The experiences of high intensity therapists delivering cognitive behavioural therapy to people with intellectual disabilities

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Abstract

Background: People with intellectual disabilities should be able to access the Improving Access to Psychological Therapies (IAPT) programme, currently a main provider of mainstream mental health services in England. IAPT offer cognitive behavioural therapy (CBT) to individuals experiencing mental health problems, although its effectiveness for people with intellectual disabilities, when delivered within IAPT, is unclear.

Method: Ten high-intensity therapists took part in semi-structured interviews, analysed using thematic analysis, regarding their experiences of delivering CBT to people with intellectual disabilities in IAPT.

Results: The rigidity of the IAPT model appears to offer a poor fit with the needs of people with intellectual disabilities. Therapists appeared uncertain about how to modify CBT and highlighted training and service development needs.

Conclusions: Findings suggest barriers to accessing IAPT largely remain unaddressed where people with intellectual disabilities are concerned. Services may need to re-consider what constitutes appropriate reasonable adjustments to ensure equitable access.

Introduction

There is a high prevalence of mental health problems among people with intellectual disabilities (Cooper et al., 2007) and they should be able to access mainstream mental health services in the UK wherever possible. Services are legally obliged to make reasonable adjustments to facilitate equal access under the 2010 Equality Act and there is evidence for the effectiveness of psychological therapies, including cognitive behavioural therapy (CBT), with people with intellectual disabilities (Vereenooghe & Langdon, 2013). However, this client group face barriers to accessing these services and there is debate as to whether their mental health needs can be met by mainstream services, or whether specialist teams are necessary (Bouras, 2016). The Improving Access to Psychological Therapies (IAPT) programme provides psychological treatments approved by the National Institute for Health and Care Excellence (NICE) to adults experiencing depression and anxiety disorders, for which CBT is recommended by NICE (2009; 2011). IAPT is currently a main provider of mainstream mental health services in England. However, the accessibility and effectiveness of IAPT therapies for people with intellectual disabilities is currently unclear.

The IAPT programme was initiated in 2008, underpinned by the assumption that increasing access to psychological therapies would improve recovery rates and result in economic benefits, through reducing public costs and increasing workforce productivity (Layard, 2006). The collection and analysis of outcome data, used to determine effectiveness of services and inform future funding, is a central feature of IAPT (IAPT, 2011a). Clients' clinical, work and social functioning are routinely assessed using a series of standardised measures known as the 'Minimum Data Set' (MDS), which include depression and anxiety inventories. The programme aims to achieve recovery for fifty percent of clients accessing IAPT therapies (IAPT, 2011a), indicated by scores on depression and anxiety inventories below clinical cut-off markers. However, the IAPT MDS has not been validated

for use with people with intellectual disabilities and difficulties with using it with this client group have been reported (Chinn et al., 2014; Shankland & Dagnan, 2015). IAPT staff have also questioned the 'fit' of people with intellectual disabilities with expectations of clients gaining or retaining employment following treatment (Chinn et al., 2014), with recent figures suggesting only 6.8% of adults with intellectual disabilities are in paid employment (DoH, 2014).

Other countries, including Australia (Bastiampillai, 2014), have described the implementation of the IAPT model within their own national mental health system and a similar model has been reported in Norway (OECD, 2013). The USA (Weir, 2015) and Canada (Farmanara et al., 2016) have also shown interest in the IAPT programme. The development and accessibility of IAPT for people with intellectual disabilities is therefore likely to have relevance to mental health service developments both within, and outside of, England.

The IAPT programme has produced practice guidelines indicating how its services should be flexible in responding to the needs of people with intellectual disabilities (DoH, 2009), which have recently been updated in collaboration with the Foundation for People with Learning Disabilities (FPLD, 2015). However, currently a national care pathway for people with intellectual disabilities entering IAPT does not exist and the literature suggests that service provision to this client group can vary significantly. Various local initiatives aiming to increase the accessibility of IAPT for people with intellectual disabilities are documented, including the adjustment of therapy materials (e.g. Salmon et al., 2013) and the delivery of specialist training and supervision for IAPT staff (e.g. Taylor & Harrison, 2013). However, whilst these are all indications of positive local service developments, rather than a national drive, service developments for this client group appear dependant on the commitment of local IAPT services and commissioning bodies (Leyin, 2011). A recent large scale study indicated that some IAPT services may even explicitly exclude this client group

(Chinn et al., 2014). Nationally, it appears that barriers to people with intellectual disabilities accessing mainstream IAPT services largely remain unaddressed (Chinn et al., 2014), potentially placing many services in breach of equality legislation.

IAPT adopts a stepped-care approach, whereby treatment is delivered at varying intensities. 'Low intensity' interventions, including self-management treatments, are delivered by 'psychological well-being practitioners' whereas 'high intensity therapists' offer more intensive, formulation-driven treatments over a longer duration, to individuals presenting with more severe presentations. High intensity therapists come from a range of professional backgrounds, including clinical psychologists and experienced graduate mental health workers, and will have completed post-graduate level training informed by the IAPT national curriculum (DoH, 2008; IAPT, 2011b). However, IAPT high intensity training does not currently feature the adaptation of CBT for people with intellectual disabilities (IAPT, 2011b). Whilst some therapists may have prior experience and knowledge regarding working with people with intellectual disabilities, others may have limited competence (Dodd et al., 2011; Thwaites, 2013) and may be unaware of relevant guidance or how to make appropriate adaptations (Chinn et al., 2014; Heneage et al., 2010).

The importance of specific training and supervision for therapists delivering therapy to people with intellectual disabilities has been acknowledged (Royal College of Psychiatrists, 2004; Scior et al., 2012) and IAPT therapists have identified a need for further training in this area (Chinn et al., 2014; Chinn & Abraham, 2016; Shankland & Dagnan, 2015). The provision of training and specialist supervision has been associated with greater confidence for mainstream mental health staff working with people with intellectual disabilities (Dagnan et al., 2014; Heneage et al., 2010; Werner & Stawski, 2012), which in turn, may improve client outcomes (Shankland & Dagnan, 2015). Therapist attitudes may also influence therapy outcomes (Beail & Jahoda, 2012) and IAPT therapists may perceive people with intellectual disabilities to require additional resource (Chinn & Abraham, 2016), or view them as a burden (Chinn et al., 2014).

A growing evidence-base indicates the effectiveness of CBT for people with intellectual disabilities for a range of psychological problems, including anxiety (Hassiotis et al., 2013) and depression (McGillivray et al., 2008). However, as with CBT for the general population, the effective components of CBT for people with intellectual disabilities remain unclear (Willner, 2005), creating confusion about how therapy should be adapted. The existing literature emphasises the importance of flexibility in approach; ranging from the use of adapted materials to adapting the length of treatment sessions (Haddock & Jones, 2006). The value of incorporating the client's wider social context within therapy is also acknowledged (Stenfert Kroese et al., 2014), particularly in supporting the generalisation of learned skills (Lindsay et al., 2013). However, IAPT is a high volume service and the time pressured and target-driven nature of services has been recognised (e.g. Chinn et al., 2014; Rizg, 2012). Heavy workloads, time constraints and limited resources have been identified as obstacles to meeting the needs of people with intellectual disabilities in mainstream services generally (Rose et al., 2007), and within IAPT services specifically (Chinn et al., 2014; Shankland & Dagnan, 2015). These obstacles may hinder the facilitation of reasonable adjustments for people with intellectual disabilities, potentially limiting the effectiveness of CBT documented within the literature.

Barriers to providing appropriate mental health support for people with intellectual disabilities within mainstream services are not unique to England; difficulties in meeting the needs of this group have been reported in countries in Europe and North America (Davidson & O'Hara., 2007). However, equality legislation and an increasingly diverse population mean services need to be able to deliver effective psychological treatments. Developing appropriate service models for people with intellectual disabilities is complex and research in this area is limited (Sheehan & Dimitrios, 2013). There is an argument that IAPT is

appropriate for people with intellectual disabilities (FPLD, 2015), although the literature presents a mixed picture. Evidence for IAPT delivered therapies for this client group currently relies on practice-based evidence and it remains uncertain whether IAPT has had any real impact (Beail, 2011). The experiences of therapists are likely to provide valuable information in this respect but only a small number of studies have addressed this.

Aims of the current study

This study aimed to explore high intensity therapists' experience of delivering CBT to individuals with intellectual disabilities within IAPT services. It aimed to explore their understanding of current (theoretical) arguments about needing to modify CBT for people with intellectual disabilities, their perceived confidence in doing this within the context of IAPT services, as well as challenges which may make therapeutic aims difficult to achieve. Therapists' confidence was explored through the use of the Therapy Confidence Scale-Intellectual Disabilities (TCS-ID). It was hoped that the findings would inform service developments, as well as highlight the on-going support needs of therapists working with people with intellectual disabilities in IAPT.

<u>Method</u>

Participants

Ten high intensity therapists (one male and nine female) who had experience of delivering CBT to at least one individual with intellectual disabilities in an IAPT service took part in the study. They held a range of professional qualifications, including professional doctorates in clinical psychology (7) or counselling psychology (1) and high intensity diplomas (2). Participants held a range of previous experience related to working with people with intellectual disabilities. Some had completed a specialist intellectual disabilities placement during clinical psychology training, whilst others had not previously worked with this client group. Some participants reported having only delivered CBT to one client with intellectual disabilities in IAPT, whereas others reported having worked with "a few".

Procedure

Participants were recruited over a six-month period from five IAPT services across three different NHS Trusts in a range of areas within inner city London. Following permission from the service manager, participants were approached via group emails and/or through oral presentations at team meetings. The research was discussed with participants individually and consent was obtained.

To protect participant anonymity a breakdown of participant demographics or professional position is not provided. Ethical approval of this study was provided by the first author's institutional ethics committee. Research and development approval was obtained from the three NHS trusts from which participants were recruited.

Measures

Therapy Confidence Scale-Intellectual Disabilities (TCS-ID)

Prior to attending a research interview, participants completed the TCS-ID (Dagnan et al., 2014) which was used to situate the population sample regarding confidence levels. It also informed discussions during interviews, including whether participants perceived their confidence to affect their experiences. Quantitative data from the TCS-ID were not used for statistical analysis.

The TCS-ID measures therapist confidence in delivering therapy to people with intellectual disabilities. Participants answer 14 items related to various stages of the therapy process, on a 5 point Likert scale ("not confident" to "highly confident"). The items are generic to any therapeutic modality, although to date the scale has only been used with CBT therapists (Dagnan et al., 2014; Thwaites, 2013). The scale is described as measuring a single construct of confidence, although Dagnan et al. (2014) noted that therapists appeared to be identifying higher levels of confidence for 'generic' therapy skills (e.g. listening skills) compared to those they perceive as more 'specialist' (e.g. using specialist assessments). The authors reported good psychometric properties (Cronbach's alpha = 0.93 and test-retest reliability = 0.83).

Interviews

A semi-structured interview schedule was designed to address the research aims and to ensure consistency of topics covered across interviews. Following a reviewing process, questions were agreed upon by the research team. The schedule mapped out areas of possible questioning and interviews remained participant led to encourage therapists to discuss issues that were relevant to them. Participants were asked open ended questions about their experiences of delivering CBT to people with intellectual disabilities within IAPT and were asked to draw on clinical examples from their practice. Questions focused on exploring how therapists had experienced different stages of therapy, any adaptations they had made to therapy and the knowledge and support they had drawn on when making these. They were also asked about their perceived confidence in delivering this work within the context of IAPT services. Interviews were conducted by the first author and lasted between 50-75 minutes. Audio-recordings of all interviews were transcribed verbatim

Analysis

Interview transcripts were analysed using thematic analysis (Braun & Clarke, 2006). Data were grouped into codes which attempted to capture the essence of what was said by participants, including similarities and differences between them. Codes were collapsed into broader themes during subsequent stages. This was a recursive process, and raw data were consistently checked against each theme to ensure the interpretations were grounded in observable data. Coded data extracts were shared and discussed among the authors to ensure a degree of quality assurance, whilst remaining congruent with a critical realist position assumed within this research.

<u>Results</u>

Therapy Confidence Scale-Intellectual Disabilities (TCS-ID) ratings

A total score calculated from the 14 questions on the TCS-ID indicated participants' perceived confidence. Table 1 illustrates participants' training, level of experience related to working with people with intellectual disabilities (ID) and total TCS-ID scores.

[INSERT TABLE 1]

Participants' reported confidence will be discussed throughout the results section where relevant. However, it is interesting to note that participants who scored higher on the questionnaire were those with the most experience of working with people with intellectual disabilities.

Themes

Four higher-order themes, each with three constituent sub-themes, were identified during the analysis process (see Figure 1). Each theme is discussed and raw data extracts are provided to illustrate them.

[INSERT FIGURE 1]

Intellectual disabilities not on IAPT agenda

Therapists had experienced people with intellectual disabilities as a low priority in IAPT and service provision for this client group was described as a tokenistic and "tick-box"

response to policy guidance. Unlike other areas of specialism, such as older adults, often no one was identified as lead for 'intellectual disabilities'.

Most clinicians will have an area in which they will lead or take a special interest and I do feel that learning difficulties is probably an area that's perhaps overlooked a little bit or um it's not so clear err it feels quite hidden ... It's not as high up the agenda as it should be. (P5)

Seven of the 10 participants had not heard of the IAPT positive practice guide for intellectual disabilities (DoH, 2009), and those who had, felt the document offered no real clinical application. It seemed that whilst there was some recognition that working with people with intellectual disabilities could be difficult, it was not an area that was given much attention within services.

There hasn't been any guidelines you know, even a kind of a A4 kind of description of kind of ideas of how to adapt ... and in supervision people always say "whoa it's a bit tricky, isn't it". And people try and do the best they can but there actually isn't any - there hasn't been any knowledge there to help. (P1)

A recurrent theme was the importance of knowledge and training regarding work with people with intellectual disabilities. Half of the participants had completed a high intensity IAPT training diploma and some felt their training had not adequately prepared them for their clinical roles. Asked whether their IAPT training included adapting CBT for people with intellectual disabilities, one participant responded:

Absolutely nothing, and that's what really concerns me if I am honest ... the pace in which IAPT services are expanding I don't know if the training is keeping up with it ... The training course didn't really cover LD ... which was concerning. (P10)

One participant noted the contradiction of the exclusion of people with intellectual disabilities from the IAPT training curriculum, despite the programme's aim to increase access to psychological therapies. Nearly all participants identified a need for more training in this area, with some envisaging this as a way of increasing their confidence. However, it seemed that the perceived low numbers of people with intellectual disabilities accessing IAPT services prevented investment in resources and training.

Cos we don't really see that many people with a learning disability within IAPT, then obviously you might think there's not much demand for that training ... It's kind of chicken and egg isn't it- you'd want people to be trained before you encourage more referrals um so people were able to modify stuff. (P7)

Some described supervision in a positive light, typically experiencing it as supportive and helpful. However, others described supervision as unhelpful, and as failing to provide them with appropriate direction for their work.

To be honest, the supervision is poor for learning disabilities. There isn't anyone here that's specialist in it and um the advice that I'm usually given is just do behavioural work and that that's kind of it. (P1)

Some participants linked supervision to increasing confidence regarding the work and felt they would benefit from more specialist support, which did not appear to be available within IAPT services. Two participants described seeking support from the local intellectual disabilities team and many felt greater collaboration between IAPT and specialist services was needed to support them in their roles and improve service provision. Three participants reported attending 'action learning sets' run by the Foundation for People with Learning Disabilities, which they described as providing useful guidance around adapting materials.

Fit with short-term recovery model

Therapists appeared to perceive the short-term recovery model underpinning IAPT services as lacking the necessary flexibility for people with intellectual disabilities. Some participants felt uncomfortable about imposing a change model on clients, which seemed to conflict with their clients' goals for therapy, and were concerned how this was experienced.

I have a worry that it's quite perplexing for her that she's coming in to tell me how she feels bad and I'm telling her to go and meet her friend or her sister for coffee ... I'm not sure she wants to make behavioural changes, I think she wants someone to listen ... so that's a bit of a conflict as well. (P2)

Participants' narratives indicated how clients were expected to demonstrate improvements in functioning, as determined by the MDS. However, some felt that service users with intellectual disabilities often did not meet the recovery expectations set by the service.

When I will go and have my progress and development review, and if it is the case that not enough people have hit recovery, and it is the case with learning disabilities ... My managers and senior managers and so on they're going to be thinking about what the commissioners are going to think because they're not going to get all these ... explanations to why some people haven't met recovery they're just going to get trends of data and statistics and recovery percentages so it's a really difficult tension. (P3)

Participants repeatedly spoke of the need to modify the structure, content and pace of therapy whilst working with people with intellectual disabilities. Behavioural interventions were frequently described as successful and as more effective than cognitive interventions, and therefore employed more frequently.

I ended up having to just take a much more behavioural and experimental approach, so trying things in the session so that he could experience them rather than trying to explain them to him. (P6)

Some participants reported therapeutic gains for clients following successful adaptations, such as increased confidence for the client and the development of coping strategies. Some reported improved MDS scores, whereas others felt that gains made by clients in other areas, such as improved risk management, were not captured by the MDS.

There's a lot of work that's been done with clients and you just don't even- you don't see it on those questionnaires at all. (P9)

Successes appeared to be dependent upon the therapist's ability to make appropriate adaptations to the work, who described relying heavily on prior experience and knowledge, as well as supportive supervision to do the work. In addition, successful work appeared dependant on clients' high functioning, as well as using mostly behavioural interventions and simplifying the work.

I think that's what I learned that just doing behavioural work did actually shift something. (P3)

In contrast, some reported the work had been unsuccessful and one participant felt that no aspects of CBT had been successful whatsoever.

The kind of CBT approach hasn't really worked and that might be how I'm doing it or it might be just because the CBT approach isn't a good option. (P4)

Some therapists felt that therapy outcomes were restricted by time constraints; not having enough time to prepare in between sessions or to extend therapy limited its potential impacts.

I always feel a sense that well I've only had that much time, and if I had a bit more time then maybe I could have done a better job. (P9)

Participant narratives revealed a strong sense that attending to contextual and systemic factors seemed more necessary. Many described numerous benefits of involving carers within the work, including supporting the utilisation of therapy skills and therapy endings. However, half of participants said they often experienced difficulties in facilitating carer involvement within the boundaries of IAPT.

Because IAPT's very much just one to one therapy with them here you don't really do much kind of liaising with other services or like family involvement ... It's a bit of a tricky tightrope but um we did touch on those issues and it was lucky the aunty was there ... You could quite easily stray outside of the remit of IAPT I guess. (P7)

Service short-comings

From an organisational perspective, some therapists experienced targets relating to the recovery of clients with intellectual disabilities as unrealistic and at times as "scary". Targets were often not adjusted to accommodate this work and some participants described having to "fight" for more realistic expectations.

So you have to see 20 people basically. So they're all very supportive that's greatbut you don't kind of get an adjustment in terms of your time ... I fought to get one contact adjustment ... I could be seeing five people with learning disabilities and I have one contact adjustment It'd be dropped down to 19 [clients] instead of 20. So it's not a lot in the grand scheme of things, in terms of how much extra time it can take. (P3)

Some participants reported relying on clients not attending therapy sessions and described having to forfeit their personal time in order to meet the pressures of the work. Over half of participants described the work as tricky and stressful, with some perceiving clients with intellectual disabilities as the most stressful "cases" on their caseload.

I felt very much with her there was a kind of, as being more- probably stress, so I feel like my stress was higher. (P5)

Many described a micro-management and blame culture in their work through monthly target meetings, in which their workload targets were reviewed. In response, some experienced a sense of resentment and reluctance relating to their work with people with intellectual disabilities.

IAPT workers are already so pushed for time ... Having kind of additional safeguarding issues that are more likely to arise ... lots of liaison work ... It's sort of time consuming so that I hadn't even really contemplated, but in terms of my

expectations of it, feeling pressured ... you're kind of hauled into a room every three months and then here's your data ... So it's quite scary ... That potentially is part of the reason why people aren't so super keen to work with people with learning disabilities. (P8)

Feeling unsure and lacking in confidence about the work also seemed to affect therapists' perceptions of working with people with intellectual disabilities.

I just don't have any training and I'm very unsure of what I'm doing and I feel a bit heart sink-y when I know I'm going to be working with someone with a mild learning disability. (P1)

Whilst adaptations to therapy were often required, it seemed that while some flexibility in the delivery of CBT was permitted, a person's diagnosis of intellectual disabilities would not in itself constitute grounds for extension to therapy.

You could have some flexibility to offer a bit more, but no more than someone with more complicated problems anyway- so just cos they had a learning disability I don't think that would mean you'd go over 18 [sessions], you would still be within that remit of IAPT. (P7)

Some participants described how their efforts to make therapy more accessible were often hampered by practical barriers, including lack of colour printing facilities and room availability. Some described using some adapted materials available within their service, although others described having none and felt more were required.

Participants described many ethical dilemmas in their work with people with intellectual disabilities arising from organisational contexts. Many spoke extensively about

the use of the MDS, experiencing both the frequency of administration and in most cases, the measures themselves as inappropriate. Despite their better judgement, participants spoke about having to adhere to service protocol regarding their administration, which they experienced as difficult.

It's a nightmare. The person I worked with ... it was four sessions in, then I realised it was the mum filling out the questionnaire. So it completely invalidated the whole thing ... I think it's a really complicated thing ... every time I've had to do it with people it's been very difficult. (P10)

In managing some of the dilemmas encountered, some participants described ignoring service protocols and instead focusing on the needs of the client in order to act ethically. One participant, when asked about MDS administration, described how, in order to practice in a person centred way, they felt forced to "violate" service protocol and conceal their actions from management to avoid potential repercussions.

I had to be pragmatic and I made a decision, which the client agreed to, which was that we wouldn't every session, we'd do it every other session but I'd report the same scores for two sessions...I had to make a clinical judgement on that, I just felt ethically what could I do because I thought this was taking so much time it wasn't helpful for the client ... I felt this was ... the only way I could really kind of get around it. (P10)

Uncertainty about the work

Therapists described a sense of uncertainty in their work with people with intellectual disabilities. This appeared to be influenced by both the perceived inadequacies of training and guidance, in addition to the increased complexities associated with the work.

Difficulties in assessing clients' abilities and therapeutic goals emerged as a key issue in trying to work out how to deliver therapy.

I don't know how much she understood of it ... I couldn't really get a sense of who she is and what she was able to do, and what she wasn't able to do ... Then it's like trial and error ... I kind of think to myself "my God, what am I doing here, she's not getting this at all- it doesn't matter how much I've simplified it [laughs] she's just not getting it". (P9)

There was a common perception among participants that the work involved more risk and vulnerability issues. One participant highlighted how the type of risk issues they faced were different compared to clients without intellectual disabilities:

At seven o'clock and she told me yesterday "my dad called me up and said if I didn't give him any money he's going to throw me off ... bridge". I just don't seem to get that kind of thing working with a non-LD population. (P3)

The limited time available raised ethical questions whether therapists are able to respond appropriately to complex risk issues.

I think there's a lot of potential safeguarding issues that I worry about ... it's very time consuming ... writing emails ... and phone calls and um there's so much work in between but there's only so much time, so it's just running on nervous energy sometimes especially when you're really busy. (P9)

There often appeared to be a mismatch between therapists' training and competencies and expectations surrounding their role. Many described feeling confused, and in some cases overwhelmed, about what and how to deliver therapy to individuals with intellectual disabilities.

I'm not quite sure if things that I'm saying, how they're being understood. Um I'm not quite sure what pace the therapy should go at, if I'm too quickly, if I'm making the ideas too complex, too simple um ... if the kind of goals are realistic or unrealistic. Um I suppose in all sorts of ways ... I feel quite out of my depth. (P2)

For many, it appeared that most of their work was guided by trial and error. This appeared to contrast with therapists' work with clients without intellectual disabilities, with whom they felt more certain about protocols. When work was not clear or deviated from the protocol, as was often the case whilst working with people with intellectual disabilities, this created anxiety for some. Their lack of confidence made the work more difficult and in some cases made therapists weary.

I don't feel very confident um not looking forward to working with the person particularly. (P1)

Some participants alluded to a sense of uncertainty among IAPT staff regarding the general suitability of IAPT for people with intellectual disabilities. One participant suggested that a person's compromised intellectual functioning may automatically exclude them from CBT and IAPT.

Well in terms of kind of assessing for suitability for CBT there's kind of clear criteria ... an intellectual understanding is one of the kind of criteria that um makes a client suitable for CBT. (P1).

Whilst some participants felt people with intellectual disabilities should be able to access IAPT, provided more work was done to ensure its accessibility, some suggested that therapists felt frustrated about the expanding nature of IAPT. It seemed that intellectual disabilities was not considered to be part of core services but instead as something 'extra', which they weren't adequately supported to do.

There is a frustration among clinicians and perhaps management ... that we seem to be broadening the remit of things that we do ... It's always like something else and something else and something else, and we don't necessarily have the skills ... we're not necessarily the best people to do the work. Um and if we are being asked to do it, we certainly need a bit of training and a bit of support and specialist supervision. (P2)

That IAPT services may actually reinforce the difficulties people with intellectual disabilities face in their everyday lives was suggested by some participants.

It would be so helpful for her to be seen in a specialist service...I think there's an idea that seeing someone with a learning disability in a non-specialist service is normalising ...but I also feel like the difficulties um that this lady faces almost are reinforced by coming to our service. (P2)

Discussion

This study aimed to increase our understanding of high intensity therapists' experiences of delivering CBT to people with intellectual disabilities in IAPT in order to inform service developments and improve accessibility. Findings suggest that people with intellectual disabilities are often a hidden population within IAPT and that consideration of this group features minimally within service design, operational management and staff development contexts. Therapists appeared to experience the conceptual underpinnings and service structure of IAPT as inflexible and providing a poor fit for this client group. The tokenistic commitment to people with intellectual disabilities within the IAPT programme appeared to have negative effects on the training, supervision and resources available to therapists in their role. Collectively, the challenges described by therapists seemed to leave many feeling uncertain about their work with people with intellectual disabilities, with some viewing such clients as the most stressful on their caseload.

Therapists described making some successful adaptations to CBT, which mapped closely to those reported previously (e.g. Haddock & Jones, 2006) and led to therapeutic gains for clients. However, whilst some reported a reduction in clients' MDS scores, by which recovery is assessed in IAPT, others felt their progress was not captured by them. It seemed that people with intellectual disabilities often do not fit in with IAPT's recovery expectations. Many appeared to feel uncertain about how to implement appropriate modifications and seemed to have limited knowledge of relevant literature. Flexibility in approach was emphasised by all participants, who recognised that strict adherence to CBT protocols, while suitable for the mainstream population, are often not appropriate for people with intellectual disabilities. The degree of flexibility therapists reported in their delivery of CBT appeared variable. However, more consistent were structural and policy constraints which often restricted therapists' ability to work in person-centred ways and hampered their efforts to make treatment adaptations. Whilst the potential benefits of adaptations, such as the inclusion of carers within therapy, were recognised, these may be harder to facilitate in the context of IAPT.

Some therapists felt the inadequate attention paid to people with intellectual disabilities had resulted in the delivery of inappropriate processes and materials, including the MDS, consequently resulting in ethical dilemmas. Many described a restricted sense of autonomy, having to adhere to protocols they were not always in agreement with. An intellectual disability diagnosis in itself was not deemed to warrant the making of reasonable adjustments, which is concerning in light of The Equality Act 2010.

Managing the demands of high work-loads and ambitious target expectations appeared central to therapists' experiences. One therapist described IAPT as a "conveyer belt", whilst another described "running on nervous energy" to manage the time demands. The time and energy consuming nature of delivering psychological therapies to people with intellectual disabilities has been highlighted (Jones, 2013) and this was apparent in many participants' description of their work. However, performance targets were often not adjusted to accommodate extra demands and were considered unrealistic, generating feelings of frustration among therapists.

Whilst many of the findings overlap with those reported previously (Chinn et al., 2014; Shankland & Dagnan, 2015), in contrast, the narratives shared by participants were less positive about the accessibility of IAPT for people with intellectual disabilities. The emotional impact of working with people with intellectual disabilities was often described in negative terms, for example, as "scary" and a "nightmare". Consequently, some therapists felt reluctant to work with this client group, who were viewed in a "heart-sinky way" and who may be seen as a burden by IAPT staff (Chinn et al., 2014). High workloads combined with a limited sense of autonomy have been linked with emotional exhaustion for IAPT workers (Steel et al., 2015) and do little to encourage therapists to work with people with intellectual disabilities. Therapists' lack of enjoyment of therapy may also be predictive of poorer client outcomes (Heinonen et al., 2012), all warranting further consideration by IAPT services.

Previous findings have indicated that psychological well-being practitioners may feel more optimistic about the accessibility of IAPT for people with intellectual disabilities, compared to high intensity therapists (Chinn et al., 2014; Dagnan et al., 2014). This may go some way in explaining the more negative views shared by participants. It may be that in addition to the pressurised nature of the role, the more formulation-driven approach high intensity therapists are trained to use, compared to the more manualised approach adopted by psychological well-being practitioners, make it more difficult for them to consider the applicability of IAPT therapies for people with intellectual disabilities.

At an organisational level, the IAPT infrastructure does not appear to provide therapists with adequate training, support and guidance regarding their work with people with intellectual disabilities. Consistent with previous research (Chinn et al., 2014; Shankland & Dagnan, 2015), many felt improved training opportunities and increased access to specialist supervision were needed to support them in their role, suggesting a gap which needs addressing. This is despite eighty percent of the sample population holding doctoral level psychology training, which provides trainees with knowledge and skills related to working with people with intellectual disabilities (BPS, 2012). This may raise important considerations for IAPT workforces whose staff have not completed doctoral level psychology training and as such their need for further training may be even greater. However, this assumption is untested.

Research indicating links between training and increased therapist confidence (e.g. Dagnan et al., 2014) supports the observation that therapists with more training and experience reported higher confidence on the TCS-ID. It seemed previous training and experience was relied heavily upon by therapists to guide effective therapy. Arguably, the lack of commitment paid to people with intellectual disabilities within IAPT may influence training opportunities and low numbers accessing IAPT may limit the effectiveness of potential training. However, the paradoxical situation these barriers create was

acknowledged by participants, who recognised that without training for therapists, it was unlikely IAPT would be able to meet the needs of people with intellectual disabilities.

The lack of helpful supervision experienced by some participants also mirrors previous findings (Chinn et al., 2014) indicating supervision may offer IAPT staff little support in their work with people with intellectual disabilities. Potential benefits associated with joint working between IAPT and local specialist intellectual disability services, including access to supervision, were indicated by participants and have been reported in the literature (Kirk et al., 2014; Salmon et al., 2013). Attending support forums facilitated by the Foundation for People with Learning Disabilities were also experienced as helpful.

Implications

The IAPT programme emphasises its aim to increase access to IAPT therapies for the whole population and UK policy directives and legislation stipulate that services should ensure their accessibility for people with intellectual disabilities. However, findings from this study suggest poor implementation of policy and legislation, and do little in the way of reassuring concerns regarding IAPT's suitability and commitment to this client group.

Historically, specialist intellectual disability teams and mainstream mental health services in England have operated independently and there is currently a lack of consensus concerning the most appropriate service delivery model for this client group (Sheehan & Dimitrios, 2013). This study has highlighted some of the potential challenges of providing psychological treatments to people with intellectual disabilities within mainstream services, including when standardised protocols are delivered with minimal flexibility and when conceptual frameworks of recovery may differ between service models. Inter-agency collaborative working between local specialist intellectual disability teams and IAPT services is encouraged to develop IAPT's ability to deliver individualised reasonable adjustments, in line with the Equality Act 2010. Greater awareness related to the needs of people with intellectual disabilities is required within IAPT. Whist the current findings relate to IAPT in particular, they have the potential to inform national and international mental health service developments for people with intellectual disabilities.

Findings from this research point to a clear need for more specialist training and supervision to support IAPT therapists to develop their confidence and skills in delivering effective and appropriate interventions to people with intellectual disabilities. Specialist services may be able to facilitate such support and course curricula for both high intensity and supervisor training should include material on the accessibility of CBT for people with intellectual disabilities. Individual performance targets also need to be adjusted to permit therapists to work more flexibly with this client group and to ensure they are able to safely and effectively respond to their needs.

At national level, IAPT targets regarding people with intellectual disabilities accessing IAPT services need to be reviewed. Currently there are no specific targets pertaining to the delivery of IAPT services for people with intellectual disabilities, who are expected to achieve the same recovery targets as mainstream populations. Re-consideration of targets may encourage investment in service development for this client group as well as greater consistency in the implementation of legislation and policy directives within IAPT. Relative to this, the use of the MDS with people with intellectual disabilities clearly requires further consideration.

Finally, there is a clear need for a more developed evidence-base and increased understanding regarding the specific components of CBT for people with intellectual disabilities. However, in the interim, clearer guidelines regarding flexible approaches to working with people with intellectual disabilities, specifically within IAPT, are required. The updated IAPT Learning Disabilities Positive Practice Guide (FPLD, 2015) may address some of the challenges highlighted in this study and provide services and therapists with increased clarity regarding the implementation of reasonable adjustments.

Limitations

The present findings are based on a small sample and participants who opted to take part in this study may hold stronger views about working with people with intellectual disabilities and may have a personal interest in this area. Consequently, this may not represent the experiences of all IAPT therapists working with this client group. However, recruiting participants across multiple IAPT services and NHS Trusts provided an enhanced overview and representation of therapists' experiences.

Conclusion

Therapists described many challenges when attempting to make CBT accessible within the context of IAPT. It is clear that it is necessary to consider the implementation of reasonable adjustments required for many people with intellectual disabilities within IAPT. Furthermore, service agreements at commissioning level are needed to offer a more realistic framework to ensure equitable access. Findings from this study have highlighted some of the potential limitations of the current IAPT model for people with intellectual disabilities. Greater integration of specialist teams within mainstream mental health services may be important in providing effective psychological therapies to this client group.

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ID	Training	Experience of ID work prior to IAPT role	TCS-ID score
P1	HI	None	9
P2	CP	Limited	23
P3	HI	Limited	23
P4	CP	Limited	25
P5	CP	Prior ID placement	31
P6	CP	Limited	30
P7	CP, HI	Prior ID placement	37
P8	CP	Prior ID placement	40
P9	CP, HI	Extensive	40
P10	CP, HI	Extensive	43

Table 1Participant TCS-ID scores and professional experience

HI: High intensity training

CP: Completed clinical or counselling psychology doctoral training

(Scale range of possible TCS-ID scores: 0-70 (14 items x5), higher scores indicate greater confidence)