Citation for published version (APA):

Citing this paper
Please note that where the full-text provided on King's Research Portal is the Author Accepted Manuscript or Post-Print version this may differ from the final Published version. If citing, it is advised that you check and use the publisher's definitive version for pagination, volume/issue, and date of publication details. And where the final published version is provided on the Research Portal, if citing you are again advised to check the publisher's website for any subsequent corrections.

General rights
Copyright and moral rights for the publications made accessible in the Research Portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognize and abide by the legal requirements associated with these rights.

• Users may download and print one copy of any publication from the Research Portal for the purpose of private study or research.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying the publication in the Research Portal

Take down policy
If you believe that this document breaches copyright please contact librarypure@kcl.ac.uk providing details, and we will remove access to the work immediately and investigate your claim.

Download date: 27. Oct. 2018
IAPT and Learning Disabilities

Deborah Chinn
Elisabeth Abraham
Christine Burke
Jill Davies

Research Report
October 2014
##Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgments</td>
<td>1</td>
</tr>
<tr>
<td>Executive summary</td>
<td>2</td>
</tr>
<tr>
<td><strong>1 Introduction</strong></td>
<td></td>
</tr>
<tr>
<td>1.1 Research questions</td>
<td>5</td>
</tr>
<tr>
<td><strong>2 Background</strong></td>
<td></td>
</tr>
<tr>
<td>2.1 Improving Access to Psychological Therapies</td>
<td>6</td>
</tr>
<tr>
<td>2.2 CBT and learning disabilities</td>
<td>7</td>
</tr>
<tr>
<td>2.3 IAPT and people with learning disabilities</td>
<td>9</td>
</tr>
<tr>
<td><strong>3 Research Methods</strong></td>
<td></td>
</tr>
<tr>
<td>3.1 Overview of study design</td>
<td>11</td>
</tr>
<tr>
<td>3.2 Qualitative data collection</td>
<td>11</td>
</tr>
<tr>
<td>3.3 National questionnaire survey</td>
<td>12</td>
</tr>
<tr>
<td><strong>4 Survey Results</strong></td>
<td></td>
</tr>
<tr>
<td>4.1 How did we define “learning disabilities” in the survey?</td>
<td>14</td>
</tr>
<tr>
<td>4.2 Who took part in the survey?</td>
<td>14</td>
</tr>
<tr>
<td>4.3 Referrals to IAPT</td>
<td>16</td>
</tr>
<tr>
<td>4.4 Mainstream or specialist psychological therapy?</td>
<td>19</td>
</tr>
<tr>
<td>4.5 Reasonable adjustments in IAPT</td>
<td>21</td>
</tr>
<tr>
<td>4.6 Confidence</td>
<td>22</td>
</tr>
<tr>
<td>4.7 Factors impacting on likely success of IAPT for people with learning disabilities</td>
<td>23</td>
</tr>
<tr>
<td>4.8 Support and training</td>
<td>24</td>
</tr>
<tr>
<td>4.9 Joint working</td>
<td>26</td>
</tr>
<tr>
<td><strong>5 Findings from qualitative data</strong></td>
<td></td>
</tr>
<tr>
<td>5.1 Summary of qualitative analysis</td>
<td>28</td>
</tr>
<tr>
<td>5.2 What is IAPT for? Two understandings of the core purpose of IAPT</td>
<td>28</td>
</tr>
<tr>
<td>5.2.1 IAPT is for everyone</td>
<td>29</td>
</tr>
<tr>
<td>5.2.2 Managerialism in IAPT</td>
<td>33</td>
</tr>
<tr>
<td>5.3 Nature of community learning disability teams</td>
<td>37</td>
</tr>
<tr>
<td>5.3.1 Direct provision role</td>
<td>38</td>
</tr>
<tr>
<td>5.3.2 Role of community learning disability teams as “enabling access”</td>
<td>42</td>
</tr>
<tr>
<td>5.4 Mental health support needs of people with learning disabilities</td>
<td>47</td>
</tr>
<tr>
<td>5.4.1 Same or different mental health needs?</td>
<td>48</td>
</tr>
<tr>
<td>5.4.2 Readiness for psychological therapies</td>
<td>49</td>
</tr>
<tr>
<td>5.4.3 Communication and understanding</td>
<td>51</td>
</tr>
<tr>
<td>5.4.4 Role of carers</td>
<td>52</td>
</tr>
<tr>
<td><strong>6 Discussion</strong></td>
<td></td>
</tr>
<tr>
<td>6.1 Limitations of the study</td>
<td>54</td>
</tr>
<tr>
<td>6.2 “Candidacy” and access to IAPT for people with learning disabilities</td>
<td>54</td>
</tr>
<tr>
<td>6.3 Conclusions and recommendations</td>
<td>59</td>
</tr>
<tr>
<td><strong>References</strong></td>
<td>61</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

1. In your experience, how usual is it for a referral to IAPT for someone with a learning disability not to be accepted? 17
2. To your knowledge does your local IAPT service work with people who need help with the following conditions? 18
3. In your opinion how likely is it for someone with learning disabilities to be offered treatment in your service following assessment (compared to other clients)? 19
4. How confident do you feel that someone with a learning disability would receive a good service from your local IAPT service? 22
5. What do you think makes an impact on whether someone with learning disabilities would benefit from IAPT input? (IAPT staff responses) 23
6. What do you think makes an impact on whether someone with learning disabilities would benefit from IAPT input? (Learning disability staff responses) 24
7. To your knowledge, what has been the impact of this training? 25

LIST OF TABLES

1. IAPT staff roles 14
2. Learning disability staff roles 16
3. Reasons for support for access to mainstream psychological therapy service 20
4. Reasons for preference for specialist services 20
5. Interview participants 27
6. Characteristics of dimensions of candidacy (Koehn, 2009) 55
Acknowledgments

We would like to thank the Bupa Foundation for funding this project through the Philip Poole-Wilson Seed Corn Fund, and for their support of health service research aimed at increasing the health care opportunities available to people with learning disabilities.

We received invaluable support from the Foundation for People with Learning Disabilities, who provided premises for meetings and excellent administrative help. Senior staff from the National IAPT team (now based within NHS England) showed interest in the project from the start, and facilitated contact with IAPT managers and teams around the country.

We are grateful for statistical support from Trevor Murrells from King’s College London. We would like to thank all those who contributed to the research and who took part in the Reflective Workshop.

Thanks also to Katrina Scior for making comments on an earlier draft, and to members of the project Reference Group for their encouragement, creative thinking and helpful suggestions. We hope that the views of the participants are reflected in this report, though of course, as authors we take final responsibility for any final conclusions and recommendations.
Executive summary

This study explores the relationships between the Improving Access to Psychological Therapies (IAPT) programme in England and people with learning disabilities and the people and services that support these service users. It sets out to answer the following questions:

1. What are the barriers and facilitators facing people with learning disabilities in accessing IAPT? How do these relate to the views, practices and service delivery models described by IAPT and specialist learning disability staff in England?

2. What are the strategies and practices that staff employ to support people with learning disabilities to make good use of IAPT services?

3. What advances are needed at the level of individual staff capabilities, service delivery models, management, commissioning and policy development to ensure equitable access to IAPT for people with learning disabilities?

Study findings were drawn from interviews with staff, service users and carers and a wider national online staff survey. We noted that staff in IAPT services do come across people with learning disabilities as clients. However, the IAPT programme as a whole has not adequately addressed access issues for people with learning disabilities. Some IAPT services exclude people with learning disabilities from the outset, by specifying eligibility criteria that rule them out. The IAPT programme prides itself on being founded on a clear evidence-based that recommends standardised inputs for common mental health problems. There is an emphasis on being a high volume service and on clear accountability in terms of adherence to treatment protocols and close monitoring of outcomes for patients. These procedures, when strictly enforced, can present access barriers to people with learning disabilities.

Despite these difficulties, a number of IAPT staff feel that their service, as a mainstream, community-based service for people experiencing common mental health problems, should be available to people with learning disabilities and can offer treatments that they will find helpful. The Psychological Wellbeing Practitioners (PWP) seem most optimistic about people with learning disabilities making good use of IAPT. These staff provide shorter, more practical interventions focusing on self-management and education about mental health.

Some specialist learning disability staff are actively involved in promoting IAPT for people with learning disabilities. However, others have either limited knowledge of IAPT services, or have had negative experiences in trying to support their service users to get treatment from IAPT. They do not feel confident that IAPT staff understand the needs of people with learning
disabilities and feel that specialist input from learning disability staff is more helpful and appropriate, particularly for people with more complex presentations.

IAPT services work best for people for learning disabilities when IAPT staff and learning disability staff have developed good working relationships and can co-ordinate their input. Some IAPT staff, who have prior experience of the needs of people with learning disabilities are adapting their materials and their work practices for this client group. They generally find it useful to involve family and carers in their work. In some cases the IAPT staff find their managers are happy to support them to work more flexibly and at a slower place. Staff also appreciate training and consultation from local learning disability specialists. However, support for work with people with learning disabilities within IAPT can be somewhat piecemeal, and initiatives are vulnerable to service cuts. This work does not appear to be a priority for commissioners, who generally do not set local goals regarding access to IAPT for people with learning disabilities.

The concept of “candidacy” (Dixon-Woods et al., 2012) provides a helpful framework to understand the position of people with learning disabilities within IAPT. In general, people with learning disabilities can struggle to see themselves, and be viewed by service systems, as legitimate candidates for IAPT services. Their claims to candidacy may be promoted in the following ways:

- Clearer statements of inclusion in IAPT services for people with learning disabilities.
- Recording systems that allow for monitoring of people with learning disabilities’ access to IAPT.
- Training for qualification of PWPs and other IAPT therapists to include material on working with people with learning disabilities, where possible delivered with the involvement of people with learning disabilities.
- Pathways for joint working between IAPT services and local specialist learning disability services.
- Clear goals and targets regarding use of IAPT by people with learning disabilities specified by commissioners and funded appropriately.
1 Introduction

Despite their widespread experiences of disadvantage and social exclusion, and high risk of poor physical and mental health, people with learning disabilities as a group are not well served by the NHS (Michael, 2008) and are at risk of missing out on centrally funded initiatives, such as the Improving Access to Psychological Therapies (IAPT) programme. The aim of the IAPT programme is to offer skilled and timely psychological support to people experiencing common mental health problems. It is an ambitious programme, aiming to reach at least 15% of the 6 million people in England of working age who are estimated to be experiencing anxiety and depression. In 2009 the IAPT taskforce produced good practice guidance for working with learning disabled clients, advising how IAPT services can make “reasonable adjustments” in line with their equalities responsibilities (Department of Health 2009a). However, the response of IAPT services to this guidance has not been evaluated and there is little evidence detailing how people with learning disabilities can be best supported to use IAPT.

This project grew out of our experiences as mental health practitioners working with people with learning disabilities, and as advocates, campaigners and researchers. In these roles we had talked to many people involved in mental health care, both as providers and service users and noticed a wide variety of attitudes and practices relating to the provision of mainstream psychological therapy services to people with learning disabilities. We had noticed that some learning disability services had developed inter-professional relationships and pathways with IAPT services to facilitate access for clients with learning disabilities. However, other IAPT teams were doing very little to accommodate to the needs of people with learning disabilities. We had even come across IAPT services whose managers made it clear that that offering services to people with learning disabilities was beyond their service’s remit and capabilities.

The aim of the study, which was funded for 12 months by the Bupa Foundation, was to develop an overall picture of the opportunities and barriers faced by learning disabled people in accessing IAPT services across England as a whole through undertaking a national online survey. We interviewed a wide range of stakeholders initially, including service users, paid and family carers, IAPT and specialist learning disability team staff to help us formulate the questions that needed to be addressed. We then launched a national survey, focusing on the views of those who provide services, either in specialist learning disability teams or IAPT services, to find out about their perspectives, practices and concerns. We also hoped to identify examples of good practice that could inform recommendations to service providers and commissioners and point to areas for service development.
1.1 Research questions

The specific research questions we aimed to address were:

1. What are the barriers and facilitators facing people with learning disabilities in accessing IAPT? How do these relate to the attitudes, practices and service delivery models described by IAPT and specialist learning disability staff in England?

2. What are the strategies and practices that staff employ to support people with learning disabilities to make good use of IAPT services?

3. What advances are needed at the level of individual staff capabilities, service delivery models, management, commissioning and policy development to ensure equitable access to IAPT for people with learning disabilities?
2 Background

2.1 Improving Access to Psychological Therapies

The Improving Access to Psychological Therapies (IAPT) programme was initiated in 2008 and has been the first centrally funded, nationwide programme to aim to bring evidence-based psychological therapies within the reach of all citizens experiencing common mental health problems in an equitable and timely manner. It is based on a model of “stepped care”, which was designed explicitly to reflect the philosophy of primary care and public health (Turpin et al. 2008) by targeting large numbers of potential service users, with “low-intensity” interventions focusing on self-management.

Turpin et al. suggest that there has been a convergence of factors that have brought about the prioritization of ensuing access to psychological therapies (Turpin et al., 2008). These include the publication of National Institute of Clinical Excellence (NICE) guidance on depression and anxiety which endorse the use of cognitive behavioural therapy (CBT) as well-evidenced treatments for these conditions (NICE 2004a; NICE 2004b). The growing emphasis on patient choice has meant an increased responsiveness to public preferences for talking therapies (Warner et al. 2006). Finally, the economic arguments for action against mental ill health as a drain on public resources in terms of its impact on disability and welfare benefits have been put on the agenda by Lord Layard and others (Layard, 2006).

From the initial two demonstration sites set up in 2006/2007 the IAPT programme has been extended to 60% of the English population (Department of Health, 2011a). The programme continues to set ambitious targets for reaching large numbers of the population affected by mental health problems, aiming for 3.2 million people to access the service between 2011 and 2015 (Department of Health, 2011a). This has required the training of thousands of additional mental health practitioners. Many of these are “low intensity” practitioners who support clients through guided self-help, bibliotherapy, psycho-education groups, behavioural activation and exercise, and signposting to other health and social care agencies. Where appropriate, clients are referred on to “high intensity” therapists who deliver more traditional one-to-one therapeutic interventions. The dominant therapeutic model for both high and low intensity interventions is CBT, though other evidence based interventions, including counselling and interpersonal psychotherapy are offered by some high intensity therapists. The current government has restated its commitment to the full roll-out of IAPT to all adults in England who have depression or anxiety disorders, including those over 65 years, and the development of a stand-alone IAPT service for children and young people (Department of Health, 2011a).

Not surprisingly given the high profile and high expectations of its proponents, the IAPT initiative has generated a great deal of debate and controversy, particularly within clinical groups involved in delivering psychological therapies. On the one hand, the architects
and supporters of the programme have celebrated its achievements, which are certainly remarkable in terms of extending availability of psychological treatments within a relatively short time scale (Clark, 2011; Gyani et al., 2012). Over a million people have been treated with two thirds of these completing a course of treatment. Recovery rates for those who engage in therapy have been reported in excess of 45% with more than 45,000 people recorded as moving off sick pay and benefits (Department of Health, 2012a; Health and Social Care Information Centre, 2013). From this camp the main concerns have been the slowing down in the rate of expansion of IAPT, leaving large numbers of citizens still excluded from access to psychological therapies or experiencing lengthy waiting times for treatment. Some social groups, particularly older adults and people from some ethnic minorities appear to be underrepresented amongst IAPT users (Centre for Economic Performance Mental Health Policy Group, 2012).

Other commentators have taken issue with the theoretical underpinnings of the IAPT programme, including the dominance of CBT, despite evidence that other psychotherapies may be equally effective (Stiles et al., 2008). Moreover, the evidence base for CBT (originally largely drawn from studies of carefully specified populations who conform to strict diagnostic criteria) has been questioned regarding its relevance for the “messy reality” of clinical practice (Marzillier and Hall, 2009). Further questions have been raised about the outcome data for IAPT, published as Key Performance Indicators (KPIs) by the Department of Health, which highlights the success rate for therapy among those who completing treatment, rather than the larger group of people referred to treatment. Reanalysis of the KPI data suggests that a much smaller proportion (12%) of those referred to IAPT derive significant benefit from the programme (Griffiths et al., 2013).

CBT as a treatment model continues to attract criticism because of its focus on individual psychological resources, even though wider social and economic factors such as employment, housing, income, marriage and family life have been found to be key determinants of psychological wellbeing at a population level (Cooper, 2009; Jahoda et al., 2009). Others have raised concerns that by extending the reach of mental health services and inviting more individuals to present for treatment of mental disorders, normal emotional responses to adversity will be pathologized and labeled as a psychiatric condition (Marzillier and Hall, 2009).
2.2 CBT and learning disabilities

Despite the struggles that many people with learning disability face to maintain good mental health, historically, this group have had little access to individual therapeutic interventions for psychological problems. In 1993 Bender described the ‘therapeutic disdain’ of mental health professionals towards learning disabled clients (Bender, 1993) and Corbett made similar points nearly twenty years later (Corbett, 2011). Traditionally psychotherapy services have made low IQ an automatic exclusion criterion, assuming that people with learning disabilities will lack the “psychological mindedness” required for engagement with talking therapies, leading to an over-reliance on medication and behavioural approaches (Whitehouse et al., 2006).

Some of these negative attitudes undoubtedly persist, particularly within mainstream adult mental health services. However, there has been a growing appreciation of the usefulness of psychological therapies in helping learning disabled people overcome emotional difficulties, with the publication of a number of key texts in the 1990s (Waitman & Conboy-Hill 1992; Sinason 1992; Kroese et al., 1997). Research since then has confirmed that cognitive factors are strongly associated with emotional disorders among people with learning disabilities (McGillivray & McCabe, 2010; Nezu et al., 1995; Willner & Goodey, 2006) suggesting that CBT is likely to be an effective treatment approach for at least some individuals.

To date the evidence base regarding the effectiveness of CBT for people with learning disabilities and common mental health problems is still quite limited (Willner, 2005; Sturmey, 2006). There are a number of published promising case study reports (Brown & Marshall, 2006; Willner, 2004), but still few randomised controlled trials (RCTs); those available have mainly focused on CBT for anger management (Willner & Goodey, 2006; Taylor et al., 2005). McCabe et al. conducted an RCT assessing the impact of CBT on depression involving 34 people with learning disabilities and found a significant improvement in functioning and self-esteem, and reductions in levels of depression, and negative automatic thoughts in the intervention group (McCabe et al., 2006). Hassiotis et al. (2013) conducted an RCT of a manualised CBT intervention for depression and anxiety with 32 people with learning disabilities. This study did not find a significant difference between measured outcomes in the therapy group, compared to usual MDT treatment. Nevertheless, treatment was well tolerated by participants and positive experiences of many in the therapy group prompted the authors to argue for larger studies in future to provide clearer evidence about which clients are likely to get most benefit from CBT.

Given the demands that CBT makes on language and thinking abilities, most researchers do not advocate CBT as a suitable treatment option for all people with learning disabilities experiencing common mental health problems. Hatton (2002) described three aspects of cognitive capability needed for CBT; (1) cognitive skills (e.g. understanding of abstract concepts, memory capacity), (2) the ability to identify different emotions, and (3) the ability to understand the cognitive model and links between thoughts, feelings and behaviours. Practitioners suggest that individuals are assessed for their readiness for CBT and their capacity to engage with this approach bearing in mind these prerequisites using structured
assessment procedures (Dagnan et al., 2000; Joyce et al., 2006). There is evidence that clients can be taught cognitive skills for CBT (Bruce et al., 2010) in order to make best use of therapy.

There is a growing consensus that CBT needs to be adapted for individuals with learning disabilities (Hurley et al., 1998), for instance using simplified language, being flexible in terms of length and frequency of sessions (Whitehouse et al., 2006), reducing reliance on written materials and homework, and employing a range of communication aids such as pictures, videos and role-play (Kirk et al., 2013).

However, some researchers and practitioners have sounded a cautionary note in response to what they see as a growing orthodoxy that CBT should be promoted uncritically as the psychological treatment option of choice for people with learning disabilities, at least those with appropriate language and cognitive skills to engage with it (Sams et al., 2006). The evidence base is growing, but much research includes only small number of participants with little analysis of exactly which aspects of a multi-component CBT intervention are likely to benefit which individuals under which circumstances (Sturmey, 2004; Emerson, 2006).

A core principle of CBT is that low or anxious mood is underpinned by unhelpful cognitive appraisals that are likely to be distortions of "reality." The social model of disability (Oliver, 1990) might critique this approach for attributing disabled people's distress to personal deficits in socio-cognitive functioning, and avoiding confronting the lived experience of disability marked by social and economic disadvantage, exclusion and discrimination. Moreover, some have argued that the Socratic questioning approach in CBT may reinforce learning disabled clients' feelings of incompetence and inability, in line with dominant social positioning of people with learning disabilities (Gerry & Crabtree, 2013). Jahoda and colleagues argue that adaptations of CBT for people with learning disabilities should not be just a matter of technical "fixes," but address aspects of the wider social context experienced by learning disabled clients (Jahoda et al., 2009).
2.3 IAPT and people with learning disabilities

The current government goal for mental health services is to provide “equity of access to treatment, prevention and promotion interventions, as well as equality of experience and outcomes across all protected groups” (Department of Health, 2011b, p. 17). The 2011 mental health strategy document “No Health Without Mental Health” recognises the vulnerability of learning disabled people to mental health problems and confirms that mental health services need to meet the needs of all disabled people (Department of Health, 2011b). Government policy has supported access to mainstream mental health services for people with learning disabilities where appropriate, with additional specialist support when needed (Department of Health, 2009b). In 1999, the National Service Framework (NSF) for Mental Health was published, to address health inequalities (Department of Health 1999). The Green Light Toolkit (GLTK) was introduced in 2004 (Foundation for People with Learning Disabilities et al., 2004) to make sure that people with learning disabilities were included, using a ‘traffic lights’ system of self-assessments to make sure that commissioners and providers of mental health services work towards equality of provision for learning disabled people.

In 2009 the IAPT Taskforce published specific good practice guidance to address the access needs of learning disabled people using IAPT (Department of Health, 2009a). The guidance makes recommendations for ensuring the engagement of learning disabled people with IAPT services by advocating flexibility in delivery of therapy services to this client group. It also recommends training and supervision for IAPT staff to develop disability awareness competencies, and skills in meeting the needs of learning disabled clients. There is widespread acknowledgement that practitioners skilled in CBT are likely to need additional support and training to work with this client group (Heneage et al., 2010). The input of people with learning disabilities themselves in training staff is likely to be a particularly effective means of increasing staff confidence and their awareness of the mental health needs of this group of service users (Morris et al., 2009; Holttum et al., 2011).

The guidance also recommends that the uptake of IAPT services by people with learning disabilities is monitored, and successful and unsuccessful referral pathways are identified. Dodd et al also call for audit and research on how IAPT services have responded to the needs of people with learning disabilities, and their effectiveness for this group (Dodd et al., 2011). However, to date, the effectiveness of the guidance has not been evaluated, and there is little information on how people with learning disabilities are faring within IAPT services and how the interface between the new IAPT services and existing community learning disability teams is being managed. This report describes the findings of a research study designed to address some of these gaps in the existing evidence base.
3 Research methods

3.1 Overview of study design

Our literature review found little existing evidence about the views of service users or providers about the issues involved in learning disabled people accessing IAPT services. Therefore, we decided to use a sequential mixed methods design (Creswell et al., 2004) (qualitative → quantitative → qualitative) to develop a survey questionnaire and subsequently reflect on the practice implications of study findings. The first phase of the study involved qualitative data collection using interviews, and data from this phase were used to develop a survey instrument that was widely distributed to IAPT and learning disability services. Data from the survey instrument were analysed primarily quantitatively. The results were then used to generate further discussion among stakeholders at a reflective workshop event in order to produce service recommendations.

Securing ethical approval for the study

Our study protocol received ethical approval from the East Midlands NRES Committee (12/EM/0187). We also secured approval from the individual NHS healthcare Trusts’ R&D departments that covered the areas where the qualitative data collection took place.

Project reference group

In the initial stages of the research we established a research Reference Group in order to secure the active involvement of stakeholders, including IAPT and specialist learning disability community team members, representatives from learning disability advocacy organisations and the Department of Health. The Reference Group met three times during the life of the project to review and advise on ethical issues, communication with stakeholders, design and implementation of the research and analysis and dissemination of the findings.

3.2 Qualitative data collection

Rather than develop a questionnaire based solely on issues arising from our review of the literature, or on ‘expert opinion’, we decided to try to collect a range of views about access to mainstream mental health services for people with learning disabilities from a wide variety of stakeholders. Our inclusion criteria for professional staff were that they had at least one year’s experience of IAPT or specialist learning disability mental health provision. Paid or family carers had to have direct experience of supporting someone with learning disabilities who had experienced mental health problems within the last three years. The learning disabled participants had to have direct personal experience of mental health services and the capacity to provide informed consent to take part in the study.
We recruited participants in this phase through a range of methods. We used our professional networks and contacts to invite people we thought might be interested in being interviewed. Other interested services contacted us when the research protocol was published through the NIHR research networks and local collaborators or research support officers identified potential participants. People we interviewed helped us to make contact with others that they knew (“snowball sampling”). When we found that we were not managing to recruit family carers of people with learning disabilities who had received psychological therapy, we advertised the project through an online network for family carers.

Once a potential participant expressed an interest in taking part we sent them an information sheet about the study. We designed an EasyRead version for people with learning disabilities. We then arranged to meet the participant in a preferred location (usually their place of work or their home for participants with learning disabilities). Four of the participants preferred telephone interviews.

The interviews were structured around a topic guide addressing general mental health issues which impact on learning disabled people, their experiences of specialist and mainstream mental health services, and the opportunities and difficulties which might accompany their use of IAPT services. The interviews were recorded and transcribed verbatim.

3.3 National questionnaire survey

Questionnaire design

The key themes and concepts determined through analysis of the interviews contributed to the underlying structure of a survey questionnaire which was then further refined and piloted through consultation with Reference Group members. The questionnaire was designed in line with guidance on the construction of online surveys, which recommends strategies to maximise the ease of use of such instruments and encourage a good return rate (Lumsden, 2006). We aimed for the questionnaire to take no longer than 15 minutes to complete, though some participants clearly spent longer on it than this and gave very full and thoughtful responses in the free text boxes. Responses were anonymous, though participants were asked to identify their role and the nature of their employing agency.

Distribution of questionnaire

We distributed the questionnaire to local IAPT and community learning disability teams using the e-survey tool Survey Monkey™. We had noted a number of advantages in using online rather than postal questionnaires, including reduced costs, wide geographical coverage, access to online communities and reduction in spoiled or incomplete returns (Lumsden, 2006). We used an internet search to identify the relevant teams in England and sent an email to team leaders asking them to forward information about the study and a hyperlink to the questionnaire to members of their teams.

1. The topic guide, information sheets and consent forms are available from the lead author on request.
In the end we sent emails to 156 IAPT teams and 298 learning disability teams, a larger number for learning disabilities than we had expected, since some areas were served by more than one local team, or by separate health and social care teams. We also publicised the questionnaire via online networks for health workers with a special interest in learning disabilities.

We were keen to make our sampling approach inclusive in order to put together an overview of the national picture regarding people with learning disabilities’ access to IAPT services. Although IAPT services have to adhere to clear governance standards, there was likely to be variation with regards to eligibility criteria, models of stepped care, and the range of services offered. We were also interested in collecting examples of innovative and creative practice where barriers to access for people with learning disabilities have been successfully overcome.

Data analysis

We used NVivo to manage and code the qualitative interviews that we conducted in Phase 1. We then used an inductive thematic analysis (Braun & Clarke, 2006) to synthesise the data, identify key themes and make links between them. The analysis of the questionnaire data involved descriptive statistics, investigations of relationships between different responses to explore specific hypotheses (for example whether IAPT services with more direct experience of working with learning disabled service users are more or less likely to anticipate better or worse therapeutic outcomes with this client group) and thematic analysis of free text responses to open ended questions.
4 Survey results

4.1 How did we define “learning disabilities” in the survey?

We decided to use the term “learning disabilities” rather than other terms, such as “intellectual disabilities” as “learning disabilities” is the term that has been adopted by health and social care organisations in England that work with these groups of users. On the first page of the survey we provided the following definition:

*In this questionnaire we will use the term “learning disabilities” throughout. People with learning disabilities have grown up with wide ranging difficulties with cognitive functioning (thinking, learning, understanding, memory) to the extent that these difficulties have a significant impact on their everyday life. People with learning disabilities are likely to be eligible for specialist health and social care services.*

We gave people reading the survey the opportunity to follow a link to a page with more information on learning disabilities that explained in greater detail the differences and overlaps between “learning disabilities”, “learning difficulties” and “autistic spectrum disorders”.

4.2 Who took part in the survey?

Our sample totalled 452 respondents. Of these 193 identified themselves as working for an IAPT service and 230 said they worked for a specialist learning disability service. Twenty-nine respondents classified themselves as “other”. These included participants who identified themselves as working for a local authority, for a learning disability charity or advocacy service, in higher education or as carers. Given that these roles indicated a learning disability background, we analysed their responses together with those who classified themselves primarily as specialist learning disability staff.

Table 1 IAPT staff roles

<table>
<thead>
<tr>
<th>Job role</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWP (Psychological Wellbeing Practitioner)*</td>
<td>54</td>
<td>28</td>
</tr>
<tr>
<td>High Intensity Therapist (HIT)**</td>
<td>94</td>
<td>48.6</td>
</tr>
<tr>
<td>Team Manager or Service Lead</td>
<td>28</td>
<td>14.5</td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>9.3</td>
</tr>
<tr>
<td>Total</td>
<td>193</td>
<td></td>
</tr>
</tbody>
</table>

* Including PWP trainees.
** Including CBT, IPT (Interpersonal Psychotherapy) Therapists, Clinical Psychologists and trainees.
The proportion of PWPs to high intensity therapists is broadly in line with IAPT service make up which is constituted of approximately 40% PWPs and 60% high intensity therapists. Despite the recent development of the IAPT programme, respondents were relatively experienced staff, with a median length of service in their current role of 3 years.

We were interested to find out whether staff working in IAPT services might have had previous contact with people with learning disabilities, either in their professional roles or in their personal lives as family members, friends or neighbours. Altogether, nearly three quarters of the IAPT staff (72%, n=139) answered that they had had contact with people with learning disabilities. Half of the respondents (n=96) had previous experience of working in a service with people with learning disabilities, and half (n=95) said that they knew someone with learning disabilities in their personal life. We were not sure whether these responses were likely to be typical of all IAPT staff or not. Perhaps IAPT staff who had had personal contact with people with learning disabilities were more likely to embark on the survey.

There is little reliable data about the percentage of the population whose lives are touched by people with learning disabilities. A survey of the Australian public (Yazbeck et al., 2004) found that 87% of adults surveyed said they had “prior knowledge” of people with learning disabilities. A more recent survey of Dutch nursing students (Ten Klooster et al., 2009) found 30% had a friend or relative with learning disabilities and 25% had worked with someone with learning disabilities.

Table 2 shows the different roles of learning disability staff respondents. They were a varied group with a preponderance of clinical psychologists. This does not reflect the number of psychologists compared to other staff in learning disability services. Rather this group are likely to have a particular interest in the topic of psychological therapies for people with learning disabilities, which may well have prompted them to participate in the survey. Learning disability staff had spent an average of 6.3 years in their current role.

Respondents who put themselves in the “other” category included support workers, adult placement officers, specialist psychotherapists, advocates and those working in higher education.
Table 2 Learning disability staff roles

<table>
<thead>
<tr>
<th>Job role</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker/care manager</td>
<td>20</td>
<td>7.7</td>
</tr>
<tr>
<td>Clinical psychologist/psychology assistant</td>
<td>97</td>
<td>37.5</td>
</tr>
<tr>
<td>Counselling psychologist/counsellor</td>
<td>11</td>
<td>4.2</td>
</tr>
<tr>
<td>Art Therapist</td>
<td>11</td>
<td>4.2</td>
</tr>
<tr>
<td>Speech and language therapist/ SALT assistant</td>
<td>5</td>
<td>1.9</td>
</tr>
<tr>
<td>Occupational therapist/OT assistant</td>
<td>6</td>
<td>2.3</td>
</tr>
<tr>
<td>Nurse</td>
<td>44</td>
<td>17.0</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>7</td>
<td>2.7</td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>4</td>
<td>1.5</td>
</tr>
<tr>
<td>Team leader/service manager</td>
<td>25</td>
<td>9.7</td>
</tr>
<tr>
<td>Other</td>
<td>29</td>
<td>11.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>259</strong></td>
<td></td>
</tr>
</tbody>
</table>

4.3 **Referrals to IAPT**

Three quarters of the IAPT respondents (77.5%, N=148) indicated that they had come across at least one client with clearly identified or diagnosed learning disabilities in the course of their work, with half of these estimating that they had seen three or more of such clients. When we included contact with clients with suspected learning disabilities without an established diagnosis, the percentage of IAPT staff rose to 90% (N=164). From the perspective of IAPT staff, the majority of clients with learning disabilities they saw had been referred by their GP (58.3%, N=137) with 14% (33) self-referring, but only 8.1% (N=19) being referred by the local CTLD (Community Team for Learning Disabilities).

The impression that specialist learning disability staff are not often referring people with learning disabilities to IAPT services was confirmed by the finding that only a third of the respondents from specialist services had done so (33.1%, N=85). Similarly, a third of this group (35%, N=83) said that a referral to IAPT would always be considered if the person with learning disabilities had an identified need for psychological therapy.

The reluctance of learning disability staff to make referrals may have been related to their perception that these referrals would not get very far. When we asked how usual they thought it was for a referral to IAPT for someone with a learning disability to be rejected, half (47.5%, N=110) said they did not know. Of those who did express an opinion (52.6% of respondents to this question, N=122), 60.7% (N=74) felt that rejection of referrals happened frequently.
Many of the specialist learning disability staff who did express an opinion (N=78, 65.5% excluding the “don’t knows”) said they felt that their local IAPT team appeared to have a policy of taking on referrals for people with learning disabilities, but then signposting them on to other services, without continuing to assess them for suitability for IAPT inputs.

An important question was whether learning disability staff were clear about the sorts of mental health problems IAPT services had been set up to address. The central IAPT website and the publicity materials prepared by other IAPT teams we have come across specify that IAPT is for people with depression and anxiety disorders, often described as common mental health problems.

Nearly nine out of ten of the learning disability staff (86.8%, N=197) knew that IAPT was for people with common mental health problems. However, some respondents also thought that IAPT worked with a range of other difficulties, including psychosis and problem drug and alcohol use (Figure 2). In each of the categories we indicated there were a number of “don’t know” responses, suggesting some uncertainty about the function and scope of IAPT services among learning disability staff. For instance, whilst 40% of the learning disability staff (N=88) knew that IAPT would not work with people who needed help because of a diagnosis of dementia, a larger percentage (51.8%, N=114) said they did not know whether IAPT worked with this group or not.
The IAPT staff had a rather different impression of the outcome of referrals of people with learning disabilities with three quarters (74.3%, N=139) asserting that their team policy would be to continue to assess the person for suitability for IAPT. IAPT staff were divided regarding the question whether prospective clients with learning disabilities would be less likely than others to actually be offered treatment following assessment with around half (45.9%, N=84) agreeing this would be the case, and others disagreeing or saying they did not know (Figure 3).
4.4 Mainstream or specialist psychological therapy?

We asked all the respondents to answer the following question:

*In your opinion should ALL psychological therapies for people with learning disabilities be provided by specialist learning disability services?*

The aim of this question was to explore whether participants felt that in theory at least, people with learning disability were likely to be served best by specialist workers with specific training and experience working with this client group, or whether, if only in some cases and circumstances, mainstream psychological therapy services would be the best option for people with learning disabilities.

We found a consensus among the IAPT staff and the learning disability staff, with very similar proportions of each group (73.8% of the IAPT staff, N = 138 and 73.5% of the learning disability staff, N = 175) answering No to this question. There was variation however, in the reasons that respondents gave for their answers. Learning disability staff were more likely to emphasise the importance of the principle of access to mainstream services for people with learning disabilities. IAPT staff, on the other hand stressed the advantages IAPT represented in offering a range of evidence-based psychological treatments (see Table 3).

On the other hand, a quarter of the participants felt that specialist input was always the best option for people with learning disabilities in need of psychological therapy support. For both staff groups the most common reason given was that they felt that learning disability staff had specialist skills in communicating with people with learning disabilities (Table 4).
### Table 3  Reasons for support for access to mainstream psychological therapy service

<table>
<thead>
<tr>
<th>Reason</th>
<th>IAPT staff</th>
<th>Learning Disability staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referring people with learning disabilities to IAPT reflects a commitment to the principle of offering mainstream support to this group</td>
<td>91 37</td>
<td>143 48.6</td>
</tr>
<tr>
<td>IAPT have more experience of working with people with common mental health problems</td>
<td>29 11.8</td>
<td>33 11.2</td>
</tr>
<tr>
<td>IAPT can offer a wide range of evidence-based therapies in different formats for people with common mental health problems</td>
<td>80 32.5</td>
<td>51 17.3</td>
</tr>
<tr>
<td>IAPT are non-stigmatising compared to specialist learning disability services</td>
<td>19 7.7</td>
<td>25 8.5</td>
</tr>
<tr>
<td>IAPT have shorter waiting times.</td>
<td>8 3.3</td>
<td>15 5.1</td>
</tr>
<tr>
<td>Other</td>
<td>19 14.1</td>
<td>27 9.2</td>
</tr>
<tr>
<td><strong>Total (number of responses)</strong></td>
<td>246</td>
<td>294</td>
</tr>
</tbody>
</table>

### Table 4  Reasons for preference for specialist services

<table>
<thead>
<tr>
<th>Reason</th>
<th>IAPT staff</th>
<th>Learning Disability staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist learning disability staff have more advanced skills in communicating with people with learning disabilities</td>
<td>41 44</td>
<td>48 40.0</td>
</tr>
<tr>
<td>Specialist learning disability teams are resourced to support people with learning disabilities</td>
<td>21 22.8</td>
<td>26 21.7</td>
</tr>
<tr>
<td>Specialist learning disability teams have shorter waiting times</td>
<td>0 0</td>
<td>1 0.8</td>
</tr>
<tr>
<td>Specialist learning disability teams can offer a wider range of inputs to people with learning disabilities and common mental health problems</td>
<td>26 28.3</td>
<td>39 32.5</td>
</tr>
<tr>
<td>Specialist learning disability teams are non-stigmatising compared to IAPT services</td>
<td>0 0</td>
<td>4 3.3</td>
</tr>
<tr>
<td>Specialist learning disability teams have shorter waiting times</td>
<td>8 3.3</td>
<td>0 0</td>
</tr>
<tr>
<td>Other</td>
<td>4 4.3</td>
<td>2 1.7</td>
</tr>
<tr>
<td><strong>Total (number of responses)</strong></td>
<td>92</td>
<td>120</td>
</tr>
</tbody>
</table>
4.5 Reasonable adjustments in IAPT

The responses of IAPT staff suggest that many feel that they are already making adaptations to their service to suit clients with learning disabilities. However, reasonable adjustments which might require changing IAPT materials or changing routine outcome measures appeared to be harder to implement.

Assessment

Although many IAPT services conduct initial screening assessments over the phone, three quarters of the IAPT respondents (73.5%, N=136) indicated that a face-to-face meeting would be the preferred format for clients with learning disabilities. Over half of IAPT staff (58.7%, N=108) also agreed that staff in their service were allowed to take longer than usual to complete assessments with people with learning disabilities.

Length of interventions

Half of the IAPT sample (50%, N=91) felt confident that staff in their service were allowed to take longer than usual to undertake interventions with people with learning disabilities.

Involving carers

IAPT staff appeared to have a positive orientation to involving significant others in their work with people with learning disabilities. When asked if they thought it would be a good idea to involve a paid worker, friend or family member in the process of therapy with a client with learning disabilities, 80.1% of the IAPT staff (N=145) felt this would be advisable, at least sometimes. The majority of respondents from the IAPT sample (57.1%, N=92) and a similar proportion of the learning disability service respondents indicated that the most helpful role for carers was to reinforce the key messages of the therapy.

Written materials

Only 20.3% of the IAPT sample (N=36) said that they had written materials that had been adapted for people with learning disabilities available in their service.

Outcome measures

There was a consensus that the outcome measures routinely used by IAPT services were not helpful for people with learning disabilities: only 12.3% of the IAPT sample felt they were suitable for these clients.

Guidance

The Learning Disability Positive Practice guidance was not well known by the IAPT staff, with only 11.1% (N=50) indicating that they had read the guidance. The guidance was not well known by learning disability staff either, with a quarter responding that they had read the guidance.
4.6 Confidence

Self-rating of confidence is likely to relate to an individual’s estimation of their skills and knowledge, as well as their rating of their effectiveness and success rate in a particular situation (Stewart et al., 2000). It is also likely to influence an individual’s willingness to engage in an activity as lack of confidence is usually accompanied by anxiety and discomfort.

We found quite high levels of personal confidence rating amongst IAPT staff regarding their work with people with learning disabilities. Seventy two per cent said they felt either very confident or somewhat confident. IAPT staff who had previously come across people with learning disabilities in a personal or professional capacity were significantly more likely to state they were somewhat or very confident to work with someone with learning disabilities (Pearson’s Chi-Square = 13.30 df = 2, p < .001).

IAPT staff also expressed an interest in improving their confidence in this area. However, only one in five (19.5% N=32) felt this was a high priority, though a further 43.3% (N=71) said it was a medium priority. A further 37.2% felt this was a low priority for their professional development.

In a related question we asked respondents how confident they felt someone with learning disabilities would receive a good service from IAPT, either the team they worked in, or the one they would refer to if they were learning disability staff. There were significantly higher levels of confidence among the IAPT staff compared to the learning disability respondents (Pearson’s Chi-Square = 47.33 df = 4, p < .001) with only 20% (N=37) saying they were not at all confident of this outcome, compared to twice the proportion of the learning disability staff (38.5%, N=87) (Figure 7).

We analysed the responses of the IAPT staff in more detail using cross-tabulations and found that the Psychological Wellbeing Practitioners (PWP’s) were significantly more confident than the more specialist High Intensity Therapists (HITs) that people with learning disabilities would get a good service from their team (Pearson’s Chi-Square = 9.43, df=2, p = 0.009).
4.7 Factors impacting on likely success of IAPT for people with learning disabilities

We gave participants a choice of possible factors that might impact on a person with learning disabilities’ likelihood of making good use of IAPT. These were a mixture of personal characteristics and aspects of the person’s social environment, such as the availability of support to make use of therapy. We noted a similar pattern of responses from IAPT and learning disability staff, with an emphasis on the importance of support from carers and the individual’s capacity to understand the model of change underpinning IAPT therapies. Although IAPT services rely a good deal on written materials, neither group felt that difficulties in reading and writing would be a major impediment to someone with learning disabilities making good use of IAPT. The learning disability staff tended to emphasise communication issues more than IAPT staff, with a larger proportion identifying individual difficulties with expressive and receptive language as a getting in the way of a good outcome (Figures 5 and 6).

Figure 5 What do you think makes an impact on whether someone with learning disabilities would benefit from IAPT input?
Responses of the IAPT staff suggested that it was not always easy for them to access help within their team to support and develop work with people with learning disabilities. Around a quarter (25.4%, N=46) could identify someone within their team who had specialist knowledge and expertise in working with people with learning disabilities, and the majority were not able to indicate that their supervisor was a good source of advice for this sort of work (70.2%, N=127). Two thirds had not received any training on involving people with learning disabilities in psychological therapies. For those who had received training, 20% (N=12) had taken part in a session lasting three hours or less, 34.4 % (N=20) had had

![Survey Results]

**Figure 6** What do you think makes an impact on whether someone with learning disabilities would benefit from IAPT input?

### 4.8 Support and training

Responses of the IAPT staff suggested that it was not always easy for them to access help within their team to support and develop work with people with learning disabilities. Around a quarter (25.4%, N=46) could identify someone within their team who had specialist knowledge and expertise in working with people with learning disabilities, and the majority were not able to indicate that their supervisor was a good source of advice for this sort of work (70.2%, N=127). Two thirds had not received any training on involving people with learning disabilities in psychological therapies. For those who had received training, 20% (N=12) had taken part in a session lasting three hours or less, 34.4 % (N=20) had had...
training lasting between 4 and 8 hours and the rest had had training lasting longer with a small number undergoing quite lengthy periods of training, for instance as part of their professional qualification. Of the training experiences identified, eleven respondents (15.3%) indicated that they had received training on working with people with learning disabilities as part of their qualifying IAPT training (N=11). Eleven respondents constitutes only 6.1% of the IAPT sample who answered the question about training, indicating that to date training on psychological therapies for people with learning disabilities has not been common component of IAPT training. Of the other relevant training experiences, 47.2% (N=34) had happened within the IAPT workplace and 37.5% (N=27) had been accessed elsewhere.

The IAPT staff (68.2%, N=122) and the learning disability respondents (67%, N=148) agreed that training should be targeted at all staff within IAPT to give them the skills to adapt their work for people with learning disabilities. They also agreed that training should not be reserved for a limited number of workers within the IAPT team who presumably would constitute a smaller specialist resource within the service. Two thirds of the IAPT staff (74.7%, N=133) said that they personally would like additional training on working with people with learning disabilities, though only a fifth (20.9%, N=28) thought that it was likely that they would actually have an opportunity to access further training of this kind in the near future.

Figure 7 shows how learning disability staff evaluated the impact of training they knew to have been provided to their local IAPT team. The respondents felt that training was most likely to promote joint working between IAPT and learning disability teams, but not very likely to lead to more people with learning disabilities actually being offered a service from IAPT.

![Figure 7: Impact of Training](image-url)

**Figure 7** To your knowledge, what has been the impact of this training?

---

2. Most clinical psychologists, for instance, have to complete a six months clinical placement in a service for people with learning disabilities as part of their professional training.
4.9 Joint working

There did appear to be some mutual awareness among IAPT and learning disability staff, and around two thirds of the respondents in each group said they knew each other’s contact details (65% of IAPT staff and 64.6%, N=44 of learning disability staff). Half of the IAPT staff had had some direct contact with a member of their local learning disability team, either face to face (23.5% of contacts, N=42) or by email (38% of contacts, N=68). The majority of the learning disability staff (61.9%, N=161) had been in direct contact with staff from their local IAPT team. However, only around 15% in each group knew of any actual protocols or agreed pathways for co-ordinated working between the two services in their own areas.
5 Findings from qualitative data

Who took part in the interviews?

We interviewed 10 people associated with learning disability services, seven associated with IAPT services, 3 people with learning disabilities and 1 family carer (details in Table 5).

Table 5 Interview participants

<table>
<thead>
<tr>
<th>Learning disability staff</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Social worker</td>
<td>1</td>
</tr>
<tr>
<td>Learning disability community nurse</td>
<td>2</td>
</tr>
<tr>
<td>Consultant psychiatrist</td>
<td>2</td>
</tr>
<tr>
<td>Learning disability mental health liaison nurse</td>
<td>2</td>
</tr>
<tr>
<td>Commissioning manager</td>
<td>1</td>
</tr>
<tr>
<td>Manager of outreach project</td>
<td>1</td>
</tr>
<tr>
<td>Advocate</td>
<td>1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>IAPT staff</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological Wellbeing Practitioner (PWP)</td>
<td>1</td>
</tr>
<tr>
<td>CBT therapist</td>
<td>1</td>
</tr>
<tr>
<td>IAPT mental health nurse</td>
<td>2</td>
</tr>
<tr>
<td>Service manager/team manager</td>
<td>3</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lived experience experts</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user</td>
<td>3</td>
</tr>
<tr>
<td>Family carer</td>
<td>1</td>
</tr>
</tbody>
</table>

Total number of interviews 21

Notes on the qualitative analysis

We decided to report our analysis of the interview data and the free text comments that people wrote when they answered the survey separately to the mainly quantitative data from the questionnaire. First, we found that the qualitative data did not simply replicate and expand on the quantitative data, it told a slightly different story. Because we could let our participants talk at greater length when we spoke to them face to face, and because we could probe a little deeper for explanations for their statements, the qualitative data deals with a wider range of topics, includes more conceptual thinking, real-life examples and space for nuance and contradiction.
The second reason for reporting the interview and free text data separately has more to do with epistemology and research methodology. Whereas the tasks involved in reporting the questionnaire responses could best be described as summary, framing and integration of data, our analysis of the qualitative data gave us more scope to be actively and creatively engaged in the interpretation of the data and beyond the purely descriptive level.

5.1 Summary of qualitative analysis

We have organised the responses from the interviews and the free text from the questionnaires into main headings:

1. IAPT services – who they are for and how they work
2. Specialist learning disability teams – their role and contribution
3. The mental health support needs of people with learning disabilities

Within these main topic areas we found that respondents represented contrasting viewpoints that we identified as linking to more general social understandings of public services and the nature of mental health difficulties and of learning disabilities. These more general understandings created links and tensions across the different topics. It is not always easy to convey in this sort of report that respondents might well have offered a mixture of understandings of these concepts as opposed to expressing views clearly positioned on one side or another. When faced with complex social problems we often represent in our talk the dilemmas and contradictions associated with different lines of argument (Billig et al., 1988).

In the final section of the report we attempt an overall synthesis of the quantitative and qualitative data. We use Dixon-Woods et al’s (2006) concept of “candidacy” to suggest an overall framework for understanding access to IAPT for people with learning disabilities. This concept points to the processes and stages of presenting oneself and being accepted as a “candidate” for services and highlights how the achievement of candidacy reflects negotiations and interactions between individuals and service structures. We also suggest some adaptations to this concept that take into account the contexts and life experiences of people with learning disabilities.

5.2 What is IAPT for? Two understandings of the core purpose of IAPT

The overall impression we gathered from the interviews, and from the comments made on the questionnaire, was that there were two underlying discourses relating to the core purpose of IAPT. These discourses presented very different opportunities and constraints to people with learning disabilities presenting with common mental health problems. The first discourse which we have called “IAPT is for Everyone”, emphasises the nature of IAPT as a public and primary healthcare project, using a preventative model to offer mental health self-help strategies to a wide range of people experiencing significant, but not yet disabling levels
of depression and anxiety in order to improve their wellbeing and reduce the risk of their difficulties becoming more entrenched and severe.

The second discourse tended to reference a vocabulary and set of arguments associated with “managerialism” in human services. This “interpretative repertoire (Potter and Wetherell, 1987) uses metaphors from industrial production, highlighting the importance of efficiency, through-put, targets, rationality, and value for money. We found that quite a few participants referenced both discourses and would expect that both would be represented within the same IAPT team. As one respondent noted in the survey:

_I have encountered very thoughtful approaches to LD and rather dismissive, bureaucratic approaches from within the same IAPT team. Learning disability service counsellor, (survey)_

### 5.2.1 IAPT is for everyone

**Creation of IAPT services**

IAPT services have come into being in very different ways. Some were developed from primary care mental health teams headed by psychiatrists and staffed mainly with mental health nurses, though also including psychologists and counsellors. Others grew from primary care psychology teams who had been working in GP practices or in community settings for many years. Others were established from third sector agencies, either local counselling services or large private mental health providers such as the Priory Group. Some of the participants commented on the different backgrounds staff brought with them before retraining as CBT practitioners as creative therapists, counsellors, mental health nurses and felt this was a strength of the service. These therapists felt they had valuable experience of working with complexity and of working flexibly within primary health care settings.

_All staff are well experienced and trained in working with a wide range of mental health problems and work with a good cross section of society_. IAPT counsellor (survey)

**“A public service”**

A key principle of primary health care services is that they are, in principle at least, available to everyone, and that they provide an important public health role in preventing ill health through programmes such as immunisations and health checks. One view of IAPT, articulated quite explicitly by its staff, locates it within this model of universal availability, emphasising the responsibility of public services to see all in need:

_Because of the fact of being a public service we have a duty to see anyone that comes to the door_. IAPT service manager (interview)

_It’s a world out there stuffed with all manner of different types of people with all different sorts of problems. And we have a duty to care for all of them_. IAPT mental health nurse (interview)
I believe IAPT should be available as a first-line primary care psychological therapy service for all who need it, including those with a learning disability. IAPT PWP (survey)

From this perspective, impeding the access of people with learning disabilities to IAPT and automatically routing them to a specialist service is described as an aspect of discriminatory practice.

It seems a little discriminating to allocate learning disability with anxiety or depression to a learning disability service, when the primary problem they say they are presenting is depression or anxiety. IAPT career coach (survey)

People with learning disabilities need not be singled out as "a special case", given that many community members may need adaptations to make use of services. The following extract illustrates how an IAPT therapist sees this as a fairly routine aspect of their work:

I am an OT by core profession and am aware that any group of people I work with may need treatment tailored to their needs, e.g. those with physical health conditions or poor writing/reading skills come across the board of referral to IAPT. IAPT CBT therapist (survey)

This approach appears to connect with a social model understanding of learning disability (Oliver, 1990), which focuses not on the disadvantages that are assumed to proceed inevitably from impairments, but on the socially created barriers faced by disabled people and the responsibility of public services to address these. Our respondents were mental health experts and some showed a sensitive understanding of the social-emotional impact of disability and exclusion (Thomas, 2004) and the possibilities that being welcomed into mainstream provision can counteract internalised aspects of stigmatisation and enhance “self-efficacy”.

I think that it is important that people with a learning disability are offered interventions in more mainstream services to ensure that they are included in services rather than being stigmatised and excluded. IAPT CBT therapist (interview)

The benefit of having mainstream is that that helps people to be independent. And self-reflection ‘okay like everybody else I’m going to IAPT’... It’s not to do with my learning disability it’s to do with my mental health...’ like everybody else. Commissioning Manager (interview)

Key aspects of therapy

The argument that IAPT, like other public services, should be accessible to all, is often supported by descriptions of the active ingredients of therapy that are low-tech and emphasise the link between physical and mental health. Strategies such as problem solving, behavioural activation, signposting to social care and community services and “social prescribing” of exercise programmes are promoted as easily accessible aspects of IAPT interventions, often undertaken by the Psychological Wellbeing Practitioners (PWP).

I think the mainstream, like within IAPT, we can definitely help with the basic skills, the information, the education, the whole self-help element of it, because they are sort of basic
things, and sometimes it’s just about eating healthily, sometimes it’s about not drinking caffeine, it’s all those sorts of basic things that anybody can have a level of understanding about, and I think they’re very useful whatever, whether you’ve a learning difficulty or not. IAPT mental health nurse (interview)

Others mentioned aspects of therapy often incorporated into CBT that appeared to have particular usefulness and face validity for people with learning disabilities. Participants mentioned the value of problem-solving approaches that focused in a concrete way on coping and help-seeking.

She made a quite a lot of progress so one of the things that we focused on was her self-harming. So when she would get stressed she would head bang on the corner of the radiator or she would scratch on her arm. So she’d stopped those behaviours by the time we'd worked together and we replaced them with more helpful behaviours which could also get rid of her frustration, so kind of screaming into pillows and telling people that she’s feeling very distressed which she wasn’t doing before which was helpful. IAPT CBT therapist (interview)

One of the service users interviewed made some similar points:

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>If you were to see another counsellor at IAPT, for example, what do you think you’d like to tell them, what they’d need to know to help you?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user:</td>
<td>Well I want coping techniques really, coping – what’s that word coping you, coping…</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>Strategies?</td>
</tr>
<tr>
<td>Service user:</td>
<td>Yeah that word. To help me to deal with when I’m upset to help me to be really able to cope with it on my own. That’s what I want is to be able to cope with it on my own and not get so upset and distressed about it.</td>
</tr>
</tbody>
</table>

Participants mentioned group work offered by IAPT as being particularly helpful for people with learning disabilities as a way of encouraging peer-to-peer support, normalising emotional difficulties as a commonly shared experience, or as a “gentle introduction” to some of the key ideas of what talking therapy involves.

These descriptions also foreground what are sometimes called the non-specific aspects of psychological therapy; having the chance to offload problems and share difficulties with a skilled listener, being met with warmth and empathy in the therapeutic relationship and the mobilisation of hopefulness of a positive outcome and better mental health. This view chimes with a humanist understanding of mental health interventions, associated with the work of Carl Rogers, and emphasises the interpersonal stance of the therapist as a key ingredient in helping people to recover from depression and anxiety and reconnect with their own life goals and essential human worth:
If we can ‘connect’ during assessment, then we can usually find a way of progressing through their issues. It may be more challenging for me in as much as I would need to work perhaps more creatively in my approach, but in terms of my core conditions (respect, empathy and genuineness) that underpin the therapeutic relationship, validate and nurture the individual and promote development, then the LD is almost irrelevant. IAPT counsellor (survey)

Because sometimes for the rest of us if we can only just talk to somebody who you know is listening it can make you feel better about things, it can help; even if it doesn’t cure, it can help. So I think definitely for Maureen [daughter with learning disabilities] she would grab it. Family carer (interview)

Spreading the word

In order for services to be generally available, all sections of the community need to be aware of their existence at the least. Some respondents felt it was the responsibility of IAPT teams to advertise their services more widely to people with learning disabilities and people who might signpost them.

IAPT Services could be more committed in advertising their services to different groups.
IAPT PWP (survey)

GPs should be made aware that IAPT is suitable for mild LD also. IAPT PWP (survey)

Some of the respondents from learning disability teams admitted that they knew little about what IAPT might offer their service users. A few mentioned that it was only taking the survey that had raised their awareness of IAPT services.

Completing this survey has made me realise how little I know about local IAPT services or the efforts that are being made to meet the needs of PLD. Learning disability service social worker (survey)

Rhetoric and reality

Although many participants endorsed the principle of universal access to public services, some expressed the opinion that this was an impossible ideal, of limited applicability for IAPT, or that universal access is a concept that people pay lip service to without taking steps or investing resources to make it a reality:

Mainstreaming is good as a theoretical idea, though with a lot of unexamined sentimentality sustaining it, and it simply does not translate to practice without additional funding or subspecialising within the IAPT service. Learning disability service clinical psychologist (survey)

I mean like because ideally everyone would get their individual support for them but obviously funding and what have you that’s not ever going to happen. Because people… support services don’t have the time to do that for everybody. Learning disability service community Nurse, (interview)
Some expressed worries that a precipitous move to extend IAPT provision to people with learning disabilities in the name of equality would result in worse services for this group and those supporting them.

*IAPT are non-stigmatising and referring people with learning disabilities would “reflect a commitment of offering mainstream support to this group”. However, this support would be inadequate and in many cases ineffective, thereby becoming a “dumping ground” which will demoralise the client, their families and carers and the IAPT staff.* IAPT CBT therapist (survey)

Some respondents suggested that IAPT services needed to be at an appropriate level of readiness before offering services to people with learning disabilities.

*Although I support 100% for LD patients to access IAPT service, it needs to be planned and funded and reasonable adjustments to processes and treatment protocols should be considered to make sure that patients’ needs are met.* IAPT service lead (survey)

Many of the comments made by learning disability staff on the survey echoed this opinion; that staff working in IAPT teams needed more training and support and needed to put reasonable adjustments in place in terms of adapting materials and working practices before more referrals of people with learning disabilities would be appropriate.

Even those who spoke enthusiastically about people with learning disabilities accessing IAPT drew the line at people whom they characterised as having more severe cognitive impairments.

*I think our service users are better served by generic services… But only if they’ve got mild LD. I think moderate/severe, we’re probably best placed to help.* Learning disability service consultant psychiatrist, (interview)

*I think of learning disabilities on a continuum and IAPT could offer effective service to people on the less severe end of the spectrum who are functioning in day to day life but have problem with anxiety or depression.* IAPT CBT therapist (survey)

However, it was not clear whether it was the nature of the interventions on offer, or the way that treatments were delivered through IAPT that led to conclusions that IAPT was not suitable for people who require more day to day support.

### 5.2.2 Managerialism in IAPT

In section 2 we briefly reviewed critiques of IAPT that associated it with a set of practices involving the strengthening of managerial controls over the work of individual practitioners and organizations including introduction of work protocols and routinization of work, setting targets and auditing measurable outputs in line with service goals. These practices are often associated with the concept of “managerialism”

*The term ‘managerialism’ denotes nothing more than a system of organisational and budgetary control directed at the most efficient and effective use of resources* Syrett et al. (1997, p. 159)
Managerialist practices have become so widespread within public services that they are increasingly taken for granted as an inevitable aspect of care provision. However, some commentators have argued that this model of service provision has negative consequences, particularly within mental health care as it leaves little space for the development of intersubjective understandings that are a key feature of human services. Fisher and Owen (2008) contrast managerialist “economies of performance” drawn from discourses prevalent in the world of commercial, profit-making businesses with “ecologies of practice” informed by experiential knowledge of practitioners and intersubjective identifications “and a holistic view of the value of a life that is not contingent on achieving externally imposed targets and quantifiable outcomes” (p.2070). Chapman (2012) argues that managerialism in mental health services runs the risk of “de-subjectifying” professional knowledge and socially intimate activities (Traynor, 1999) and replacing these with standardised and manualised work routines that are rolled out uniformly in all settings to all service users (Chapman, 2012). Within this context, the main driver for work will be working to targets and contracts in line with a priori definitions of success:

So for me I interpret that, for me, as a manager as being really clear about my core business: what is my core business, what’s my core contract? I have to have a service that delivers to that. My core contract at IAPT the global population with common mental illness if they can’t access the service then we should go home, we’ve failed. So we’ve got to do that first. And then we can work out who are the outliers and how do they get a service too. IAPT service manager (interview)

Lack of flexibility in IAPT: past and present

Concerns about the way that IAPT has evolved into adopting a protocol-driven approach with limited flexibility, a pre-determined process for assessment, a set number of sessions of fixed duration, and session content and outcome measures specified in advance were raised by both IAPT and learning disability staff. The two respondents quoted below felt that originally IAPT had been conceived more in line with a flexible, person-centred primary health care model, which offered possibilities for support for people with learning disabilities, but had changed in response to higher expectations from commissioners.

That’s the unfortunate thing, in its inception in 2008 IAPT was very much going out to leisure centres, GPs, and that does happen but not to the extent that it used to. Workers are more chained to their desks now unfortunately because the commissioners want a 10% throughput rather than a 7% throughput, so they have to stay and do appointments.... and now IAPT has become a machine not just an innovative service. IAPT service manager (interview)

I feel IAPT itself has gone from a very immediate inclusive project to having tight criteria-waiting lists and being rather robotic in applying their criteria. I’m disappointed for IAPT and especially in relation to PWLD. I was very keen -very involved and very determined to make our area IAPT service work for and with us. Sadly I feel I have failed. Learning disability service community nurse, (survey)
The machine metaphor and use of words like “throughput” suggest a system where people are seen as units to be processed with an emphasis on keeping to targets and prioritising “quantity over quality”. Some IAPT staff saw this as a consequence of extending the service to a wider range of potential service users (such as people with learning disabilities). Therefore excluding the “outliers” as the IAPT manager put it above could be regarded as a strategy to maintain quality in the face of increasing demand.

Workload pressures

The pressure of workloads experienced by IAPT staff was mentioned repeatedly. IAPT is a high volume service and staff are expected to log clinical contacts at a consistently high level.

*We do have the targets that we have to do for daily people, we have to see five people a day, um, so that is the target for mental health nurses, counsellors and CBT therapists. The PWPs are up to seven a day, because a lot of their telephone contact is half-hour sessions usually.* IAPT mental health nurse (interview)

*We do – I’m trying to think how many assessments we do a week – about 800 assessments a week.* IAPT service manager (interview)

Not surprisingly, this can exert considerable day-to-day pressure on staff and make working conditions stressful, particularly for PWPs (Shepherd & Rosairo, 2008):

*Part of my job is very much to go around and find out worker perceptions and fears and all of that, and they are just snowed under… literally they’re booked back-to-back.* IAPT service manager (interview)

This situation was described as generating risks for people with learning disabilities regarding the service that they might receive from IAPT. Even if they are open to working with people with learning disabilities, staff may not have the time or thinking space to make reasonable adjustments to their work for people with learning disabilities, who can come to be seen as an extra burden.

*I think the other difficulty is how we are expected to work in IAPT services. We see high volumes of clients and we don’t always have appropriate clinical space for the work we do. This can mean that making adaptations for LD clients impossible in some instances. There simply may not be the time or space available to IAPT therapists to be accommodating to LD clients.* IAPT CBT therapist (survey)

Evidence based treatments and NICE

According to Clark (2011), the publication of NICE guidance on the treatment of depression and anxiety (NICE, 2004; 2009), and the prominence given therein to CBT as a well-evidenced intervention provided part of the impetus behind the foundation of IAPT. The NICE guidelines endorsed a particular psychological intervention (CBT, and more recently Interpersonal Therapy, or IPT) as a treatment of choice, based on a consideration of published studies, with particular attention paid to large Randomised Control Trials (RCTs). They also recommended
a service delivery model of stepped care that became the framework for IAPT services. The rollout of IAPT services was based on arguments that “treatment fidelity” (adherence to CBT techniques and protocols) will produce better clinical outcomes (Shafran et al., 2009), though some researchers have suggested that research evidence underpinning these arguments is contradictory (Simons et al., 2013; McHugh et al., 2009).

There was some uncertainty among respondents about how far the available evidence-base endorsed the effectiveness of CBT for people with learning disabilities:

*The evidence suggests that people with mild to moderate learning difficulties respond well to evidence based psychological therapies such as CBT.* IAPT team manager (interview)

*Tricky as the evidence base for CBT interventions for LD is not available to us.* IAPT team manager (survey)

Nevertheless, some participants expressed concerns that departing from NICE guidance and the treatment protocols associated with them would undermine the effectiveness of the therapy offered in IAPT. One participant felt that offering treatments that were not supported by a robust evidence base could be seen not only as misdirected, but also unethical:

*I certainly believe passionately in people getting services but still getting services that help. I also believe passionately in ethically delivered services; I don’t think it’s right for a service to think they can help someone when the evidence suggests what they’re delivering as intervention really don’t for any particular reason.* IAPT service manager (interview)

However, others argued that adherence to evidence-based protocols can be too rigid, and that following guidance could be compatible with flexible methods of delivery, as long as the underlying change principles in CBT were respected.

*I think the only barrier to working with people with learning difficulties is that many IAPT courses do not prepare their students to think about how to adapt CBT to people who may have difficulty with the traditional methods used in CBT (i.e. writing, keeping thought diaries etc.) due to their strict adherence to NICE guidelines and the “evidence base”.* IAPT CBT therapist (survey)

Another IAPT participant described being able to deliver protocols in a more flexible way as a developmental skill that is associated with greater therapist experience. These responses suggest an intuitive grasp of the concept of “flexibility with fidelity” which has been explored and endorsed by researchers in the field of evaluation of evidence-based psychological therapies (Kendall et al., 2008; Herschell, 2010). The principle of “flexibility with fidelity” encourages adjustments to protocol components in line with individual differences, including cognitive abilities, whilst maintaining fidelity to the key features of the treatment model.
Outcomes and outcome measures

Although use of outcome measures is not new in mental health care, they have become much more consistently a feature of everyday practice in IAPT services as a method of monitoring effectiveness of interventions and assessing progress towards targets for success. Making regular use of standardised outcome measures is a central feature of all IAPT interventions and though it can provide helpful feedback and an convincing rationale for ongoing service funding, it can also limit what is viewed as valuable about therapy to the rather simplified measurable outputs (McGivern & Fischer, 2012). Users of the service are asked to fill in mood rating forms at every session, and other assessments examine changes in social and occupational status.

There was widespread endorsement of the view that the routine outcome measures used in IAPT services (PHQ9 and GAD7) were not suitable for people with learning disabilities (see p.21). Practitioners found it a struggle to work through them with these clients and to convince clients with learning disabilities of the utility of the measures. A number of IAPT respondents noted that it was not unusual for other service users without learning disabilities to balk at repeated administration of these measures.

Apart from repeated administration of these measures being stressful, some respondents made the point that they did not reflect the usual life experiences of people with learning disabilities, who were less likely to have children or paid employment. Figures from the Adult Social Care Outcomes Framework 2013/14 show that only 7% of people with learning disabilities known to social services have any kind of paid employment (Department of Health, 2012b). One interview participant told us that she had adapted the routine outcome measures to include activities such as voluntary work, which was more relevant for people with learning disabilities. Some noted that the emphasis on paid employment as a key performance indicator on which the success of an IAPT service would be judged made it less likely that someone with learning disabilities would “fit the bill” as someone who would like to benefit in hoped-for ways from IAPT interventions.

5.3 Nature of community learning disability teams

Forty years ago many people with learning disabilities in the UK lived in large hospitals. These were “total institutions” where all aspects of care provision including health, employment, leisure and education were provided on the same site. Since the replacement of institutional with community care as the dominant model in learning disability services, and the publication of the “Valuing People” White Paper in 2001, with its emphasis on rights and inclusion, there has increasingly been an expectation that people with learning disabilities will access ordinary, mainstream community facilities, with support as necessary.

The remit and configuration of specialist community learning disability teams has evolved over this period. Many teams are now integrated with both health and social care staff co-located and working together, usually with the local authority acting as the lead agency. The most recent guidance on commissioning learning disability services produced by the learning
disability public health observatory, Improving Health and Lives (IHaL) outlines two main roles for community learning disability teams (IHaL, 2012). The first is enabling access to other services through health facilitation, teaching and advice to mainstream services and service development. The other role is direct provision including assessment and formulation of difficulties and implementation of specialist interventions.

In our participants’ responses related to the role of specialist learning disability teams in supporting people who experience poor mental health, we noticed that either the health facilitation or the direct provision role was foregrounded.

5.3.1 Direct provision role

“We have a specialist team for that”

Most community learning disability teams include a range of mental health specialists. These may be psychiatrists, clinical psychologists, counsellors, and in some instances mental health nurses. One participant suggested this configuration led to an assumption that these staff would see any local people with learning disabilities who needed input.

I think part of it is historical, that, ‘ah learning disability, we have a specialist team for that… I think that’s part of the mind-set of history and the way originally… anybody who has learning disability [who] needed mental health sort of assessment, okay there’s one or two psychiatrists in Learning Disability specialist team or the psychology money has been put into Learning Disability service, could you go there? Commissioning manager (interview)

This hypothesis was supported by the short comments added after the question on the survey “If your team is working with someone who has an identified need for psychological therapy, would a referral to IAPT always be considered?” A number of participants noted briefly, “we have our own psychologists in the community learning disability team”.

A couple of the participants highlighted the negative consequences such decisions might have for the development of capabilities for working with people with learning disabilities within mainstream services:

We’re deskilling them. The longer we’re picking those cases up the less likely they are to actually learn about learning disabilities. So we’re actually doing them a disservice in a way. Learning disability service community nurse, (interview)

We have in the LD service benefited from having in house, the various health disciplines ie psychology, psychiatry, occupational therapy. This has led to close client to therapist working relationships and knowledge that has helped the client in the long term. However it has meant that mainstream services don’t offer their expertise or develop expertise in the LD field.
This has an impact when clients who don’t fit social service eligibility criteria access mainstream services, which, because of their policies, lack the expertise of working with LD. Learning disability service clinical psychologist (survey)

Others raised concerns that relying uniformly on in-house specialist learning disability inputs would mean that service users might not receive the expert mental health support they needed.

| Learning disability service consultant psychiatrist: | We’ve all realised that, um, and I agree, actually, that people with mild learning disabilities are probably better served by generic services. With… with a degree of support. |
| Interviewer: | Mm. And why do you think that would be the case? Why are they better served by generic services rather than specialist services? |
| Learning disability service consultant psychiatrist: | I think it’s because the generic services see far more of the common conditions. You know? If it’s straightforward depression, straightforward anxiety, even schizophrenia, you know? The generic services see far more than we do. I mean, we… I’m using the royal we, you know, I think we tend to see a lot of the physical comorbidities, um, a lot of epilepsy. A lot of challenging behaviour. Yes, we see mental illness. But, the generic services have more of the expertise. |

Such concerns about negative unintended consequences of specialist community learning disability teams and their indirect role in the under-development of practitioner skills in mainstream healthcare can be found in reports by academics and third sector agencies (Mencap, 2004; Mir et al., 2007). This might be an uncomfortable line of argument for learning disability team members, who after all might have quite a lot to lose if aspects of their roles were redirected to mainstream services.

And do you know what if generalists worked with all people with learning disabilities there wouldn’t be any need for specialists. So that raises another interesting question doesn’t it?
IAPT service manager (interview)

Benefits of specialist input

Participants mentioned the different dimensions of the unique contributions of specialist learning disability teams. These include expert knowledge about learning disabilities and about individuals who present in this way – knowledge that may have built up over many years and through repeated contacts with the individuals, their families and support networks.

The world in which we live in is just totally not designed for adults with learning disability. And from experience the only people that have any kind of knowledge on how to deal with people with learning disability and not to be scared about dealing with people with
Learning disability is to contact people that deal with learning disability every single working, working day. Learning disability service outreach manager (interview)

The knowledge translates into skills in pacing work appropriately, and understanding and adapting to individuals’ cognitive and communicative capabilities. One service-user participant talked about how she felt specialist services would have supported her more appropriately whereas she was struggling to get her point across when she was referred to a mainstream mental health service:

Because it’s very frustrating, you know? Trying to explain how you’re feeling… And you don’t know how to put it. Where maybe if I’d been put in the other stream, they would have been able to ask me simple questions… Where I would have been able to answer them better. Service user (interview)

Participants from both specialist learning disability teams and from IAPT services emphasised how understanding the communication preferences of people with learning disabilities was a specialist skill that takes a great deal of training and experience to master.

It is a specialist skill to adapt and differentiate a typical IAPT psychological therapy protocol to make it meaningful and accessible to most people with a learning disability. IAPT CBT therapist (survey)

As many teams are multi-agency and employ social care as well as health staff, some respondents pointed out that they are able to offer more joined up and holistic assessments and interventions that take into account the complexity of people’s presentations:

And I think because learning disability teams tend to be very multi-disciplinary, um, you’re kind of appreciating an individual with a learning disability can be very multi-faceted. So that when you’re actually looking at the mental health diagnosis you also have to take into account other elements that make them up as a person. Um, whereas I think sometimes with mental health services it’s slightly more just about the person’s diagnosis. Learning disability service community nurse (interview)

Having practitioners from different disciplines working together in the same team means that there are opportunities for joint working, co-ordination of care plans and sharing of skills and expertise within the team. Participants from learning disability teams also appreciated the potential for being able to engage in longer term work with service users presenting with complex difficulties. They felt that they had more time to work with service users and their families.

Some cases were very long term and participants gave examples of slow-moving work that required a lot of patience and persistence from staff in order for progress to be made. They felt that building a secure, trusting relationship with service users and their families made it more likely that service users would accept the input on offer from different members of the team, despite initial reluctance.
However, there was not a universal perception that specialist services had more time and capacity to take on new clients compared to mainstream mental health services. Some participants mentioned brief, time limited inputs becoming standard practice within community learning disability teams and long waiting lists for service users to see clinical psychologists.

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>Do you have specialist psychology services here?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability service mental health liaison nurse:</td>
<td>There is specialist psychology services. The biggest problem with all, I mean with all the specialist, all specialist services is waiting lists, you know...As far as I'm aware all the psychology is the same... You know they're snowed under.</td>
</tr>
</tbody>
</table>

And now when you’re allocated... Well it’s the same with social workers if you’re allocated... if you’re referred the person who’s working with you, whether it be a nurse, a support worker or a social worker and they have support workers as well now they are giving a six week window and they’re expected to deal with what you need within that six weeks and sign you off. Family carer (interview)

This family carer, as well as other participants, noted that specialist learning disability services were being scaled back, and were enforcing more stringent eligibility criteria. In some localities integrated teams were being disbanded, or specialist social work input withdrawn and replaced with input from generic social workers.

Specialist services as last resort/fall back

We went out and did an assessment and found that certainly the person probably didn’t have a learning disability, it was more mental health related and then we went round and round and round and round for about 18 months with the person getting no input from anybody. And I think then our service said, “Do you know what, her presenting issue is more mental health than it is learning disability but given that nobody wants to take responsibility for the person we’ll just take them and provide the input.” Learning disability service community nurse (interview)

Learning disability staff talked about repeated experiences of trying and failing to support people with learning disability to access mainstream mental health services. Some mentioned identification of a learning disability seemed reason enough for some IAPT teams to reject a referral:

And I can think of sort of one negative example where we received a letter that was, you know, had been screened by the team coordinator in this case, and what was scrawled across it was ‘learning disability not suitable for IAPT’ and the letter was posted to us with nothing else. Learning disability service mental health liaison nurse (interview)
Have tried to refer mild/borderline individuals to main IAPT and had them returned as not suitable. Learning disability service clinical psychologist (survey)

Others mentioned that individuals were automatically excluded from IAPT because they had an allocated social worker or were receiving input from other community learning disability staff, which identified them as already in receipt of secondary healthcare and therefore ineligible for IAPT input. Sometimes the process of exclusion was more subtle:

I think in emails later on… once they found out there was a learning disability involved they were very keen to see if the community team option had been explored, explored first because of his learning disability. And I remember a particular line in an email along the lines of “we do work with adults that have a learning disability but we don’t routinely work with them and, hence, we feel that it might be the Learning Disability Community team that would be better to provide psychological therapies.” Learning disability advocate, (interview)

There was widespread concern about service-users being “bounced around” between services, finding closed doors at every turn. Even when they did manage to secure an assessment after a referral to IAPT, in the experience of some of the respondents working in community learning disability teams, those individuals would be referred back to the specialist learning disability service, either because the referral was judged inappropriate or because the treatment had not been a success.

The referral is accepted by IAPT, what you hear further down the line (When the person with a LD gets referred back to your service) is that they had an initial assessment and they ‘didn’t need IAPT’. They pretend to accept people, then don’t really. Learning disability service clinical psychologist, (survey)

Participants mentioned that the lesson learned from these experiences was that there was not much point in referring or signposting people with learning disabilities to IAPT:

Colleagues in our team (community LD team) have often attempted to make referrals to our local IAPT service but these referrals are not accepted, the team has now stopped making referrals to IAPT. Learning disability service clinical psychologist (survey)

The next quotation brings together the two themes of “No need to look further” and “Specialist services as a last resort” and suggests how they can become mutually reinforcing and part of the culture of learning disability teams and create a self-identity as the only realistic option for people with learning disabilities and mental health needs:

I can imagine that once you’ve worked in like learning disability for a while, and I start to think this sometimes anyway, is that you automatically think like they’re not going to work with them so I’m going to try and do it myself. Or get it within the specialist service because you come across it so much that you kind of think why bother. Learning disability service community nurse, (interview)
5.3.2 Role of community learning disability teams as “enabling access”

A clear statement regarding the “enabling access” role of community team members is made in Valuing People (Department of Health, 2001).

Specialist staff will need to give more time to facilitating the work of others in mainstream services, to developing the capacity of services to support those with complex needs, to service design and less to direct interventions (p. 68).

The following quotation indicates how these recommendations have affected how community learning disability staff view their role:

*A major part of our job should be helping people that we support to access mainstream services, or to helping mainstream services adapt.* Learning disability service community nurse, (interview)

Valuing People (Department of Health, 2001) spells out these tasks in more detail as comprising a health promotion role, a health facilitation role, a teaching role and a service development role. These specifications are repeated in the latest guidance for commissioners (IHaL, 2012).

**Health facilitation**

The descriptions of health facilitation activities provided by specialist community learning disability staff gives an indication of the complexity of this role and how it can be particularly helpful in ensuring that people with learning disabilities can use IAPT services. One method of promoting successful access to IAPT for people with learning disabilities is for specialist staff to undertake a preliminary screening exercise with the service user to check whether IAPT services would be suitable for them.

*At first most clients were refused. I now screen clients for suitability before referring them to IAPT.* Learning disability service clinical psychologist (survey)

These screening assessments can identify the sorts of reasonable adjustments and supports that people with learning disabilities might need, that can be worked on before the start of the intervention.

*Information about the person’s communication, health and behaviour shared with IAPT and symbol resources provided by SALT [speech and language therapist] specific to an individual provided to help them understand the key messages of their therapy. IAPT and SALT liaised to make resources for a service user.* Learning disability service speech and language therapist (survey)

As well as providing more information for IAPT staff about the person with learning disabilities, learning disability staff mentioned undertaking preliminary work with the service user and their network, so that they understood how IAPT and CBT worked, were prepared for the commitment needed and could arrange necessary support in advance.
In some cases, “enabling access” can mean attending IAPT sessions with the person with learning disabilities, either to support them to feel relaxed and confident in a new setting, or to facilitate communication between them and the IAPT worker.

Another one… the triage assessment had already been done by the IAPT worker and it was the psychological wellbeing practitioner that gave me a call saying, “Help!… There’s somebody with a learning disability what do I do?” So, you know, I went and attended every one of their sessions, I never provided any accessible information or anything but I did facilitate their understanding. Learning disability service mental health liaison nurse (interview)

In this case the specialist practitioner was present at all of the service user’s sessions, but participants also mentioned examples where after some initial support, the IAPT therapist was able to continue the intervention on their own.

Health facilitation can also involve adaptation of written information using Easy Read formats that use simpler language, symbols, pictures and design and layout features that make the information easier to understand (Department of Health, 2010).

We’ve produced accessible information some of it bespoke, some of it trust-wide, you know, timetables and things like that if the person’s doing some sort of CBT based work with mood diaries and stuff, some of them aren’t that clear and easy so, you know, we’ve produced successful versions of those. The IAPT standard data set questions we’ve done a slightly simplified version of those. Learning disability service mental health liaison nurse (interview)

This participant had liaison between specialist learning disability teams and mainstream mental health services as an explicit part of their job description, along the same lines as the learning disability liaison nurses attached to hospitals in many health trusts. However, a more usual situation is that members of learning disability teams are expected to include health facilitation as part of their work, even though they might not have received training on the requirements of this role (Mir et al. 2007) or have a detailed understanding of the structures and working practices of mainstream services.

Staff in liaison roles are likely to have the time, as well as an explicit remit, to develop relationships with practitioners in mainstream services through personal meetings and conversations. Some participants pointed out that these one-to-one communications between staff in different services were crucial to supporting access for people with learning disabilities:

You can write protocols and systems to make that happen. But ultimately, you need people to… it happens when people pick up the phone and talk to each other and realise it’s kind of all right. IAPT service manager (interview)

[Response to question 75 – Have you come across examples of good practice in joint working between IAPT and specialist learning disability services?] Lengthy telephone conversations preceding and following assessment. Learning disability service clinical psychologist (survey)
Teaching and training

The questionnaire results suggested that only a minority of IAPT staff are offered training in working with people with learning disabilities, and only a minority of the respondents from community learning disability teams had been engaged in providing training. When learning disability staff do offer training it appeared from the survey responses that IAPT staff found this very helpful, particularly practical suggestions about how to adapt working practices. Learning disability staff felt that training was most useful in generating more opportunities for joint working. However, some noted that their local IAPT teams had not responded with much enthusiasm to offers of training, appearing to assign little priority to this area of work. Where little time was available for training, some respondents expressed concerns that the input would be tokenistic and superficial, and a way of side-stepping the necessity for further reaching service adjustments:

And I guess like on a higher level, managers and what have you need to sort of put in that time and say yeah so we are going to let people from LD services come in or we're going to go and shadow them, we're going to learn about it. But often it will just be like, er, you've got one hour to do some training, off you go, go and deal with people with LD, you know.

Learning disability service community nurse (interview)

The wide range of responses from IAPT staff about what they felt should be essential components of training suggest that learning disability staff will face challenges in designing and delivering a definitive curriculum to IAPT. Moreover, training by itself, particularly training that is locally organised and not part of the professional training courses that are compulsory for IAPT staff, is likely to be ineffective if not supported by service structures that support work with people with learning disabilities and this work is valued and prioritised within working cultures and practices in IAPT. Without this, there is a risk that training on working with people with learning disabilities positions them as a special case and an additional burden on IAPT services, rather as part of the core constituencies of IAPT service users. As one respondent put it:

'Specialist' training may inadvertently reinforce the idea that this group requires 'specialist' input which may undermine the purpose of providing it in the first place. IAPT clinical psychologist (survey)

Service development

There were a number of examples of service development initiatives promoted by members of community learning disability teams. These included the development of protocols for making referrals between services, and for joint working; the design and delivery of programmes of training; creation of specialist posts such as “learning disability champions” within IAPT or mental health liaison staff within learning disability teams; creation of a “Special Interest Group” for learning disabilities with an IAPT service involving staff from both services. Some referred to models of joint working that have been disseminated within the research literature (Dagnan et al., 2014; Kirk et al., 2013; Salmon et al., 2013; Heneage et al., 2010; Morris et al., 2009).
Our Trust has a “Joint Working Protocol” which sets out how mental health and learning disability services may work together to meet clients’ needs. Our Liaison Service helped to develop Learning Disability Awareness Training for IAPT practitioners in order to raise confidence and expertise. Learning disability service clinical psychologist (survey)

However respondents mentioned a tendency for these sorts of initiatives to originate from learning disability services, with only superficial sign-up from the mainstream mental health services.

*We have things like the Green Light Toolkit, which in this borough again has kind of lapsed, to be honest with you. I don't think it's seen really as a useful document because the document is supposed to be actually led by the mental health service and it's not, to be honest with you here. And you know very much sometimes you feel you've got a document in front of you but actually it's, for want of a better term, it's not actually worth the paper it's written on because no-one's really signed up for it or bought into the kind of ethos or what it's actually trying to say.* Learning disability service community nurse (interview)

As this respondent points out, service development initiatives designed to advance inclusion for people with learning disabilities rely not only on the enthusiasm of staff from learning disability teams, they also need commitment and engagement from mainstream services. In some cases this does not appear to be forthcoming:

*I was asked as head of specialist LD psychology services to provide training to mainstream IAPT staff in working with LD clients, which we were very happy to do, and to continue our links, but I understand the IAPT LD link person I had been speaking to left and was not replaced, and there was no further contact from the IAPT service for this training. I tried repeatedly to contact them, but no one in IAPT locally could tell me who best to speak to. This is extremely frustrating when we are trying to increase access to therapy for LD clients.* Learning disability service clinical psychologist (survey)

In an organisational climate affected by cuts in services and the instability generated by successful waves of service redesigns, some respondents noted concerns regarding the sustainability of even successful and well-evaluated projects that had resulted from effective joint working.

*We had an excellent system before financial cuts and changes in teams ended the project… basically we had both services ‘ghost’ or shadow clients who may sit between the two. The LD team provided supervision, training, adapted correspondence etc- the IAPT team had a SIG [special interest group] and offered twice as many sessions to the clients [within the adapted service]. The scheme was recognised as gold star practice and awarded places on the Trailblazers project development team.* Learning disability service clinical psychologist (survey)

These sorts of projects can be vulnerable if they are not part of ongoing commissioning arrangements. A number of participants highlighted the importance of service developments being underpinned by contractual arrangements determined by commissioners that make allowances for additional time and resources needed to support people with learning disabilities in IAPT.
Absolutely, it needs to be, definitely needs to be I think at the commission level. It needs to be put in as part of the contract when the contract comes up to renewal. This is the expectation and that needs to come from the Needs Assessment. Commissioning manager (interview)

Simply requiring IAPT services to make “reasonable adjustments” in line with their legislative requirements did not offer enough clarity about expectations about the level of provision required for different client groups. Inevitably IAPT managers saw meeting targets defined by contracts as a key priority.

I don’t mean reasonable adjustments they’re completely within merit here but some of the extra adjustments beyond what might be defined as “reasonable” become quite difficult to deliver if they’re delivered at such a level that delivering your contract becomes impaired. IAPT service manager (interview)

Moreover, some respondents were wary of the expectation that IAPT and other mainstream services would be able to cover gaps created by cutting back on specialist learning disability provision without provision for additional support, training and resources.

5.4 Mental health support needs of people with learning disabilities

In this section we explore how participants conceptualised the mental health needs of people with learning disabilities and their understanding of the sorts of interventions that would best address them. We’ve used the dimension of “same/different to the rest of the population” to make sense of participants’ responses. There is a debate in the academic literature along these lines (McBrien, 2003), which addresses the question whether the main issue is with the deficiencies of standardised assessment tools in identifying emotional problems in people with learning disabilities, or whether people with learning disabilities experience different triggers for episodes of anxiety and depression, and present with emotional problems in different ways to others in the population (for instance by displaying challenging behaviour) (Matson & Shoemaker, 2011; Smiley, 2005).

Understandings of the mental health needs of people with learning disabilities interconnect with participants’ judgements whether the sorts of interventions offered within IAPT will be suitable for this group. An important subtheme was participants’ characterisation of the role of family members and carers in addressing mental health needs of people with learning disabilities.
Some of the respondents asserted the commonality of experiences of depression and anxiety between people with learning disabilities and others.

So, um, I think sometimes there’s a tendency to think, “Mm, no, no”, straight away, “No, I couldn’t be doing that because I know nothing about that client group”, whereas you think, “Well, they’re not any different. They don’t walk around with two heads, or… do you know what I mean? I think sometimes there is a tendency to kind of back off and think, um, “No, no, no, I don’t know enough about the client group”. Well, just get yourself a little bit of training then, and find out a little bit more about that client group. Because they’re exactly the same as you or I, only they just have different needs. IAPT mental health nurse (interview)

…not automatically assuming that this person’s got a learning disability, it’s to do with their learning disability, because people do suffer from anxiety and depression sometimes in their lives including people with learning disability it could be, you know, people with learning disability live a normal life like everybody else and they occasionally suffer from depression, as we all do. Commissioning manager (interview)

The second quotation alludes to the concepts of “diagnostic overshadowing”, the idea that aspects of a person’s presentation that indicate an emotional problem, such as being withdrawn or non-communicative, are ascribed to the person’s learning disability, heading off any further investigations.

People with learning disabilities and their carers who we interviewed mentioned a range of life events, particularly involving losses and far-reaching life transitions that they identified as triggers to anxiety and depression. They also mentioned long-term stresses and worries, for instance about money or getting appropriate support that wore down the person with learning disabilities’ resilience and ability to function. One would imagine that these are similar to the negative life experiences of people without learning disabilities who find their way to IAPT services. Some IAPT staff appeared quite confident in addressing these sorts of issues with clients with learning disabilities:

So it had kind of happened in a transition and she’d come out of college and gone into a work environment. She’d lost contact with… with a wider circle of people… and then we were looking at actually how that was one of the main triggers for her low mood and looking at therefore kind of building that back up and that seemed to work fairly well. IAPT team manager (interview)

Others argued that people with learning disabilities are even more likely than the rest of the population to experience negative life experiences because they are more likely to be living in poverty, to be unemployed, and to have restricted social networks, all factors known to place someone at greater risk of poorer mental health. Not only are these sorts of issues often entrenched and resistant to change, because of their more limited access to capabilities and resources required to change these life circumstances, people with learning disabilities will
need extensive support to bring about the sorts of changes that will be conducive to their emotional wellbeing.

*You can treat the depression in that sense of, you know, you can give the person the work and give them that sort of stuff. But if the person hasn’t got the right levels of support to allow them to access activities and stuff like that in the first place that’s the actual root cause of the problem and it needs a review by, you know, generally speaking the local authority in terms of what support they’re providing.* Learning disability service mental health liaison nurse, (interview)

Participants were concerned that there was not scope within IAPT services to address these more far ranging aspects of mental health. Most descriptions of joint working mentioned by our participants were in the service of establishing reasonable adjustments so that clients with learning disabilities could make use of IAPT services (adapting materials, sharing assessment information). Co-ordination of IAPT and other health and social care inputs were not often mentioned.

Participants also raised concerns that people with learning disabilities are exposed to a range of life events linked to discrimination and exclusion that most others in the population are spared:

<table>
<thead>
<tr>
<th>Interviewer:</th>
<th>Do you think that people with learning disabilities are more likely to have mental health problems?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service user:</td>
<td>I do, personally.</td>
</tr>
<tr>
<td>Interviewer:</td>
<td>You do? Why?</td>
</tr>
<tr>
<td>Service user:</td>
<td>Because I think a lot of… a lot of the time we’ve had stigma against disabilities. Throughout our lives, You know? I know I have. I've had people tell me how thick and stupid I am and what have you. And it makes it… it makes it worse, and it makes you believe it. And what have you. And I think that sometimes causes the mental health.</td>
</tr>
</tbody>
</table>

One participant in the survey wrote about a “culture” of being learning disabled which required understanding by anyone working therapeutically with this group. We have already noted how IAPT staff who had received training regarding learning disabilities valued opportunities to think about the impact of discrimination and stigma on the mental health of this group.
5.4.2 Readiness for psychological therapies

People with learning disabilities who are experiencing low mood or anxiety might struggle to describe their feelings and thoughts in ways that indicate that they meet the eligibility criteria for IAPT. One respondent to the survey described this very clearly:

*In IAPT problems are conceptualised as a passport into services, necessitating a categorisation of problems in order for people to receive support. People with LD often do not use the common labels (e.g., depression, anxiety etc.) to conceptualise their difficulties and distress, however in IAPT a cluster/label is required to access the service. And it is often the use of that language when speaking with a GP that allows access to IAPT services.*

Learning disability service clinical psychologist (survey)

The family carer we interviewed had many years’ experience of supporting people with learning disabilities informally and as a practitioner described how in her experience service users had low expectations of being listened to and understood and this undermined their confidence in speaking out about emotional problems. She had noticed that people she met tended to minimise their difficulties, perhaps out of concerns about upsetting or worrying their carers. The quote below reflects a practitioner’s view of the same issue:

*I will normally pop in the conversation at some point the opportunity for psychological services. And some people really you mention it and they don’t, they’re quite resistant to the idea. “Oh no I don’t have a problem, I’m alright, I’m alright.” Other people will say, “I’m not, I’m not that bad yet” you know - I’ll be alright later on.*

Learning disability service social worker (interview)

Moreover, people with learning disabilities may have only a hazy notion of what engaging in psychological therapies entails and might find themselves referred to IAPT by a family member or carer without a great deal of discussion. This may contribute to what some participants noted as a reluctance on the part of service users with learning disabilities to embark on therapy.

*Patients with LD are more likely to have been encouraged to attend by a carer or support worker rather than be self-motivated. Initially this can make engagement harder and it would be helpful to have more time / sessions to do this. It is helpful for patients to understand the rationale behind L.I. [low intensity] treatments, it is sometimes harder to do this with LD patients.*

IAPT PWP (survey)

To compound the discomfort some people with learning disabilities might feel when they first meet an IAPT worker, some IAPT services are located in a mental health clinic or hospital that might hold negative associations for people with learning disabilities. It might even be a placed where they had been detained under the mental health act or received coercive treatment in the past.

There was very little discussion of the possibility of people with learning disabilities themselves being offered choices regarding the location of therapy, whether it was provided within a learning disability context or not, or the form of psychological therapy they might like (e.g. individual talking therapy, family therapy, or art or music therapy).
5.4.3 Communication and understanding

There were many references to “communication difficulties” and “problems with understanding” as key characteristics of people with learning disabilities and important markers of difference between them and others presenting to IAPT services. In some responses these issues were presented in a rather condensed way as if these terms are self-explanatory. Others distinguished between different aspects of communication, expressive and receptive language skills; different modalities for communication (words, pictures, gestures) and showed an understanding of communication as jointly achieved between communication partners (Bartlett & Bunning, 1997).

Aspects of the organisation and delivery of IAPT services make particular demands on communicative competencies of service users. Written texts are important at every stage, from appointment letters, to assessment and outcome measures, to use of psycho-educational resources, mood and behaviour diaries and written goals and tasks and satisfaction and evaluation questionnaires. A number of respondents pointed out that these texts present literacy challenges for many service users, not only for people with learning disabilities.

Use of the telephone is widely used in IAPT services dealing with high volumes of referrals. Initial screening assessments are often conducted over the phone, and some services are organised so that the default mode for low intensity work is via telephone. Reducing communicative information to the auditory channel alone, cuts out other sources of information from facial expressions and gestures that greatly aid communication between people with learning disabilities and others.

You know, you can’t… for someone with learning disabilities, it’s really hard on the phone to… not have a face to face… I find face to face easier, because if… if there’s something you don’t understand, at least they can do a diagram or something.

Service user (interview)

It might be a challenging process to determine whether CBT employed in IAPT services is based on concepts that are cognitively too complex for the great majority of people with learning disabilities (Dagnan et al., 2000; Joyce et al., 2006), or whether the concepts are expressed in ways that are beyond the receptive language capacities of these service users. CBT introduces clients to a range of specialist terms and constructs associated with its theoretical basis which unlikely to be familiar to people with learning disabilities. One respondent felt that the key task for IAPT therapists working with people with learning disabilities was to find a simple and accessible form of words to express CBT concepts:

Mental health uses a lot of complicated words and a lot of complicated terminology… if they don’t understand the fact that you have to have very short simple sentences and you’ve got to think of how to explain ERP – exposure response prevention – how are you going to explain that? You keep on saying it but how are you going to explain it? So it’s a case of I think once they get the language right then there’s no reason why then it couldn’t be delivered.

IAPT service manager (interview)
Participants described using a variety of communicative approaches using pictures, drawing, stickers, and colour coding to support the understanding of people with learning disabilities. For some, however, learning to use these approaches appropriately felt like a daunting prospect that made demands on IAPT therapists as communication partners requiring additional time and support.

*Communication may need to be augmented with pictures, video, etc. It is a skill to communicate in short simple sentences, use suitable vocabulary/language, adapt work sheets etc. It all takes extra skill and time.* IAPT CBT therapist (survey)

Two of the participants queried why communicative adjustments for people with learning disabilities were seen as an additional burden on IAPT services, when communication support was offered more routinely to people who had hearing impairments or did not speak English.

*And the way I always feel is, although it’s meant to be a mental health initiative, there is no way that IAPT would be thrown in to working with somebody where English wasn’t their first language and they hadn’t got enough English to be able to support the appointment. We would get a translator.* Learning disability service mental health liaison nurse (interview)

*Someone with hearing problems or partially sighted we… it’s automatic at the moment for people with, um, English as their second language… to be automatically given that extra session time, because we’ve got a lot of our people from ethnic minorities coming into the service. So, that’s an automatic process. I think if we got more people with learning difficulties again it would be an automatic process.* IAPT PWP (interview)

This seems to reflect underlying judgments on whose needs for additional support are viewed as legitimate, perhaps based on assumptions not only on the nature of the community of citizens that IAPT was set up to support, but also on estimations of the likelihood of success of therapy with different groups.

### 5.4.4 Role of carers

Another important area of “difference” relating to mental health and people with learning disabilities was the role of carers in their lives and how this might affect their receipt of therapy.

Carers were often seen as allies for the therapist who can provide extra information about the service user, make recommendations based on their understanding of the service user’s difficulties and remind the service user to orientate to messages in therapy and to do homework tasks between sessions. Carers can also provide emotional support for people with learning disabilities after difficult sessions.

*So, maybe have three-quarters of your session with the patient; but then towards the end have the carer come in to kind of recap what you’ve gone through and use their knowledge of their difficulties to help support them.* IAPT PWP (interview)
Carers might not understand the CBT model or rationale for homework tasks and some carer respondents highlighted their need for support and information about IAPT practices. Participants raised concerns that in some cases carers may come with their own agendas and find it hard to act as neutral facilitators of the therapy for the person with learning disabilities. Moreover, some of the issues that people with learning disabilities might wish to bring to therapy might touch on difficult relationships with carers and require a confidential one to one relationship with the therapist in order to be aired. Consistent and sensitive support from carers may be more difficult to ensure for people who do not live with their family.

<table>
<thead>
<tr>
<th>Service user:</th>
<th>But also I think… also the supporter shouldn’t be one that just takes over… They… the supporter… the person needs to talk to the supporter and ask the questions. But if the person with learning disabilities is struggling, they should be able to… be able to say it... And they need to be somebody who is a good advocate.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviewer:</td>
<td>Uh huh. So maybe they need an advocate to come with them.</td>
</tr>
<tr>
<td>Service user:</td>
<td>Or someone who actually knows a person… And not just a staff member who’s just come on duty and decided that, “Oh, tick the box, I’m just coming down to see the person”.</td>
</tr>
</tbody>
</table>

For more than one respondent, engaging the person’s close family members in ongoing work was an important component in the success of therapy with any IAPT service user, and not an issue only for people with learning disabilities:

*So a lot of IAPT, certainly CBT interventions more so than maybe IPT interventions, I think are reliant in the longer term in engaging someone you might you call a co-therapist in someone’s family; so either their mum or their partner or someone and them being someone who becomes as aid to that person carrying on that work. IAPT service manager (interview)*
6 Discussion

6.1 Limitations of the study

Although we expended considerable effort to make sure that our questionnaire survey reached as many IAPT and specialist learning disability staff as possible, our method for distributing the questionnaire was far from perfect. We relied on team leaders and administrators to forward an invitation to participate to their staff. As we could not track how many staff actually received the invitation, we were not able to determine response rates.

We were pleased with the number of IAPT staff who chose to participate in the survey. However, we cannot claim that these respondents are necessarily representative of the national workforce. It is certainly possible that those who chose to respond to the survey already had an interest in working with people with learning disabilities, as well as experience in this area. Equally, the staff from learning disability services who took part in the survey may have been more likely to have had some involvement with IAPT services than others who did not respond to our invitation to take part in the survey.

6.2 “Candidacy” and access to IAPT for people with learning disabilities

Research on health inequalities experienced by people with learning disabilities usually focuses on factors that are identified as “barriers” to access to healthcare. Barriers have been identified at the individual level of attitudes, knowledge and skills and at the organisational level of work practices and routines, with links to higher levels of context at a legislative and policy level. However, we did not feel that using the concept of “barriers” as a synthesising construct to pull together our findings was the most appropriate strategy. Firstly, identifying barriers leads usually to a call for their removal, but from our findings it was not clear what an ideal level of access to IAPT in its current form would look like for people with learning disabilities or how one would be able to measure that the proper level of access had been achieved. For instance, some of the participants argued that IAPT was not suitable for all people with learning disabilities. Secondly, we noticed a very mixed picture, with evidence of an orientation towards inclusiveness from a number of IAPT staff, and many examples of good joint working with community learning disability teams. Finally, we wanted to avoid the impression that barriers add up in a cumulative fashion, with the prospect that enough barriers can block access once and for all.

Instead we turn to the concept of “candidacy” to synthesise our findings. This term was adopted by Dixon-Woods and her team in their review of studies on access to primary care for vulnerable groups (Dixon-Woods et al., 2006). They describe candidacy as “the ways in which people’s eligibility for medical attention and intervention is jointly negotiated between individuals and health services” (p. 11). Whereas the concept of “barriers” uses a metaphor of impediments that are established or removed one by one, candidacy is described as a dynamic, multi-dimensional and contingent process. Candidacy is not automatically claimed...
or granted. It involves work on the part of patients and health workers and brings in to play the resources they have at their disposal, namely their cultural, social and economic capitals. It involves negotiation and interaction between the potential service user, the healthcare provider and their home or organisational workplace contexts.

Dixon-Woods et al. divide the candidacy construct into seven dimensions. The first six describe junctures in a healthcare trajectory where work must be undertaken to negotiate a person’s candidacy. The seventh dimension, which Dixon-Woods et al. consider to be hugely important, are the operating conditions that impact on interactions between practitioners and service users.

*Candidacy... is a continually negotiated property of individuals, subject to multiple influences arising both from people and their social contexts and from macro-level influences on allocation of resources and configuration of services... “Access” represents a dynamic interplay between these simultaneous, iterative and mutually reinforcing processes (Dixon-Woods et al., 2006, p.8).*

See Table 6 for an outline of the dimensions of candidacy summarised in Koehn (2009).

**Table 6 Characteristics of dimensions of candidacy (Koehn, 2009)**

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identification</td>
<td>Differential recognition of symptoms as needing medical attention</td>
</tr>
<tr>
<td>Navigation</td>
<td>Awareness of the services on offer. Mobilisation of practical resources</td>
</tr>
<tr>
<td>Permeability of services</td>
<td>Services are more or less accessible (‘permeable’) depending on the qualifications of candidacy required to use them (e.g. a referral) and the degree to which resources need to be organized. Less permeable services &quot;demand a higher degree of cultural alignment between themselves and their users&quot; (Dixon-Woods et al., 2006, p.8)</td>
</tr>
<tr>
<td>Appearances at health services</td>
<td>Involves people asserting a claim to candidacy. This requires a specific set of competencies e.g. the ability to formulate and articulate an issue for which help is being sought. More disadvantaged people are less adept at using their voice to demand better services</td>
</tr>
<tr>
<td>Adjudications</td>
<td>Judgment calls made by the health professionals whom clients initially consult. “Professional perceptions of the cultural and health capital required to convert a unit of health provision into a given unit of health gain may function as barriers to healthcare... In addition, perceptions of social ‘deservingness’ may play a role” (ibid., p.8)</td>
</tr>
<tr>
<td>Offers and resistance</td>
<td>Resistance by service users to referrals and offers of intervention</td>
</tr>
<tr>
<td>Operating conditions</td>
<td>Locally-specific influences on interactions between practitioners and patients. &quot;The perceived or actual availability and suitability of resources to address [a claim to] candidacy” (ibid., p.8)</td>
</tr>
</tbody>
</table>
In the light of our findings, we would like to elaborate how candidacy is formulated as it relates to people with learning disabilities accessing IAPT. We would like to add the concept of “recursivity”, which refers to the impact of past experiences of health services on future actions a person might take with relation to help-seeking (Kovandžić et al., 2011; Hunter et al., 2013). Secondly we would like to extend Dixon-Woods et al.’s focus on the interaction between the individual potential service users and healthcare practitioners and systems to highlight the importance of mediators of these processes. A range of intermediaries, including family members of people with learning disabilities, their support staff and health and social care service representatives appear to be actively involved in the negotiation of candidacy vis a vis each of the dimensions described by Dixon-Woods et al. Our findings highlight the involvement of others in determination of people with learning disabilities’ candidacy for IAPT as a socially mediated achievement. This is not to undermine the agency and autonomy of people with learning disabilities themselves in these processes, but acknowledges how many are situated in networks of care and support whose representatives may be the ones to initiate contact with services, sometimes even without fully explaining their justification to the person with learning disabilities (Merriman & Beal, 2009) and to make sure that engagement with the service is sustained (Redley et al., 2012).

Identification

The process of identifying oneself as potentially able to benefit from psychological therapy is not easy for people with learning disabilities, although we did come across examples of people with learning disabilities who clearly identified their own mental health problems and need for support relating to these. For others, coming to an understanding of what might constitute “symptoms” of anxiety or depression was a process that involved repeated interventions from practitioners, friends or family members. The research literature highlights problems regarding practitioners’ recognition of mental health problems within this population and we have mentioned the dangers of diagnostic overshadowing. The pressing nature of the complex socio-economic difficulties people with learning disabilities may be dealing with may mean that accompanying emotional problems are seen to have a lower priority. Given our finding that staff from learning disability services often do not have a very clear picture of what IAPT offers and who it is for, there is a risk that some people with learning disabilities may be misidentified as candidates for IAPT, for instance people with more serious mental health problems or people who present with challenging behaviour. People with learning disability themselves may be reluctant to speak up about mental health problems in the context of feeling not listened to or ignored in the past.

Navigation

None of the participants described people with learning disabilities finding out about IAPT services on their own. Awareness of IAPT services among specialist learning disability staff, who are likely mediators of the process of referral, was sketchy, and some admitted to knowing very little about their local IAPT service. In a few places there are agreed pathways between learning disability and IAPT teams that may assist the process of navigation, but these are absent in most areas. We found a wide variety of responses among IAPT teams to referrals of people with learning disabilities, from cursory dismissal to thoughtful engagement. This complex picture is likely to generate uncertainty among potential referrers about whether it is worth even finding out more about their local IAPT services. In general, learning
disability staff appeared to have low expectations about the likelihood that IAPT services would offer helpful interventions for their service users and these assumptions might impact on their readiness to address issues of navigation with people with learning disabilities.

**Permeability**

The permeability of IAPT services was a key factor in establishing or impeding candidacy. Some IAPT services explicitly exclude people already in receipt of social care support, or with an allocated social worker, or those supported by what they would define as "secondary health services", which would include community learning disability team input. Others have agreed pathways designed with community learning disability team practitioners that gave a clear route of entry into IAPT services for people with learning disabilities. Dixon-Woods et al. (2006) describe less permeable services as demanding a higher degree of cultural alignment between themselves and service users and suggest the degree to which service users feel comfortable with the organisational values of the service is a reflection of this.

Our findings do not provide us with enough information about the cultural alignment between people with learning disabilities and IAPT staff. However, we did note some characteristics of the formulation of the mental health needs of people with learning disabilities expressed by practitioners from community learning disability teams that might not fit comfortably with the value system and philosophies of IAPT staff. We noted that some learning disability practitioners did not feel that the targeted, time-limited inputs offered by IAPT were appropriate for people with learning disabilities who need more holistic, long-term interventions delivered in the context of established relationships by specialist practitioners. The concept of permeability might usefully be extended to the domain of joint working and service development, where the issue of cultural alignment between partners is crucial.

**Appearance**

People with learning disabilities may struggle to use the right language to present their difficulties at initial sessions with IAPT staff and have little awareness of the services on offer and how to request them. IAPT staff may also interpret lack of confidence and unease in a new situation as indicating lack of motivation on behalf of the person with learning disabilities. People with learning disabilities constitute a marginalised group who have little leverage to demand more appropriate and extensive services. The self-presentation of people with learning disabilities at IAPT as appropriate candidates for mental health support could be facilitated by support from carers, who were generally welcomed by IAPT staff, or by learning disability staff “smoothing the way” by providing information about the individual or helpful ways of working.

Given an underlying goal of the IAPT programme is to combat the impact that that mental health problems in the population have on employment levels and welfare benefits spending, candidates for the service are expected to present as suitable and available for paid employment, once their mental health problems are treated. Since people with learning disabilities struggle to secure any kind of paid work, and their appearance within IAPT services will be out of step with service goals directed at supporting service users into employment.
Adjudications

Our findings explored the sorts of judgments that IAPT might make about the likely success of therapy that would determine their willingness to persist with work. These judgments might refer to calculations about how ready a person with a learning disability is to make use of therapy, whether they have the skills and support the therapist judges necessary, and also whether the therapist judges there is a reasonable match between their skills and capabilities and what they calculate will be the demands of working with an individual. There is a potential for training on working with people with learning disabilities received by IAPT staff to influence these judgements, though this has not been well integrated into the qualifying training required by IAPT staff, and appears to organised in an idiosyncratic and ad hoc basis in different IAPT services. We also noticed that therapist adjudications about the legitimacy of claims for additional support by people with learning disabilities compared negatively to others who might require reasonable adjustments, such as people who do not speak English or those with hearing impairments, and suggestions that these individuals might be more favourably judged as potentially successful users of IAPT. Adjudications might also involve assessments of the capacity of carers to support the person with learning disability to attend therapy and to make use of recommendations outside sessions.

Offers and resistance

We felt that formulating IAPT as a public service “for everybody” was likely to encourage IAPT staff to make offers of interventions to people with learning disabilities. Other conditions for making offers were IAPT staff’s orientation of optimism that their inputs could be useful for people with learning disabilities and staff having permission to work flexibly with these service users. We did not hear much about offers of support being explicitly refused by people with learning disabilities. We did hear that people with learning disabilities attend IAPT sessions because of decisions made about their mental health needs by others without a clear idea of the purpose of the intervention. We heard very little about people with learning disabilities being offered choices of different treatments or of consent and capacity receiving thorough examination. Under these circumstances people with learning disabilities would have limited opportunities for resistance, either presenting as disinterested and disengaged in therapy sessions, or as not adhering to treatment tasks, or simply dropping out. Unfortunately these strategies would most likely reinforce perceptions that people with learning disabilities are unable to benefit from IAPT, rather than prompt a re-evaluation of the way that IAPT services are delivered.

Operating conditions

The perceived or actual availability of the key resources of time, skills development and therapist support to facilitate access to IAPT for people with learning disabilities were crucial to the local production of candidacy. Not only are IAPT services predicated on high volume use and short-term inputs making accommodation to time pressures a defining aspect of working practices, specialist learning disability services have been experiencing sweeping reductions in resources. Putting aside these material conditions, candidacy for people with learning disabilities in IAPT is further impeded in the context of assumptions that the availability and suitability of these resources are located only within specialist learning disability services. Although there appeared to be considerable variation between IAPT services in their ability to husband these resources for their work with people with learning
disability teams, local operating conditions were subject to constraints imposed by wider service structures and commissioning arrangements. For people with learning disabilities, resources also needed to be found outside IAPT services for their candidacy to be advanced, since the time, skills and flexibility of carers was also essential to ensure access to therapy.

Whereas securing resources to make reasonable adjustments to IAPT for people with learning disabilities is at times presented as an impossibly burdensome task, resources for other service users needing adapted provision (such as those who do not speak English, or people with sensory or physical impairments) are provided more routinely. There does seem to be some determination made by service providers about the legitimacy of claims for resources needed for different service user groups.

**Recursivity**

Recursivity was seen particularly in the accounts of the specialist learning disability staff. They described instances when their attempts to support people with learning disabilities in accessing IAPT had not been successful and either the referral had been refused, or from the point of view of the learning disability practitioner, IAPT input had been inadequate or misguided. These experiences shaped their judgments of candidacy for IAPT for service users with learning disabilities and whether pursuing this in future was worthwhile. On the other hand, positive experiences of joint working and recognition of positive outcomes achieved for people with learning disabilities within IAPT fostered a sense of optimism and encouraged further referrals to IAPT and confirmed the candidacy of people with learning disabilities.

6.3 Conclusions and recommendations

Using the concept of candidacy highlighted to us how its achievement for people with learning disabilities within IAPT is shaped by values, assumptions and practices located not only within IAPT services, but also within specialist learning disability services and within other key domains including the commissioning environment and the support settings experienced by people with learning disabilities.

In the current climate of service reductions, specialist learning disability teams may interpret directives to channel more people with learning disabilities to mainstream health services like IAPT as a smokescreen for eliminating a highly valued specialist resource. They can feel that their skills, knowledge and hard-won network of relationships are being dismissed as dispensable. They have had little chance to formulate what health facilitation with regards to mental health might look like. When people with learning disabilities they refer to IAPT do not get a service, or when their own attempts at service development are rebuffed, the possibility of real inclusion for people with learning disabilities in IAPT services with appropriate supports seems far-fetched. The mental health facilitation role of specialist learning disability staff is likely to be enhanced and supported by:

- Greater awareness of local mainstream mental health services, their eligibility criteria, working practices and treatment modalities;
- Establishment of joint-working pathways and protocols between IAPT and specialist learning disability services;
Training and supervision regarding mental health facilitation for specialist learning disability staff;

Clear reference to this role in contracts and commissioning documents

We noted interest and enthusiasm for supporting people with learning disabilities among a number of IAPT staff and linked these positive and hopeful trends to a set of values that contributed to setting up IAPT as a public service “for everyone”, focused as much on prevention and the promotion of mental wellbeing as treatments for emotional disorders. These IAPT staff reported positive outcomes for people with learning disabilities. This work could be enhanced and extended with more systematic support from learning disability specialists who can help them access appropriate resources and work alongside them on addressing service users’ practical health and social care needs. Specific inputs might include:

- Inclusion of curriculum material on working with people with learning disabilities in qualification training for IAPT staff. This can be delivered by learning disability specialist staff and people with learning disabilities themselves;
- Ongoing supervision and support for IAPT staff provided by specialist learning disability practitioners;
- Sharing of resources and materials (Easy Read documents, picture, photo and symbol banks) between IAPT and specialist learning disability staff;
- Support and psycho-education for family and paid carers of people with learning disabilities who are experiencing common mental health problems;

For those in IAPT services who orientate more to a managerialist discourse, what is needed is a more robust and better disseminated evidence-base about the effectiveness of CBT and other IAPT therapies for people with learning disabilities and a clearer determination of what works best for whom. There also needs to be a renegotiation of service contracts with commissioners that explicitly give greater scope for working more flexibly with people with learning disabilities. It is clear that unelaborated assumptions about “fitting in” reasonable adjustments within existing service contracts is not a realistic way to address equity of access to psychological therapies for people with learning disabilities.

Developments in this area include:

- Robust and workable systems for recording take-up of IAPT inputs by people with learning disabilities;
- Adaptations of outcome measures for people with learning disabilities;
- Clear expectations from commissioners of IAPT services that people with learning disabilities will receive treatment within IAPT and the allocation of appropriate resources to support this;
- Further research on the effectiveness of psychological therapies for people with learning disabilities.
References


Published by King's College London

For information on alternative formats, or to give feedback on the content and accessibility of this publication, please contact: deborah.chinn@kcl.ac.uk
Telephone: 020 7848 3240

© King's College London 2014