TITLE: 'Reasonable Adjustments' for People with Learning Disabilities in IAPT

AUTHORS:

Dr Kate Theodore[a], Kate Bexley[b], Natalie Eyre[b] & Dr Louise Healey[a]

[a] Hammersmith & Fulham Learning Disability Service, Central London Community Healthcare NHS Trust

[b]Back on Track Hammersmith & Fulham IAPT, West London Mental Health NHS Trust

AUTHORS:

Dr Kate Chatters[a], Dr Rachel Blundell[a] & Dr Simon Powell[b]

[a] TLC, Oxleas Foundation NHS Trust

[b] Greenwich Community Learning Disability Team, Oxleas Foundation NHS Trust

SUMMARY:

This paper describes two different service models and care pathways developed to improve appropriate access for people with learning disabilities to IAPT services.

BACKGROUND:

Despite there being a higher prevalence rate of mental health problems in people with learning disabilities (Hatton & Taylor, 2010), this group have traditionally been denied access to a range of psychological therapies (Taylor, 2010). The government-backed Improving Access to Psychological Therapy (IAPT) initiative intended to ensure people with common mental health problems had fast, easy access to NICE approved psychological therapy in primary care; including provision of 'low intensity' Cognitive Behavioural Therapy (CBT)-based

interventions (including 'guided self-help') for people with mild-moderate depression and anxiety disorders, and 'high intensity' therapy for people with moderate-severe depression and anxiety disorders. IAPT proposed to reverse inequalities that existed in terms of the demographics of those receiving treatment by being especially responsive to marginalised communities (Care Services Improvement Partnership, 2007), including people with learning disabilities. Documents produced by IAPT and the DoH have highlighted guidance and suggestions about how to understand the needs of, and remove the existing barriers for people with learning disabilities within IAPT (DoH, 2008; DoH, 2009).

However, Dodd, Joyce, Nixon, Jennison and Heneage (2011) reported that IAPT services remained largely inaccessible for people with learning disabilities. They highlighted a lack of evidence regarding 'reasonable adjustments' made by IAPT services. Specifically, that guidance and figures concerning equality of access and treatment outcome for people with learning disabilities was underdeveloped compared to that of the general population and other marginalised groups. In 2012, the NHS Confederation, on behalf of the DoH commissioned the National Development Team for Inclusion (NDTI) to report on the reasonable adjustments being made in mental health services for people with learning disabilities and autism. The resulting report *Reasonably Adjusted?* (NDTI, 2012) highlighted few services comprehensively and systematically audited their practice and redesigned accordingly. It is thought that without 'reasonable adjustments', IAPT may increase the risk of people with learning disabilities being offered inappropriate psychological interventions, non-attendance, and contribute to the additional social and economic costs of untreated mental health problems (Hatton, 2011).

In 2013, the charity *Foundation for People with Learning Disabilities* contacted IAPT services nationally about a project initiated by them in partnership with Kings College London, funded by the DoH. The project aimed to explore ways that mainstream psychology services, particularly IAPT, could better support people with mild to moderate learning disabilities and mental health problems. A year

on, a number of IAPT services have begun increasing their services' accessibility. The resulting increase in numbers of people with learning disabilities seen in IAPT may be appealing to both IAPT commissioners and Community Learning Disability Teams (CLDTs) and is a success for the *Foundation for People with Learning Disabilities*. Whilst there seems to be an increasing agreement nationally that it is good practice for local CLDTs and IAPT services to strengthen their care pathways in an effort to improve accessibility of IAPT services for this marginalised group (e.g. Goodey & Stirk, 2014; Salmon et al., 2013), different services are utilising very different service models to achieve this aim.

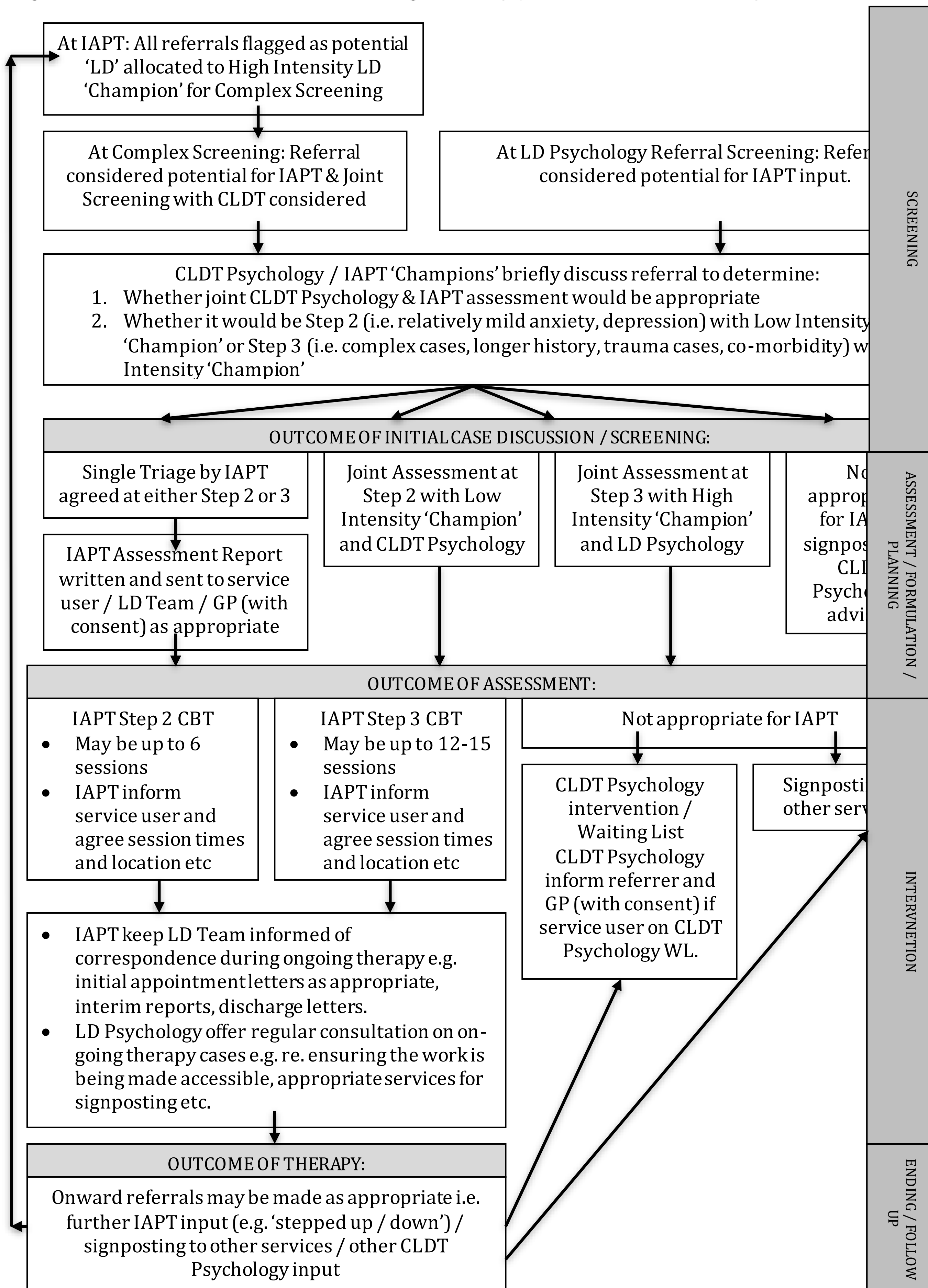
Therefore, this current paper outlines the experiences of two different service models in the South East of England, both involved in the *Foundation for People with Learning Disabilities* project; Hammersmith & Fulham joint care pathway incorporating improved joint working between the separate CLDT and IAPT services, and Oxleas, where a specific IAPT service for people with learning disabilities has been established. As different local areas will have different commissioning structures and resources, it is hoped that sharing our own processes and reflections on this will be helpful for other areas considering different options. For the purposes of this paper, we are considering access to IAPT for people who would ordinarily meet criteria for a global learning disability (namely having an impaired intellectual and social functioning, present since childhood with a lasting impact on development).

Hammersmith & Fulham: Joint Care Pathways between CLDT & IAPT

Local Context & Service Model: Hammersmith & Fulham IAPT offers a number of NICE-approved CBT-based interventions at both low and high intensity, including guided self-help informed by CBT principles, CBT, and mindfulness-based cognitive therapy, which can be delivered in both individual and group formats, as well as individual therapy drawing on interpersonal therapy, cognitive analytic therapy, and behavioural couples therapy. Locally, there has been no dedicated funding, commissioning or additional resources allocated to specific IAPT services for people with learning disabilities, however involvement in the *Foundation for People with Learning Disabilities* project has allowed

members of both the separate CLDT and IAPT services to develop shared care pathways and improved joint working between services. Referrals to IAPT, including those for people with learning disabilities, can be made by self-referral, GP or other health/social care/third sector organisation. As part of the project work, an agreed care pathway has been established between the local IAPT and CLDT psychology service, to facilitate improved access for people with learning disabilities (see Figure 1).

Figure 1: Hammersmith & Fulham Learning Disability / IAPT Joint Care Pathway



Outcomes: The agreed pathway has led to increased communication between IAPT and CLDT psychology services, in particular between the identified 'champions' in both services, for consultation about clinical issues, e.g. discussions about potential referrals to each service, or discussion or joint working around potential Safeguarding issues that arise. In total, between September 2013 and November 2014, 11 people with global learning disabilities (eligible to receive a service from the CLDT) have received assessments for psychological therapy with IAPT, of which three involved joint assessments between IAPT and the CLDT psychologists. Six were referrals from the CLDT, and the remaining five were referrals from other primary (e.g. GP) or secondary mental health services. Of these 11, nine went on to be offered high intensity treatment with IAPT (one of which had received previous low intensity intervention, and was subsequently 'stepped up' to high intensity). In addition to this, five service users have attended a low intensity CBT-based community workshop (on the topic 'good sleep') offered by IAPT low intensity workers, supported by CLDT psychology. A further total of 15 carers of people with learning disabilities have accessed three separate workshops (on topics of relaxation and mindfulness).

To ensure CBT-based interventions offered to people with learning disabilities accessing IAPT are accessible, easy-read resources (e.g. accessible information for service users on CBT, diaries, therapy worksheets, crisis plans) have been shared with IAPT by the CLDT. This has also included developing easy-to-understand prompts to support the use of the IAPT 'Minimum Data Set'; a battery of outcome measures required to be completed by all service users seen by IAPT at each therapy session. Adaptations have included delivering the outcome measures verbally in session (rather than relying on service users completing written versions independently prior to the session), using consistent additional prompts to break down each item, or asking for carer support to complete where appropriate, and using time-anchors to orient service user to completing the scales to represent how they have felt 'over the past two weeks'.

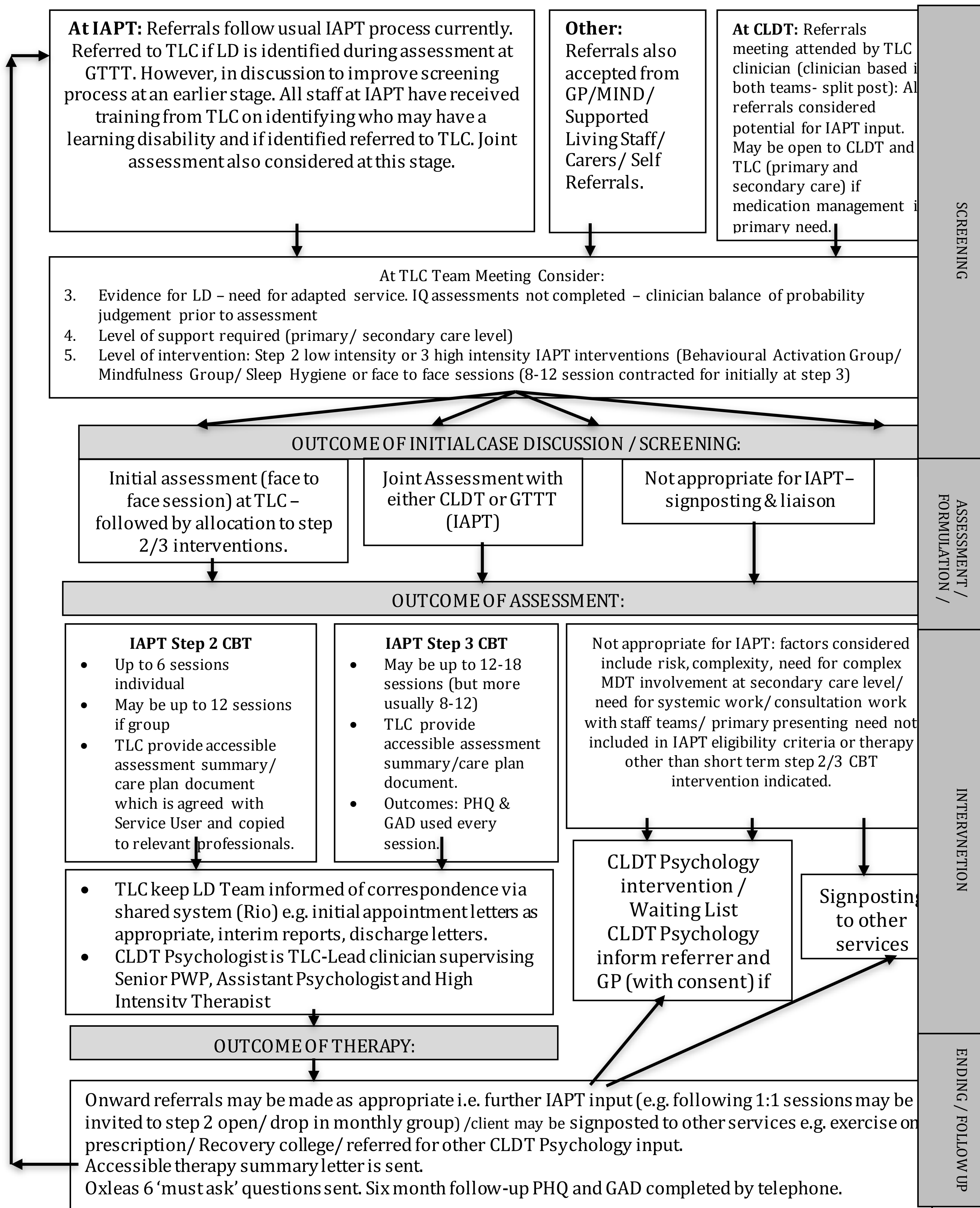
Regular, fortnightly telephone consultations with a CLDT clinical psychologist has also been offered to the IAPT high intensity therapist delivering individual therapy to people with learning disabilities, to support provision of high-quality therapy that is accessible to the individuals' learning needs. Initial training on working with people with learning disabilities has been delivered to the IAPT service, and further training will be offered. Additionally, it has now been agreed that the high intensity clinician from IAPT will be placed for some time each week within the CLDT in an 'in-reach' model of care; spending one weekly session providing IAPT therapies for people with learning disabilities and their carers, and another weekly session gaining wider clinical experience working within the CLDT with a view to enhancing clinical practice in IAPT.

The local IAPT have also for the first time implemented a system using the standard client electronic record system in use at that service ('IAPTUS'), whereby clients identified as potentially having a learning disability can be recorded as such; thus allowing ongoing monitoring and audit of service delivery for the future. To date a total of 74 individuals have been recorded as such on this system. Although a positive move to improve identification and monitoring of the needs of this group, it should be noted that this is still a 'catch all' category that can include individuals with broader learning needs, such as memory difficulties, difficulties with reading and writing, and general difficulties in learning, and not more specifically those with global learning disabilities. There is also a research project underway which will take place over the next 18-24 months, investigating perceptions of IAPT clinicians and service users with learning disabilities who have accessed the IAPT service regarding how they have found the service and inviting recommendations for further improvements. Following a period of implementation of these recommendations, a further review will allow re-evaluation of the service; this will be measured with guidance from the GreenLight Toolkit (NDTI, 2013) self-assessment audit tool.

The Oxleas Model: A 'stand-alone' IAPT service for people with learning disabilities in Greenwich.

Local Context & Service Model: *Talking Therapies for people with Learning disabilities and their Carers (TLC)*, is a service in Oxleas NHS Foundation Trust based in Greenwich. In line with mainstream IAPT service providers TLC is an outcomes focused, short-term interventions team that provides Cognitive Behavioural Therapies via a stepped care model. The service model is unique in that it is a 'stand-alone' service which is separate, but sits between, mainstream IAPT services and the local CLDT (see Figure 2) whilst maintaining good links to both.

Figure 2: Oxleas Specialist IAPT Team for People with Learning Disabilities (TLC)



Outcomes:

Since the service launch in July 2013 TLC have received 72 referrals. Of these, 57 service users attended initial face to face assessments. Fifteen service users were either signposted to other services or did not engage at the stage of referral. To date 46 clients have been seen for step two or three therapy sessions. TLC have run a number of step two groups. The 'Chill out and be Happy' group covered topics such as basic emotion regulation skills in addition to providing an introduction to the basic tenets of CBT. An eight session 'Introduction to Mindfulness' group has just ended. The group was supervised by the Trust's lead clinicians for mindfulness based approaches and was specifically adapted for service users with a learning disability. TLC will soon launch a further pilot step two group, the 'Do More – Feel Better' group will explore the use of Behavioural Activation in a group setting as a primary intervention for depression and anxiety.

The development of TLC appears to have met its central aim of increasing access to psychological therapies for people with a learning disability in Greenwich; a key objective from the commissioners. In the vast majority of cases the people seen by TLC would not have received a service elsewhere – they either did not meet eligibility criteria for the local CLDT (which is a fully integrated health and social care team) or would be likely to have struggled to access mainstream IAPT services due to the significant adaptations required.

As a 'stand-alone' service which sits between CLDT and mainstream IAPT the service is able to adopt a 'best of both' approach. Whilst TLC is much smaller than either team and has limited clinician hours (1.5 whole time equivalent clinicians on average over the period), a real strength is that clinicians have experience of working in both CLDT and mainstream IAPT services. Close liaison with both CLDT and IAPT counterparts throughout the development of the referral and care pathway has been extremely important and as a result TLC has received a high proportion of appropriate referrals from both services. Training has been provided to all staff at GTTT and CLDT.

The service model has enabled adjustments to be made specifically for people with learning disabilities from the outset. Some of the many adjustments include greater flexibility around carers or family members attending appointments, more active engagement processes including reminder phone calls or texts, accessible letters, adapted therapeutic resources, in addition to significant adaptations to usual CBT treatment protocols and outcome tool administration. There is regular dialogue between team members about what might work, what others have found helpful and ongoing evaluation of how things could be done differently.

It was identified early in the process that completion of the full Minimum Data Set (MDS) required by the majority of IAPT services may present a barrier for clients with a learning disability. TLC's position as a 'stand-alone service' was helpful in this regard, enabling us to opt not to complete the full set of MDS measures. Elements of the assessment battery were retained, specifically the Patient Health Questionnaire (PHQ-9) and the Generalised Anxiety Disorder 7 (GAD-7) scales which measure depression and anxiety respectively. These measures are completed every session. The administration of the measures is adapted as previously discussed.

Both TLC and GTTT are Oxleas NHS services. This has been key to facilitating liaison and joint working. In other areas of the country the Any Qualified Provider (AQP) system can result in multiple teams having to be engaged if initiatives are to be agreed county or borough wide.

As a new and developing service model TLC is keen to receive service user feedback on their experience of the service. An external researcher from the Tizard Centre, University of Kent, recently conducted a qualitative analysis focussing on the experience of TLC service users. The findings will be shared in due course but anecdotally feedback has been very positive. Initial treatment outcomes also appear very positive, with reliable improvement and reliable recovery rates broadly in line or better than national IAPT key performance

indicator data. This data is currently being analysed with support from colleagues at National IAPT.

Summary: Models Strengths and Limitations

It is hoped that the illustrations of these two differing models has provided some varying examples of how IAPT services can begin to meet the needs of people with learning disabilities. In the box below (figure 3), we have summarised what we feel are the strengths and limitations of each of the models described in this paper. We feel that it is likely that different models will better suit the needs of different local contexts; just as local IAPT and CLDT services are configured in varying ways nationally, so IAPT services for people with learning disabilities will need to be offered using flexible models to suit the needs of different local contexts, commissioning priorities and budgetary constraints. What is perhaps most important is that local areas are considering the unique needs of their local service users and making improvements to mainstream psychological therapies services to meet these needs.

Figure 3: Strengths and Limitations of each service model

	Strengths	**Limitations**
Hammersmith & Fulham: Joint Care Pathways between CLDT and IAPT	• Improved communication between CLDT & IAPT • Improved understanding of each services' processes • Care Pathway for people with learning disabilities developed jointly • Joint psychological therapies assessments conducted by IAPT and CLDT clinicians • Delivery of CBT	• Current expertise remaining with specific IAPT clinicians as 'champions' rather than spread throughout IAPT team • Limited delivery of step 2 low intensity interventions • Emphasis on minimum dataset may limit measurement of meaningful recovery

	(particularly step 3) interventions for people with learning disabilities with positive outcomes • IAPT workshops made accessible and delivered for services with learning disabilities, their carers, and CLDT staff • Sharing of accessible CBT resources • Improved recording, monitoring and auditing of people with learning disabilities accessing IAPT • Increased research opportunities • Training for IAPT clinicians by CLDT psychologists • Outcomes achieved without additional funding	goals for people with learning disabilities • On-going IAPT service priorities that could restrict access, such as service recovery targets, DNA policies • Lack of specific service funding, leading to limits to clinician time for this project work, and competing clinical priorities • Limited funding and focus additionally for people with high functioning autism / Aspergers
Oxleas: <u>Specialist IAPT Team for People with Learning Disabilities</u>	• A coherent Care Pathway for people with learning disabilities to access IAPT interventions. • Reasonable adjustments made more easily with fewer barriers • Clinicians with 'dual knowledge' of IAPT approaches and LD population - reduces time needed for liaison and interface. • Dual skill set and specialist nature of service allows for	• Limited clinician hours available (1.5 whole-time equivalent on average). • Continued service provision dependent on on-going commissioning (smaller stand-alone service may be more vulnerable cuts). • Expertise not widely disseminated throughout mainstream IAPT team and may be vulnerable to staff turnover/ staff absences in a small team. • Lack of access to IAPT

	exploration of possible adapted step 2 interventions and other innovations. • Increased research opportunities – developing practice based evidence • Positive outcomes at step 3 (good reliable change and recovery rates). • Very low dropout rates and positive numbers progressing to 'complete' treatment. • Flexibility to select outcome measures specifically for LD population	training budget/ no 'low intensity' or 'high intensity' training places available. • Difficult to establish GP links - team is not within GP surgeries or usually directly referred to.

Discussion & Reflections

Despite very different service models, as outlined above, there are a number of common initial reflections on the process of increasing access to IAPT for people with learning disabilities experienced by the different services involved in the *Foundation for People with Learning Disabilities* project work. A positive outcome of the work has been increased communication between the CLDT and IAPT, and improved understanding regarding each service's processes; this has seemingly led to a more streamlined service for people with learning disabilities. Services are increasingly able to monitor how many people with learning disabilities are accessing IAPT, allowing more transparent audit of service and service user need. This work is clearly of some significance, if people with a learning disability accessing IAPT services can be clearly identified the resultant data set would form one of the largest evidence bases regarding CBT treatment outcomes for people with a learning disabilities.

One of the challenges faced by several services attempting to improve IAPT services for people with learning disabilities, is that whilst there may be good practice guidance on increasing access and making reasonable adjustments, this may not always be associated with additional funding, or commissioning priorities for IAPT (Chinn, Abraham, Burke & Davies, 2014), who by nature of their wide remit to improve access to all marginalised groups, have other conflicting clinical priorities. Locally, this may leave services reliant on the enthusiasm and passion of local staff to act as 'champions' for this work, without dedicated time or resources to apply to adaptations. This may also mean that expertise remains with these service 'champions', rather than being distributed more widely throughout the service, unless LD training becomes a more substantial part of the core low intensity and high intensity training programmes.

A shared barrier encountered by IAPT services attempting to increase access to people with learning disabilities has been the use of the standard IAPT 'Minimum Data Set' (MDS). This battery of outcome measures has not been developed specifically for people with learning disabilities, and yet it is still a national IAPT requirement for all IAPT service users to complete this at every therapy session. However, there is as yet no known research regarding the appropriateness of these measures to understand mental health problems in people with learning disabilities, and whether this is an ecologically valid way to measure 'recovery' in this group, or whether there may be other more appropriate measures to be used. As IAPT services often apply stringent criteria regarding 'recovery' rates using the MDS, this may leave people with learning disabilities vulnerable to increasingly restricted access to services if they appear to be less likely to demonstrate that they are reaching recovery 'targets' using the measures, which may be an artificial effect of the use of an inappropriate measure. It may also be that at least some people with learning disabilities take a longer time to reach 'recovery', as defined by the MDS, which may also be a tension for IAPT service managers if needing to meet 'payment by results' or other service targets.

Over the course of the project work, there has been an increased number of people with learning disabilities accessing CBT-based interventions via IAPT, with reduced waiting times for these interventions. However, these are still at relatively small numbers; similar to that found by Goodey & Stirk (2014), this may still reflect a low identification of people with learning disabilities experiencing depression or anxiety disorders that may benefit from IAPT interventions. Alternatively it may be appropriate that given current limits on interventions and adaptations offered by IAPT, there are only a certain group of people with learning disabilities and mental health problems who will be able to access IAPT services, and other psychology interventions for people with learning disabilities (such as interventions focusing on a more systemic level, work with challenging behaviours, and interventions for those unable to access brief CBT-based talking therapies) will continue to be most appropriately delivered by CLDT psychology.

We have found an even more limited number of service users have been able to make use of CBT-based interventions usually delivered at a 'low intensity' level (shorter-term interventions for mild-moderate depression and anxiety disorders e.g. 'guided self-help'). The low intensity groups currently being developed at Oxleas are showing promise as viable 'low intensity' treatment alternatives. Given the complexities of the mental health needs of people with learning disabilities, and that there can sometimes be a reliance on literacy skills in 'low intensity' interventions (e.g. if using written 'guided self-help' resources), it is not surprising that interventions delivered at a 'high intensity' level have been favoured; where greater adaptations and flexibility can be incorporated to meet clients' needs. However, to increasingly improve access to the mainstream psychological services accessed by people without learning disabilities, there is perhaps greater research and service-development required regarding what, and how, CBT-based 'low intensity' interventions can also be delivered to people with learning disabilities.

It has been our experience that despite some recent additional research into manualised CBT for people with learning disabilities (e.g. Hassiotis et al., 2012),

there still requires additional policy guidance on how IAPT can be more standardly and appropriately adapted for delivery to people with learning disabilities, including guidance on appropriate length and frequency of therapy sessions, and flexibility needed of services in order to meet requirements of 'reasonable adjustments' (e.g. flexibility in attendance policies, use of standard MDS/outcome measures to measure stringent 'recovery' targets). Until such guidance is available, IAPT clinicians are likely to continue to face barriers in making the necessary reasonable adjustments required to support meaningful access to the service for people with learning disabilities. The Positive Practice Guide (DoH, 2009) offers some helpful suggestions for improving engagement of people with learning disabilities in IAPT by advocating flexibility, training and supervision of staff. However, this document offers recommendations that are often too vague (e.g. stating that clinicians may need to offer longer sessions, but not being clear whether this is related to each session length, or overall session duration), without giving reference to research that could help guide interventions, and can seem to be overly focused on challenges to including people with learning disabilities in IAPT services, rather than offering solutions or good practice examples. As part of the project work, the *Foundation for People with Learning Disabilities*, intend to review and update the 'Positive Practice Guide' (DoH, 2009), and it is hoped that this will continue to support the work of services attempting to improve access for people with learning disabilities to IAPT.

In summary, initial indications suggest that a stepped care 'IAPT' model can work extremely well for people with learning disabilities ***if*** reasonable adjustments are made. Further research is needed to establish which components of the IAPT treatment programme may be most accessible and effective for this population.

ACKNOWLEDGMENTS:

With thanks to the *Foundation for People with Learning Disabilities* for the support provided to services through involvement in the Improving Access to Psychological Therapies for people with learning disabilities project work.

CORRESPONDENCE:

Kate Bexley
Cognitive Behavioural Therapist
Back on Track, IAPT / Hammersmith and Fulham Learning Disability Service
NHS Hammersmith & Fulham & West London Mental Health NHS Trust
Email: Kate.Bexley@nhs.net

Dr Kate Chatters
Clinical Psychologist
Community Learning Disability Team/ TLC (IAPT-LD)
Oxleas NHS Foundation Trust
Email: Kate.Chatters@oxleas.nhs.uk

REFERENCES:

Care Services Improvement Partnership. (2007). Commissioning a Brighter Future: Improving Access to Psychological Therapies. London: Department of Health.

Chinn, D., Abraham, E., Burke, C. & Davies, J. (2014). IAPT and Learning Disabilities. London: Kings College London.

Department of Health. (2008). Commissioning IAPT for the Whole Community: Improving Access to Psychological therapies. London: Department of Health.

Department of Health. (2009). Learning Disabilities: Positive Practice Guide. London: Department of Health.

Dodd, K., Joyce, T., Nixon, Jennison, J. & Heneage, C. (2011). Improving Access to Psychological Therapies (IAPT): Are they applicable to people with learning disabilities? *Advances in Mental Health and Learning Disabilities 39*, *3*, 243-251.

Goodey, R. & Stirk, S. (2014). Facilitating access to a local IAPT provider for people with learning disability: A six month prospective audit. *Clinical Psychology Forum, 262,* 22-27

Hatton, C. (2011). The impact of a screening questionnaire on access to and effectiveness of IAPT primary mental health care for adults with learning disabilities and mental health problems. *Cumbria Partnership Journal of Research Practice and Learning, 1,* 1, 13-15.

Hatton, C. & Taylor, J. L. (2010). Promoting healthy lifestyles: Mental health. In G. Grant, P. Goward, M. Richardson & P. Ramcharan (Eds.), *Learning disability: A life-cycle approach*, 2nd edition (pp. 381-408). Maidenhead: Open University Press.

National Development Team for Inclusion. (2012). Reasonably Adjusted? Bath: National Development Team for Inclusion.

National Development Team for Inclusion. (2013). Green Light Toolkit. Bath: National Development Team for Inclusion.

Salmon, B., Gibson, S., Nagal, B., Roscoe, S., Vidalaki, V. & Ubhi, H. (2013). Offering IAPT to people with learning disabilities: Partnership working and an innovative approach. *Clinical Psychology Forum, 252,* 40-44.

Taylor, A. (2010). Still striving to get it right. *Learning Disability Today 10, 7,* 10.