated one – I know I also looked at one on paper when we met in Cardiff. Not sure if you had updated some of the images on the paper copy I saw.
		Perhaps of all the documents, this one could be a priority for service user feedback? Be a good one to get their perspective on. Some other thoughts from me: Page 3 'Learn new ways of coping with <b>??difficult</b> thoughts, feelings and behaviours' - instead of 'bad'?? Just a thought, 'difficult' is perhaps too difficult a word! Perhaps something that could benefit from service user feedback.
		Page 4 'Talking about your thoughts and feeling <u>s'</u>
	CLIN PSYCH-LD	really good!! feeling worried photo on pdf version is not that obvious the person is worried. Like the map on pdf version Good you make it clear you are not an emergency service and that you list numbers for what to do in a crisis.
	HIIAPT	IS it worth using the same colour scheme for the posters and booklets, so it's easily recognisable? There's an extra word (if) in the blue writing about needing help reading and writing. Do you need to say re-refer? Can it just be refer?
		I'm not a fan of labelling TF&Bs 'bad' but I'm guessing this is a term used in work with PwLD as it's more understandable? Is there a reason it says we start at 9:30?
	HI IAPT	I really like the clocks showing the opening and closing time- I just wonder if its too lengthy?
	PWP	States 'you can re-refer' – is this only for people that our already in the service?
MEASURES		
MDS	SU 1	I like this one- the pictures are funny and help understand the questions
	SU 2	Its better but I still don't know what has happened over the past two weeks! Its should say over the last week
	SALT	Medication- add pictures of anxious/ sad faces. Add example of legal highs
	CLIN PSYCH-LD CLIN PSYCH-LD	Another key document that it will be good to get more service user feedback on – and of course we are hopeful this will be part of the next research project collaboration between X and Y! But some initial feedback from me – I think it's a good first step to make this accessible. Be interesting to get some feedback on the scale, I like the way you have illustrated the 'several days / more than half the days / nearly every day' but also wonder how service users will find this scale compared to e.g. a graph type scale similar to that used with the CORE-LD? Again, a point for the next research project to consider I'd say rather than immediate feedback for now. I also like the way the questions for each item are broken down – again something to consider for the next research project, but maybe having some guidelines / script for staff administering the MDS to make the administration of the items / questions consistent will also be important (e.g. how to help service users consider the timescales for the measure being 'in the last 2 weeks' etc). The images used could also be considered for the next research project I think, e.g. some of the images could be more explanatory for the item such as item 9 'have you wanted to hurt yourself? Etc'. On the 'Employment Questions' maybe the first question should read 'At the moment, are you working? Then have the options? Under the alcohol and drugs question, should read 'If yes, what have you drunk?' photo 9 on phq9 – not obvious enough it is about suicidal thoughts. GAD7 photo 3, the worries in the boxes are too abstract, I would have common worries, money, family, no job, no friends, don't like where I live, etc. otherwise good, like the boxes for amount of days something affects someone.
	HI IAPT	IT's nice and clear. Managing to format the pictures so that they are not distorted would be good. The way the wording is changed to make it more clear is helpful
	HI IAPT	
	PWP	Picture for 'illegal drugs and legal highs' – maybe could be clearer, unless they know what the marijuana symbol is.

# **SECTION C: PUBLISHABLE PAPER**

# Improving access to psychological therapies for people with learning disabilities from service users' and clinicians' perspectives: An Action Research approach

Article intended for publication in the 'Journal of Intellectual Disabilities'

# Improving Access to Psychological Therapy (IAPT) for people with learning disabilities from service-users' and clinicians' perspectives: An Action Research Approach

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# Abstract

This project aimed to investigate what changes Improving Access to Psychological Therapy (IAPT) could make to improve accessibility for people with learning disabilities; then implement, and evaluate these changes. An action research design, comprised of planning (phase one), action (phase two) and evaluation (phase three), was undertaken within an inner-London IAPT service. Seven service-users with learning disabilities and 12 IAPT clinicians were interviewed using a revised version of the Green Light Toolkit (National Development Team Inclusion; 2013). Thematic analysis was used to analyse qualitative data from phase one and three. Themes identified in phase one included 'doing well', and 'recommendations for clinicians' and 'recommendations for services'. A clinician-only theme was: 'uncertainty'. Phase two saw implementation of actions based on phase one themes. Phase three saw both groups approved of actions taken. Findings are discussed in relation to clinical and policy implications.

## **Keywords**

action research, IAPT, learning disabilities, Green Light Toolkit, service-users, thematic analysis

Date accepted:

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E-mail:

# Introduction

Despite higher prevalence rates of mental health problems among people with learning disabilities (Hatton & Taylor, 2010), and a requirement for all mental health services to meet the needs of all disabled people (Department of Health; DoH, 2011), the report *Reasonably Adjusted?* (National Development Team for Inclusion (NDTi, 2012) highlighted few psychological services comprehensively and systematically audited their practice to ensure people with learning disabilities had equitable access. The NDTi was asked by the DoH to develop an audit framework applicable to mental health services and resulted in the Green Light Toolkit (GLTK; Turner & Bates; NDTi, 2013). However, a recent study by Chinn, Abraham, Burke & Davis, (2014) reported some Improving Access to Psychological Therapy (IAPT) services still used 'learning disability' as an exclusion criterion.

## Mainstream or specialist services?

The debates surrounding access to mainstream psychological services for people with learning disabilities are numerous and complex (e.g. Chinn et al., 2014; Rose, O'Brien & Rose's, 2007). However, legislation clearly advocate inclusion (e.g. Equality Act, 2010). In a similar vein, the recently published IAPT Learning Disabilities-Positive Practice Guide (LD-PPG; Dagnan, Koulla-Burke, Davies & Chinn, 2015) states that IAPT cannot exclude people with learning disabilities; it also states that only specialist services are likely to have the skills and service structures for some people with learning disabilities. This ambiguity could lead to cautiously low referrals of people with learning disabilities to IAPT and low numbers of people with learning disabilities accessing IAPT may result in this population not being seen as a priority by IAPT commissioners. In turn, this may minimise learning experiences for IAPT clinicians, which is important as a lack of experience and consequential low confidence in their abilities to work with people with learning disabilities is considered a key access barrier to IAPT (Dagnan, Masson, Cavagin, Thwaites & Hatton, 2015; Marwood 2015). This may consequently perpetuate marginalisation of this group.

## Improving Access to Psychological Therapy

IAPT aimed to reverse the inequalities that existed in terms of those receiving psychological support, including people with learning disabilities (IAPT, 2008). It uses a stepped-care approach where Psychological Wellbeing Practitioners (PWPs) with relatively brief Cognitive Behavioural Therapy (CBT) based training, predominantly offer guided self-help and psycho-education groups at 'step two', whilst High Intensity Therapists (HIs), mainly offer one-to-one and group CBT at 'step three'. Although ambiguity surrounding the appropriateness of CBT for people with learning disabilities exists, research is increasingly advocating this modality (Osugo & Cooper, 2016). IAPT is a high-volume service that encourages strict adherence to National Institute of Clinical Excellence (NICE) approved protocols. It is recognised as being particularly targetdriven; key performance indicators including 'recovery' rates (thus therapeutic success) are assessed by IAPT commissioners through completion of the Minimum Data Set (MDS; IAPT, 2011) an outcome measure administered each session.

## IAPT and Learning Disabilities.

Two recent studies exploring the views of IAPT clinicians on working with people with learning disabilities found that IAPT clinicians were unsure how to modify CBT and required training in this area (Marwood, 2015; Shankland & Dagnan, 2015). Whilst both studies helped determine IAPT clinicians' views of IAPTs accessibility for people with learning disabilities and recommendations for improving this, data from service-users with learning disabilities was not gathered, and no steps to implement findings appear to have been taken. Chinn et al. (2014) also investigated barriers and facilitators for people with learning disabilities accessing IAPT through an online survey and interviews with learning disability staff and IAPT staff, people with learning disabilities and their supporters. Barriers within IAPT included a 'lack of flexibility' due to an emphasis on adhering to protocol-driven approaches, 'workload pressures' and 'communication difficulties'. Concerns were also expressed about the validity and consequential implications of the currently unadapted MDS (IAPT, 2011). Chinn et al. (2014) synthesised their findings with reference to 'candidacy' (Dixon-Woods et al., 2012), suggesting people with learning disabilities may not see themselves, nor be viewed by their systems, as candidates for IAPT, and concluded by recommending ways to promote this. Unfortunately, as with much existing related research, there is no reference to any direct actions taken as a result of their study. Furthermore, the qualitative aspect of their report suggested a paucity of IAPT clinicians whose principal role was offering therapy (one PWP and one CBT therapist). It is also unclear whether the three service-users interviewed had any personal experience of IAPT.

# Mental health support for people with learning disabilities: Clinicians' and service-users' perspectives

Self-reported experiences of people with learning disabilities has been overlooked in much of the research about them. In addition to concerns about marginalisation, this may lead to inaccurate conclusions; staff, carers and people with learning disabilities may use different information when rating emotional states (Flitton & Buckroyd, 2005; Rose, et al., 2013). The resulting potentially partisan view of the effectiveness of psychological interventions may have unintentionally further thwarted access to IAPT, and underscores the need to obtain their views when considering the value of mainstream mental health services.

Rose et al. (2007) investigated the views of specialist and mainstream clinicians on working with people with learning disabilities in mental health services. One central theme found was 'perceived staff competence'. This pertained to mainstream clinicians feeling that they were not capable of providing the best service to people with learning disabilities, and reports that additional training would be needed before they felt proficient to work with this group. However, numerous participants also indicated that much of the expertise in this field could only be gained from 'learning on the job'. In a similar vein, the LD-PPG (2015) suggests IAPT clinicians' competencies will improve through gaining experience in working with people with learning disabilities.

Service-users with learning disabilities and staffs perspectives of psychological service provision for this group were investigated by Stenfert-Kroese, Rose, Heer and O'Brien (2013). Focus groups with service-users with learning disabilities and learning disability support staff, as well as individual interviews with staff were conducted. Themes elicited included the importance of communication styles, awareness of past-present links and staff training. Service-users, but not staff, highlighted the importance of staff 'being interested, not just there for the money'. Sternfert-Kroese et al. (2013) also noted staff frequently commented on challenges of their jobs, and managers lack of empathy towards them in favour of higher management demands. The last two points are particularly relevant in IAPT settings where clinicians may feel under pressure to meet targets, thus may struggle to be fully attentive to service-users. Regrettably, Sternfert-Kroese et al. (2013) did not interview service-users nor do they refer to implementing

any recommendations made in their study. Pert et al. (2012) did interview people with learning disabilities about their experience of CBT and reported three overarching themes: 'talking in therapy', 'feeling valued and validated' and, 'change in therapy'. In addition to not acting on findings, a limitation of this study is that findings were not validated by participants. This could be rectified through 'member checking' as occurred in the current study.

## Rationale and research aims

Current legislations emphasise the importance of including people with learning disabilities in mainstream psychological services, yet they continue to face barriers accessing IAPT (Chinn et al., 2014, Dodd et al., 2011). Two main gaps in the research emerged from a review of the literature; a general omission of the views of people with learning disabilities, particularly those who had accessed IAPT, and an omission of implementation of findings to improve mainstream services such as IAPT. There was also disappointingly little acknowledgement of existing policies and guidelines aimed to facilitate inclusion, such as the GLTK (2013). Accordingly, as elaborated on shortly, this study used an action research approach to answer the following questions:

 How well do service users with learning disabilities who have accessed IAPT, and IAPT clinicians, think IAPT fares in relation to the GLTK (2013) and what do they think can be done to improve this?

Following a six-month implementation period of these suggested improvements:

2. How successful do service users with learning disabilities who have accessed support from IAPT and IAPT clinicians think the changes implemented have been, and what further actions do they think could improve IAPT?

# Method

## Design

Action research offers the dual advantages of empowering people with learning disabilities, and increasing the research's validity by clear utilisation of their expertise (Stack & McDonald, 2014). Lewin (1946) described action research as a '*spiral of steps, each of which is composed of a cycle of planning, action and fact finding about the result of the action*'. (Lewin, 1946: 206) and it typically follows three key phases: 1) Planning (data gathering) 2) Implementation and 3) Evaluation. A flowchart depicting the key steps within the action research process, including the participatory aspects of the implementation phase leading the thematic analysis process can be seen in the 'procedure' section that follows.

## Service setting

The study and recruitment took place in an inner-London IAPT service made up of approximately 40 members of staff. Since the study began, three clinicians have been identified as 'LD Champions', two HI's (including the lead author) and one PWP. There has been no dedicated funding, nor additional resources allocated for people with learning disabilities.

## Inclusion / exclusion criteria and sampling considerations

## Inclusion criteria:

Service-users identified within IAPT as having learning disabilities, meeting the IAPT services eligibility criteria (i.e. over 18, experiencing anxiety, depression and/or anger) and had had at least one assessment and six treatment sessions within the IAPT service within 18 months of the initial interview. All clinicians within the IAPT service who offered CBT were also eligible.

## Exclusion criteria:

Service-users who did not meet IAPT eligibility criteria (including those who lacked capacity to provide informed consent). Clinicians who acted as interviewers in this study and IAPT staff who did not work therapeutically with service-users (i.e. those in purely managerial roles) were also not eligible.

Table 1 offers a pen profile of the seven service-user participants. One service-user who participated in phase one was uncontactable after this and a new service-user participant was recruited for phase three. Table 2 offers a pen profile of clinician participants. One HI Therapist and two PWPs who participated in phase one left the service during phase two. Two new PWPs who were in post before the study began were recruited for phase three.

Participant	Age	Gender	Self-	Number	Presenting problem	Phase
•	Ũ		reported	of IAPT		participated
			ethnicity	sessions		in
'Sally'	54	Female	Black-	13	Anger	1 and 3
			British			
'Clara'	21	Female	White-	15	Depression/	1 and 3
			British		Irritability	
'Jade'	23	Female	White-	12	Anxiety	1 and 3
			British			
'Dena'	18	Female	Pakistani-	12	Anger	1 and 3
			British			
'Alan'	24	Male	Pakistani-	12	Panic/ Anger	1 and 3
			British			
'Daniel'	32	Male	White-	6	Depression	1
			British			
'Kayleigh'	24	Female	White-	12	Anger	3
			British		Management/Trauma	

Table 1. Pen profile of service-user participants. Pseudonyms are used to protect anonymity.

Table 2. Pen profile of clinician participants. Pseudonyms are used to protect anonymity.

Participant	Age - range	Gender	Job title	Approximate time worked in service	Phase participated in
'Emma'	30-34	Female	PWP	1.5 years	1 and 3
'Jasmine'	35-39	Female	PWP	4.5. years	1 and 3
'Priya'	30-34	Female	PWP	1.5 years	3
'Tanya'	25-29	Female	PWP	2 years	3
'Rachel'	25-29	Female	PWP	2 years	1
'Amy'	25-29	Female	PWP	1 year	1
'Anthony'	35-39	Male	HI Therapist	2.5 years	1 and 3
'Adam'	30-34	Male	HI Therapist	4 months	1
'Joe'	45-49	Male	HI Therapist	4.5 years	1 and 3
'Harriet'	35-39	Female	HI Therapist	3.5 years	1 and 3
'Nancy'	35-39	Female	Senior HI Therapist	2 years	1 and 3
'Ben'	40-44	Male	Senior HI Therapist	3.5 years	1 and 3

Key: PWP: Psychological Wellbeing Practitioner HI: High Intensity

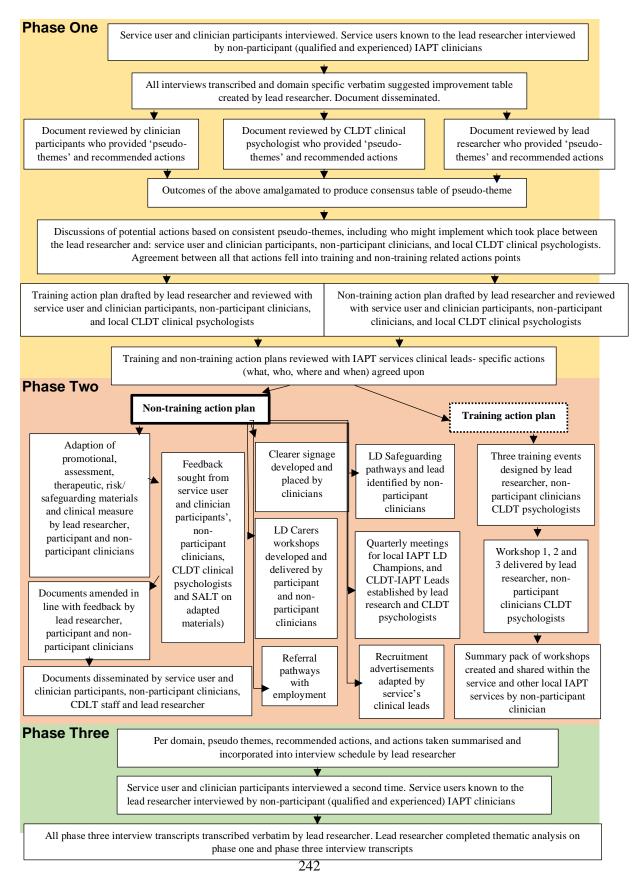
# Recruitment

A screening tool within the service's computer system identified eligible service-users. They were contacted by telephone and advised of the study's aims. If interest was expressed, they were offered an accessible information leaflet via email or post. Support was offered to review these with them. If expressions of interest persisted after seven days 'thinking time' an interview was arranged. IAPT clinicians were recruited through a service-wide email outlining the study's background and aims with an information sheet attached. Similarly, an interview was arranged if initial interest persisted after sevendays.

### Ethics

This study complied with the Ethical Guidelines of the British Psychological Society, Health and Care Professions Council, and City University, London. Permission to complete the research within the IAPT service was obtained from the IAPT service's Clinical Leads and was approved by the Trust's Research and Development Team. Regular consultation with a Clinical Psychologist specialising in learning disabilities took place throughout. Further ethical issues including consent, right to withdraw, and confidentiality were carefully considered. All participants were advised of, and consented to, being recorded, anonymised interview transcripts being kept on a password protected computer, and anonymised extracts being used for additional articles or publications.

# Procedure Flowchart depicting key steps in the action research process



#### Phase One: Planning

Phase one consisted of one-to-one, face-to-face interviews lasting approximately 30-80 minutes. For each GLTK (2013) domain, participants were asked to provide a rating of Grey ('not yet started'), Red ('on the journey, but stuck at red'), Amber, ('ready for more') or Green ('continuous progress') according to the GLTK's traffic light colour coding system. Participants were then asked for an example of why that colour was chosen and how the domain could be improved. Initial analysis of phase one interviews was for the purposes of generating recommendations for phase two (implementation) and consisted of a pragmatic review and possible action points based on participant's suggested improvements for each GLTK domain. A table was also constructed displaying all verbatim responses that pertained to the participants suggested improvements for each domain. Broad topics and ideas were then reviewed with the service's 'LD champions' and local Community Learning Disability Team (CLDT) Psychologists before approval of specific actions was sought from the service's Clinical Leads. Clinician participants were also provided with copies of this table and asked to note key 'themes' and 'actions' per domain. A rudimentary, descriptive analysis of researcher and clinician participant 'themes' and 'actions' showed feedback from clinicians seemed overall, quite consistent with the researcher's, but no specific agreement level was specified.

#### Phase Two: Action/ Implementation

Phase two involved collaborative implementation of suggested improvements made in phase one over a six-month period and is expanded on in the 'Results' section.

# Phase Three: Evaluation

Phase three occurred approximately six-months after the final phase one interview. For all participants, it consisted of a repetition of the interview procedure that occurred in phase one with the addition of, per domain, a summary of phase one responses, pseudothemes (i.e. themes noted by clinicians during the post- phase one preliminary analysis), and a description of the actions during phase two taken.

### Research materials

All participants were provided with a revised version of the GLTK (2013) with an accessible version available to service-users. Domains not relevant to IAPT (e.g. regarding secure/forensic settings) were omitted. On reviewing the domains with a Clinical Psychologist who specialises in learning disabilities, it was agreed service-users could not be expected to answer some questions that clinicians might (e.g. those regarding data capture). Thus, of a possible 27 GLTK (2013) domains, clinician copies omitted seven, and that service-user copies omitted 12.

#### Analytic procedure

All interviews were recorded and transcribed verbatim. Transcripts were analysed using Braun and Clark's (2006) method of thematic analysis because it is considered appropriate for under-researched areas and is not beholden to any pre-determined theoretical positioning (Braun & Clarke, 2006). As the analysis was coded for specific research questions, theoretical rather than inductive thematic analysis was favoured. Sematic coding was primarily used as themes were identified based on explicit surface meanings within the data.

# **Results**

# Phase one (planning): service-user themes

An overview of two higher order themes and associated subthemes is provided in Table

3.

Table 3. Phase one service-user higher order themes and subthemes

Higher Order Themes	Subthemes
Doing Well	Helpful clinicians
	Inclusive service
Recommendations	Recommendations for clinicians
	Recommendations for the service

Doing well

*Helpful clinicians.* All service-users commended individual clinicians. For many, this took the form of having a positive therapeutic alliance. One service-user expanded on this by suggesting that the positive alliance instilled a sense of hope.

... when you get along so well you can work on anything.

Many service-users positively remarked on how clinician's helped through acknowledging and adapting to meet their increased needs, such as putting things "in words that I can understand". Three service-users noted clinicians helped through provision of information, be it psycho-education of presenting difficulties, or information on keeping safe. Three service-users also reflected how talking therapies positively impacted emotional wellbeing.

... it actually made a huge impact in my life. I've changed quite a lot since the first session, and been more positive and more courageous. It's very very good.

*Inclusive service*. In four cases, feeling accepted by and included within the service was associated with the reality that they had learning disabilities and had received support within the service. Three service-users further commented on a sense of being included within the wider team and three service-users recognised inclusion of their family. The impression of inclusion further encompassed a sense of being involved in service development, which was rated highly by all service-users.

# Recommendations

*Recommendations for clinicians.* Four service-users conveyed that their increased needs ought to be acknowledged by clinicians. Three proposed clinicians provide additional support with written information, such as:

[making] things easier to read, not long words...break it down.

The importance of clinicians acknowledging individual differences was also highlighted by three service-users and three service-users recommended clinicians asked questions to help them comprehend their idiosyncratic needs. Provision of information was an offmentioned recommendation for clinicians.

*Recommendations for the service*. Many service-level recommendations reflected reasonable adjustments. Three service-users advocated additional and/or longer sessions, two with reference to increased needs.

...15 or 20 minutes longer sessions, or more than once a week...because once a week I don't think will be enough for people that have quite, if they have disabilities.

Five service-users implied interventions were required to aid communication.

...information in different sorts of ways people with disabilities like braille and pictures, faces just like that, and also maybe audio?

Another area highlighted as a reasonable adjustments involved making IAPT buildings more accessible. Although all service-users were able to use stairs, five suggested that the upstairs of the main IAPT building be made accessible for wheelchair users. Three service-users recommended staff have training to better understand and accommodate their needs, and two service users suggested greater promotion of the service through advertising in the community such as in "Doctors, Health Centre… The chemist as well?" A further recommendation made by half of the service users was working better with other services.

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# Phase one (planning): clinician themes

An overview of two higher order themes and their associated subthemes identified in clinicians' transcripts is provided in Table 4.

 Higher Order Theme
 Subtheme

 Doing well
 We are inclusive

 Working well together
 Working well together

 Clinician uncertainties
 Feeling unskilled / ill-equipped

 Recommendations for clinicians
 Recommendations for the service

 LD is not our core business
 LD is not our core business

Table 4. Phase one clinicians higher order themes and subthemes

# Doing well

*We are inclusive*. Five clinicians referred to the service's openness to working with people with learning disabilities. Of these comments, some referred to the service having a "clear expectation" that this group could access support within the service; others suggested a personal openness towards working with this population. Another stream of inclusiveness reflected recognition that both clinicians and the wider service made adjustments where possible to support people with learning disabilities; however, the specifics of the adjustments made were unclear:

... the clinician will go out of their way to ensure that they get that the adjustments that are the most helpful.

*Working together.* One stream within this subtheme indicated that most clinicians felt that the service offered a supportive, sharing environment. Another stream indicated that clinicians felt that the service was working well with local learning disabilities services.

...there's very good links thanks to [LD Champions] with the Learning Disability Team, for sure.

### Clinician uncertainties

All clinicians referred to feeling uncertain about working with this population in IAPT. It was difficult to untangle these anxieties; explanations for them and solutions for these were frequently expressed in the same sentence.

...[we] don't have any other training in LD, and struggle working with LD, so I think that's where more progress needs to be made, training and confidence building.

Nonetheless, it was possible see four subthemes associated with this theme.

*Feeling unskilled and ill-equipped.* Nine clinicians referred to feelings of inadequacy regarding treating people with learning disabilities. One discourse within this subtheme related to uncertainty about what the services policies and procedures were regarding people with learning difficulties. For example, two clinicians expressed uncertainties about the service's remit and many suggested polices be clarified. Most, however, linked 249

their uncertainty with a lack of training and skills deficits; two clinicians specifically indicated a personal sense of being unskilled in this area, and it was clear in two cases that perceived inadequacies led to a reluctance to work with people with learning disabilities.

...I fear learning difficulties. Erm, I don't like working with it. I don't think it's something I'm good at.

Relatedly, clinicians expressed concerns about 'getting things wrong', be this through seeming to patronise service-users, or making errors and being held responsible for this due to a perceived "blame culture".

...it can be quite difficult to assess and know what we're meant to be assessing...I haven't had any sort of training in [learning disabilities]

Four clinicians also spoke of their sense of being ill-equipped due a lack of "exposure" to people with learning disabilities:

...my own lack of exposure to this stuff... means that I'm not very sure if I'm right.

Relatedly, another clinician indicated increasing confidence through increasing exposure was problematic due to the low numbers of people with learning disabilities entering IAPT.

...because we only have like odd scatterings of cases come through it's really difficult for people to build up their confidence and then have regular learning points to evolve properly.

*Recommendations for clinicians.* One suggestion made by many clinicians and feasibly achievable without managerial involvement, was improving links with other services. Often underpinning this suggestion was uncertainty about what they offered or what they knew IAPT offered. Nine clinicians spoke of "reciprocal arrangements" whereby staff shared knowledge, skills and resources cross-services. Two clinicians proposed working together better might be achieved 'in-house' through "peer training" or a "journal club". Echoing suggestions proposed by service-users, another clinician-led improvement included acknowledging individual differences and asking questions about how best to support them.

...trying to spend a bit more time asking who is close to them, who do they like spending time with, who seems to be helpful? Getting more of an idea about their support network...

Many also suggested providing support to carers themselves through "a specific LD carers support group". Another clinician-led improvement was obtaining a greater awareness of the evidence-base on therapy for people with learning disabilities.

...so there is quite an interest in evidenced-based practise in IAPT, and I think most people that work here kind of hold that interest.

*Service-led changes.* The foremost suggestion noted by every clinician as a means to increase the certainty in working with people with learning disabilities was training. All 10 clinicians relayed training should be broad and practical:

...it would be good to have that in a practical, "This would be a good way to work with this group of people," and to offer some practical advice.

Training topics included: how to adapt practice and/or assessments, information about other services, safeguarding procedures, learning disabilities-centric materials and experiences of IAPT clinicians who had worked with people with learning disabilities. All clinician's asserted all staff members ought to receive training in this area. Possibly reflecting uncertainty about working with people with learning disabilities at 'step two', all PWP participants suggested "step-specific" training.

Eight clinicians recommended the service provided guidance on its policies and remit regarding learning disabilities and seven requested clarity on the 'LD label' (i.e. administrative 'flag' on the computer system to record that someone has learning disabilities). Several noted this would enable more accurate monitoring/auditing of access. In line with service-user recommendations for the service, clinicians suggested better reasonable adjustments including more accessible forms of communication and flexibility with session number/duration.

Also echoing service-user suggestions, five clinicians suggested better promotion, including highlighting that the service did work with people with learning disabilities. Two clinicians proposed this might increase the number of people with learning disabilities accessing the service, which may in turn help improve clinician confidence. Six clinicians also highlighted the importance of service-user involvement. *Not our core business.* The final subtheme reflected references to learning disabilities not being the services or IAPT's "core business", or as one clinician noted:

...my initial thought was just like, people feel so far removed from that, I think people don't see it as part of their core job...

Such allusions were implicit and explicit across clinicians and domains. Sometimes this was with reference to learning disabilities not being a priority within the service, or indeed IAPT. Doubts about the feasibility of this work were also expressed with reference IAPT ideologies, such as it being "a high pressure, high volume service". Four clinicians linked IAPT's limitations to budgetary constraints and time pressures. There were consequential repeated references to learning disabilities being of less significance in comparison to "competing demands". Comprehensibly, many clinicians highlighted a need for commissioner-led changes to occur in order for efficacious transformations to occur.

# Phase two (implementation)

Recommendations for improvement fell broadly into 'training' or 'non-training' categories. All were discussed and implemented within the six-month time-frame in collaboration with service-user and clinician participants, non-participant IAPT clinicians and local CLDT Psychologists.

#### Training related recommendations

Three half-day training events reflecting participant's suggestions, and delivered by IAPT and local CLDT clinicians were delivered. All more implicitly aimed to increase clinician's confidence and promote the idea that IAPT can work with people with learning disabilities. The first event was designed for, and attended by PWPs, HI Therapists and IAPT employment support staff. It aimed to provide an introduction to working with people with learning disabilities in IAPT and included topics such as: 'Who is suitable for IAPT?', 'Who are the CLDT and what do they do?' and 'Safeguarding'. The next two training events were 'step-specific' workshops, offering more practical advice on therapeutic work and covered areas such as: 'Possible obstacles and how to overcome them' and 'How to make easy read documents'. Over 40 IAPT staff, including clinicians from neighbouring boroughs, attended these events.

#### Implementation of non-training related recommendations.

Twenty key documents including marketing materials, assessment documents, clinical measures, risk documents and therapeutic materials were adapted into an accessible format by service-user and clinician participants, non-participant clinicians and a Psychologist from the local CLDT. Feedback sought from service-users, clinicians, a local speech and language therapist and CLDT Psychologists led to refinements before the documents were adopted within the service and shared with other IAPT services. Easy read promotional materials including leaflets and posters were disseminated by service-user and clinician participants to local services, including GP surgeries and third sector learning disabilities services. An easy read overview of the service was also added to the service's website.

Further non-training related actions included the production of a 'quick reference guide' to working with people with learning disabilities in IAPT. This was based on the training events and LD-PPG (2015) and produced by non-participant IAPT clinicians and was similarly disseminated within the service and other IAPT services. To maintain awareness within the service, it was agreed that a bi-annual slot would be dedicated to this in the service's Team Meetings. A specific learning disabilities safeguarding pathway and a learning disabilities Safeguarding Lead were identified. Recruitment advertisements were also adapted to highlight a desire for those with an interest in learning disabilities and a 'Carers of People with Learning Disabilities' workshop was initiated.

Regarding joint working, meetings were held with the IAPT service's in-house employment support team to discuss how they could best support people with learning disabilities. This led to the creation of clear pathways between this service and local mainstream and special employment support services. Quarterly meetings for local IAPT services learning disabilities Champions, and their associated CLDT-IAPT champions were also established to share ideas about implementing good practice according to LD-PPG (2015) and GLTK (2013). Also as a result of this project, a referral pathway was established with the local Higher Functioning Autism service and plans were made for further training to be carried out on working with this population in IAPT.

#### Phase three (evaluation): service-user themes

Two higher order themes and five subthemes were identified as noted in Table 5

Higher Order Themes	Subthemes
'Better'	Adaptations
	Staff training and attitudes
'More work to be done'	Recommendations for clinicians
	Recommendations for the service
	Keep us involved / informed

Table 5. Phase three service-user higher order themes and subthemes

# 'Better'

All service-user participants broadly indicated that the service had improved.

It's doing well, the service is better...much better, it's improving a lot.

Adaptations. Three service-users indicated their approval of the adapted and accessible documents, "the worksheets are really good", and many seemed appreciative of the changes that had taken place regarding service-user involvement, the employment service, and endeavours to work with local services. When asked whether she thought the IAPT service worked well with other services, one service-user, who had attended a workshop offered by IAPT in a local learning disabilities service after phase two, commented:

... from what I seen when I go to the workshops. I think they work well together.

*Staff Attitudes.* Many service-users also referred to what they felt might be a positive shift in staff attitudes and the ability to understand people with learning disabilities as a result of the training in phase two:

... it's really good that they learnt a bit more about disabilities and how they can communicate with them, and also how to work with them.

#### 'More work'

*Recommendations for clinicians*. Service-users continued to recommend clinicians improve their awareness of and acknowledging individual differences.

...Like, get to know us, like, know us more, and um, and trying...not just only one person, speak [to] others.

Increasing awareness of learning disabilities often overlapped with a requirement for clinicians to acknowledge individual differences, one service-user proposed ongoing training may facilitate this. Staff awareness sometimes coincided with improving staff attitudes; for example, three service-users implied a need for clinicians to be more patient.

Yeah, be aware, people with learning disabilities because they got, can get mood swings...and the staff have to be aware and patient.

This perhaps suggests a need for clinicians in IAPT to pay more attention to how they are interpersonally, especially with regards to the therapeutic alliance.

*Recommendations for the service.* Three service-users suggested increasing access by widening dissemination of promotional materials and making the referral process easier. One service-user proposed making "a film of like what the service provided for". Many also requested that they and their supporters be kept involved with the service. Suggestions to improve service-user involvement included "a talking group" and "leaflets" for supporters. Similar reasonable adjustments noted in phase one were proposed, including: more and/or longer sessions, alternative forms of communication such as staff learning "sign language", improving the buildings accessibility, and joint working. One service-user indicated that joint working may aid the sustainability of the project.

...to improve it again, I think you should, um, talk to, work together...all the different teams, the doctors, everyone...That's to improve it long period. You know, you're all doing same work.

# Phase three (evaluation): clinician themes

As shown in Table 6, three higher-order themes were identified. The first two closely mirrored those identified by service-users. The third encompassed ongoing uncertainties about IAPT's ability to adapt.

Higher Order Themes	Subthemes
Making progress	1
Auxiliary recommendations	Ongoing commitment
	Better service-user involvement
	Better working together
	Further need for clarity
	Increase exposure to increase confidence
Can IAPT Adapt?	Limits to flexibility
	Need for a 'cultural shift'

Table 6. Phase three clinicians higher order themes and subthemes

# Making progress

All clinicians inferred some progress had been made. References to progress especially reflected increased confidence, awareness and knowledge working with people with learning disabilities.

There is definitely an increase in awareness... beforehand, it was like walking on egg shells...I didn't know how to approach this and I didn't want to offend anyone, I feel now it's okay to say 'I'm not sure how to ask'...for me, that's been really good.

Increased confidence also extended to assessing and managing risk and there appeared to be less concern about "blame". Six clinicians indicated training had aided awareness on a practical level, for example by understanding how to make and use 'easy read' documents. Eight clinicians spoke favourably about having more clearly identified learning disabilities leads.

I think now we've got named people and that's important, because you can't hold everything in your head all of the time, as long as there is a clear pathway of where to get more information...

Potentially, increased awareness of the service's points of contact for learning disabilities related issues positively correlated with the clinicians increased confidence levels; knowing with whom to speak to perhaps decreased the uncertainty, and thereby, the risk of 'getting things wrong' and being blamed for doing so highlighted in phase one. Additional developments approved of by clinicians concerned better, clearer reasonable adjustments, joint working with other services, and the inclusion of service users' supporters in the service.

#### Auxiliary recommendations

*Ongoing commitment.* Every clinician suggested ongoing commitment was required to maintain and continue progress. Many suggested means of achieving this reflected recommendations made by service-users. For instance, four clinicians indicated promotion could be further improved, for example through advertising what had been done to make the service more accessible. Three clinicians suggested making further improvements regarding accessible forms of communication.

[adaptations] needs to be at every level of the service, including accessible voicemail messages Six clinicians also suggested further documents be made accessible including *"appointment letters"*. Frequent suggestions regarding training included making it mandatory and experiential. Nine clinicians inferred a need for ongoing training to aid the project's sustainability.

We can't just offer the training once, things change.

Six clinicians stated a need for this project to "stay in people's mind" and put forward specific suggestions reflecting this, including sending "email updates" and "reminders to use [the LD] labels and easy read materials". Six clinicians suggested a need for ongoing progress reviews in the form of auditing, however, three expressed associated concerns about the accuracy this given the ongoing ambiguity of the 'LD label'. Finally, four clinicians suggested having a space or "forum" to discuss and feedback on their experiences of working with people with learning disabilities.

*Better service-user involvement.* Almost every clinician indicated more could be achieved to include service-users. Most clinicians spoke about getting "general feedback" from service-users about their experiences, five suggested this be through "service-user forums". However, four clinicians expressed uncertainty as to whether they ought to be included in the existing, or a separate service-user forum, perhaps suggesting ongoing uncertainty among clinicians about how inclusive the service could be going forward.

*Better working together.* Many clinicians noted that the progress that had occurred between IAPT and the CLDT during and following phase two had not necessarily extended to other local services. Accordingly, seven clinicians suggested further joint working, such as:

...maybe training GPs and other professionals, just letting them know what we have been doing.

Perhaps underscoring notions of sustainability noted earlier, five clinicians indicated that the service could improve through local "strategising" or planning "in terms of where you want to go locally with the developments"

*Clarity.* Despite efforts to clarify the LD label, five clinicians indicated hesitance about using this, possibly reflecting ongoing hesitations, or fears of errors. Four clinicians requested clarity on the number of sessions that could be offered to people with learning disabilities, although most did so with an acknowledgement that this would be determined on "a case by case basis", suggesting increased awareness of the heterogeneity within this group.

*Increase exposure to increase confidence*. Four clinicians explicitly stated that increased confidence required increased 'exposure' to people with learning disabilities. Many also expressed doubts about increased exposure to this client group becoming a reality.

More exposure and more experience...I don't really know how you can force that to happen, I guess the more referrals we have, we will naturally get more exposure... but I don't know how realistic that is.

Clinicians continued to reflect that they were unlikely to feel confident working with this group until they gained experience and recognised 'exposure' was dependent on service leads and commissioners.

# Can the IAPT model adapt?

*Limits to flexibility*. Under this sphere, were frequent discourses regarding limitations to IAPT's flexibility and associated concerns about how realistic it was for IAPT clinicians to work with people with learning disabilities within the existing framework.

Flexibility...doesn't fit that well in an IAPT model, you can be flexible a bit, but there's a limit.

Specific concerns spanned several areas including: buildings, cancellation policies, and reliance on written materials. Concerns about the limits within IAPT also extended to perceived unrealistic expectations being placed upon them, "…no one can be an expert in everything". Appreciatively, five clinicians indicated their unease with such expectations without corresponding means or adjustments in place to support them, and corresponding references to a need for top-down recognition and flexibility.

*'Cultural shift'.* Seemingly overlapping perceived unrealistic expectations, four clinicians proposed learning disabilities ought to be included within IAPT training courses. One clinician commented that a much broader cultural shift may be needed for working with people with learning disabilities in a mainstream setting to become normalised.

...needs to be a cultural shift, not just us to be more inclusive, but for all mainstream services. Then it will just be the done thing. Many also highlighted a need to validate adapted measures, and improve communication with commissioners. At the end of her interview, one clinician effectively summed up the tensions felt and expressed amongst the clinicians.

... the training was fantastic and that's all brilliant but it's just making sure that in practice that it's done and kept that way going forward, so they're not shaving off bits as we go along, it needs to be truly meeting the need.

# Discussion

This qualitative action research enabled an insight into and action on the views of IAPT service-users with learning disabilities and IAPT clinicians regarding changes that could be made to enhance IAPT for this service-user group. By offering a novel insight into the views of service-users with learning disabilities who had accessed IAPT and PWP and HI clinicians with and without experience of working with people with learning disabilities, the current study built on existing research that offered either a largely quantitative account of IAPT staff perspectives (Chinn et al, 2014), or a qualitative account of only HI clinicians who had worked with this client group (Marwood, 2015). Critically, by using an action research framework, the current study built on limitations to existing research that could or did not implement findings, and enabled participants to be part of, and evaluate the change process. This study therefore supports claims that services users with learning disabilities can offer rich insights, and recommendations for psychological services (Melville et al., 2006), and play a key role in the research process (O'Brien, McCinkey & Garcia-Iriarte (2014).

#### Clinical and organisational implications

Phase one saw both service-users and clinicians provide rich examples of features that suggested the service was supporting people with learning disabilities. For example, service users indicated that talking therapy had been helpful to them, supporting Pert et al's. (2012) findings of a similar nature. Service-users also spoke of how clinicians sensitively modified their communication to facilitate assessment and treatment prior to the training offered in phase two, supporting the assumption that IAPT clinicians [already] have the skills to work with this population (PPG-LD; Dagnan et al., 2015) and furthermore, hold qualities considered desirable to service-users such as the ability to adapt communication styles (Stenfert-Kroese et al., 2013). However, phase one findings that mainstream clinicians felt ill-equipped to work with people with learning disabilities echoed existing research reporting similar findings (e.g. Marwood, 2015; Rose et al., 2007; Shankland & Dagnan, 2015). In some cases, clinician's perceived inadequacies led to a reluctance to work with this client group, thus corroborated suggestions of low confidence in IAPT clinicians may present barriers in the delivery of therapy to people with learning disabilities in IAPT (PPG-LD, 2015).

Service-users frequently expressed appreciation of, or recommendations for clinicians to acknowledge their increased needs and individual differences and adapting accordingly, supporting Stenfert-Kroese et al's. (2013) findings. Whilst clinicians also referred to a need to be 'sensitive' to individual needs, this was proportionally less than service-users and there seemed to be a simultaneous, arguably contradictory, desire for a 'one size fits all' training, as seen through repeated requests for practical 'how to' guide for people with learning disabilities. This could be indicative of a slight lack of appreciation of the diversity within this population among clinicians, and a need for training to emphasise its

heterogeneity. Further clinical implications included the importance of keeping people with learning disabilities and their supporters involved through provision of information and elicitation of feedback, for services to provide clear reasonable adjustments and guidelines on services policies, to enhance joint working and for clinicians to familiarise themselves with the evidence base on therapeutic work with this population.

Clinicians especially highlighted a need for training in this area, that the training be mandatory within IAPT curricula, and ongoing. This was often due to a perceived mismatch between what they felt the IAPT training had prepared them for and what they felt was expected of them within IAPT, echoing Marwood's (2015) findings of a similar nature. Arguably, the deficit in training led IAPT clinicians to feel working with people with learning disabilities was not part of their "core job", in line with Rose et al's. (2007) findings. Therefore, inclusion of learning disabilities in IAPT curricula may normalise this work, and enhance candidacy as described by Chinn et al (2014).

# Recommendations

In addition to a lack of training, clinicians frequently referred to feeling ill-equipped to work therapeutically with people with learning disabilities due to minimal 'exposure' to this group. This could be rectified by commissioners making reasonable adjustments a clear requirement and ensuring services have sufficient flexibility in terms of meeting targets. Through setting access targets, IAPT services may see an increase in the numbers of people with learning disabilities, which may increase clinician's confidence, competencies and expertise in working with this client group. However, as both serviceusers and clinicians noted, ongoing training will be required, therefore, commissioners may also need to ensure access to funding for this. The above recommendations add weight to recommendations made by Chinn et al (2014) and within the LD-PPG (2015). Future research could also seek to elicit views and service commissioners regarding the dilemmas and challenges of commissioning this area.

#### Methodological issues

A key limitation of this research was the lower than ideal level of participant inclusion with its design and execution. The neglect to include participants, particularly serviceusers, in every aspect of this research's design, delivery and dissemination, leaves it open to criticism, particularly from emancipatory researchers, who may consider this study as evidence of further systematic exclusion of people with learning disabilities. Other limitations include the sampling strategy, which was self-selected. This may have meant those with particularly strong views about this topic were more likely to participate, and may have favourably or unfavourably biased findings. Furthermore, the generalisability of this study is limited due to the small sample size and the research only taking place in one IAPT service due to time constraints. Another significant is the use of the GLTK which generated a very structured interview schedule for applying qualitative analysis.

#### Conclusions

This study provided further support for existing research that sought to elicit the views and experiences of IAPT clinicians on working with people with learning disabilities (e.g. Chinn et al, 2014; Marwood, 2015; Shankland & Dagnan, 2015). In line with the philosophy of action research, this project continues to move forward with the latest recommendations to emerge from phase three and aims to continue in this reflective cycle, with structures in place to do so, such as the ongoing quarterly IAPT LD Champion-CLDT meetings. Whilst this study has demonstrated that effective changes can collaboratively occur 'on the ground', the topic of people with learning disabilities is likely to require prioritisation by IAPT commissioners, service leads, and training course providers in order for this service user group to receive adequate support within IAPT. IAPT clinicians are likely to also require clear guidance on reasonable adjustments and service polices, as well as sufficient flexibility when working with this group. Another key possibility that emerged from the research concerned the low numbers of people with learning disabilities accessing IAPT. It is hoped that publication and dissemination of the current study through this journal may encourage those involved with people with learning disabilities and common mental health problems to consider their local IAPT service as a source of support. It is possible that in addition to the existing legislation, greater numbers of referrals of people with learning disabilities may inspire further IAPT services to consider their accessibility and implement adaptations where necessary, and increase clinicians' confidence in working with this service-user group, thereby enabling more equitable and effective access to psychological therapies within mainstream settings for people with learning disabilities.

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