



Title: Adapting the GAD-7 and PHQ-9 clinical measures for people with learning disabilities

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ABSTRACT:

People with intellectual disability continue to face barriers to accessing psychological support, due to a lack of 'reasonable adjustments' (NDTi, 2012). An issue to accessing IAPT has been that the standard clinical questionnaires used to measure recovery from depression (PHQ-9) and anxiety (GAD-7), can be difficult to use for many people with intellectual disabilities. Stage 1 of this research used a cognitive interviewing approach to investigate whether adaptations to the GAD-7 and the PHQ-9 help to make these measures more appropriate for use with adults with intellectual disabilities. Two rounds of such interviewing were completed with participants to evaluate the suggested modifications and develop final adapted versions of these measures. Stage 2 of the research investigated the initial psychometric properties of the adapted measures predominantly via investigations of validity and reliability, and comparisons to established measures in the intellectual disability population. Participants in Stage 1 suggested further adaptations to increase accessibility and indicated that the adapted measures are appropriate for use with adults with intellectual disability. Stage 2 demonstrated support for the adapted measures as helpful for assessing symptoms related to depression and anxiety in this population; the adapted PHQ-9 correlated with the established self-report GDS-LD ($r = 0.80$), had good internal consistency ($\alpha = 0.85$) and the adapted GAD-7 correlated with the established self-report GAS-ID ($r = 0.66$) and had good internal consistency ($\alpha = 0.91$). Thus, the current research project provides support that the adapted versions of the PHQ-9 and GAD-7 could be used in IAPT services to facilitate access for adults with intellectual disabilities as part of a set of reasonable adjustments.

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CHAPTER ONE: INTRODUCTION

National policy requires mainstream psychology services to offer effective and appropriate psychological support for all (Department of Health [DoH], 2009). In practice, however, individuals with intellectual disabilities seeking to access these services are faced with obstacles arising from a paucity of consistently implemented '*reasonable adjustments*' (Dodd, Joyce, Nixon, Jennison, & Heneage, 2010; National Development Team for Inclusion [NDTi], 2012). A particularly significant obstacle arises from the routine outcome measures used by many Increasing Access to Psychological Therapies [IAPT] services. These measures, usually termed the minimum dataset, have been deemed unsuitable for use with clients with intellectual disabilities (Chinn, Abraham, Burke, & Davies, 2014). This judgement is based both on their format and on how such measures are delivered by services. Indeed, though the use of self-report clinical measures to assess the mental health problems of individuals with intellectual disabilities is well established (Skelly, 2016), far too little research has been done into the appropriateness of using the minimum dataset within this population. Adapted versions of the two key measures in the minimum dataset have been created and piloted, but as yet no formal investigations of validity have been completed. The present study accordingly aimed to determine whether or not these adapted minimum dataset measures are appropriate for use within adult intellectual disability populations. The following review of the literature and national policy documents relating to this area of enquiry establishes the context within which the study has been pursued.

INTELLECTUAL DISABILITY – A NOTE ON TERMINOLOGY:

The terms '*learning disabilities*' and '*intellectual disabilities*' are both in current use, with

debate attached to their relative merits. Essentially, the question is which of the two offers the more fitting diagnostic label when considered in light both of the clinical presentation and of sensitivity to the needs of the individuals in the population thus described. Traditionally the former term has been commonly used in the UK, but more recently there has been a shift to the latter within the academic community. This change brings the UK into alignment with the international community, where the term '*intellectual disabilities*' has long been current. This shifting landscape is reflected in the name change implemented by the British Psychological Society Faculty for People with Intellectual Disabilities' in 2014. Nonetheless, in most clinical contexts, amongst service users and self-advocacy groups the identifier '*learning disabilities*' remains the term of choice in the UK. To be consistent with the current academic literature, the term '*intellectual disabilities*' is used in this thesis to refer to the research study population. However, to acknowledge and respect the preference which emerged from consultations with service users and clinical practitioners, the participant information sheets and guidance developed for clinicians utilises the alternative term '*learning disabilities*'.

1.1 INTELLECTUAL DISABILITY:

The concept of intellectual disability can be viewed as a social construction and accordingly it varies between cultures and over time (Clements, 1998; Sternberg, Grigorenko, & Bundy, 2001). It is also the case that current definitions may involve arbitrary cut offs on standardised clinical measurement tools (Whitaker, 2004) and that evidence suggests that scores do not reflect permanency (Mackintosh, 2011). Whilst it is important to bear these caveats in mind, it is also necessary to have clearly defined diagnostic criteria if vulnerable individuals exposed

to our legal and social systems are to be safeguarded. (British Psychological Society [BPS], 2001).

The most up to date definitions of intellectual disability reflect the debates provoked by the social consequences of 'labelling' individuals. Emphasis has accordingly moved away from diagnoses based only on psychometric testing scores. DSM-5, for example, defines intellectual disability as a significant impairment in intellectual functioning characterised by deficits in general mental abilities (abstract thinking and reasoning, for example) and adaptive functioning across conceptual, social and practical domains (American Psychiatric Association [APA], 2015). These deficits must have been evident since early childhood, must present across multiple environments and must result in an individual being unable to cope independently (APA, 2015). Intellectual disability presents very differently across individuals and diagnosis is made on the basis of a comprehensive assessment. This last includes norm reference assessments of intellectual functioning and adaptive behaviour with a recommended diagnostic cut off of two standard deviations from the mean general population score (BPS, 2015). Motor or language issues and other individual factors likely to limit performance are usually carefully taken into account so as to increase the accuracy of diagnosis by preventing Type I errors (APA, 2015). Even so concerns about the validity of neuropsychological testing for the whole population remain, especially those arising from consideration of the impact of cultural and social influences (Harris & Llorente, 2005). Sub-classifications of intellectual disabilities vary, with differences arising both in their number and in their basis; some, for example, are defined by impairments in intellectual functioning (BPS, 2015; World Health Organisation, 1992) and others on impairments in adaptive functioning (APA, 2015).

No national database records the prevalence of intellectual disabilities in England and estimates are often based on the number of individuals known to services. Unsurprisingly, the accuracy of such estimates has been called into question (Einfeld, Ellis, & Emerson, 2011). Based on the normal distribution curve, the prevalence of intellectual disabilities arising from cognitive deficits alone is estimated to be around 2.5% of the general population (BPS, 2015), meaning that around 1.2 million people in the UK are thought to have intellectual disabilities (HM Government, 2001). However, this estimate neglects the dual nature of cognitive and adaptive deficits reflected in current diagnostic criteria. Epidemiological studies have thus produced prevalence estimates which vary considerably in accordance with the different criteria and methodology applied (Whitaker, 2004). Prevalence is also predicted to rise under the influence of multiple factors. These include longer life expectancy, improved medical treatments for children with complex disabilities, and the greater incidence of problems within some ethnic minority groups (Emerson & Hatton, 2008). These issues of accuracy in prevalence and the challenges surrounding accurate diagnosis impact more broadly on working clinically with and completing research with people with intellectual disabilities, as will be discussed later in this thesis.

The intellectual disability population has a high level of healthcare needs and these are not well met by the National Health Service [NHS] (Michael, 2008). Individuals with intellectual disabilities have more physical health problems (Cooper et al., 2015; Disability Rights Commission [DRC], 2006) and a significantly increased mortality rate (Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998) which in part arises from healthcare inequalities, a lack of accessible information and other preventable factors (King, 2011; MENCAP, 2012).

Adults with intellectual disabilities are less likely to be employed and more likely to be receiving welfare benefits than the general population (Einfeld et al., 2011; HM Government, 2001). Secondary handicaps of intellectual disability such as learned helplessness, where an individual's learning is impaired by negative perceptions about the future and poor motivation (Gacek, Smoleń, & Pilecka, 2017), and a lack of opportunities to develop skills also impact on individuals' ability to function optimally in society (Sinason, 1992).

Recent debates have questioned the helpfulness of dividing individuals (and hence society) using the presence or absence of a degree of intellectual disability. The fact that diagnoses may be based on inaccurate or arbitrary psychometric testing and that the population thus defined is heterogeneous has served to fuel the debate. The situation is made worse by the fact that health and social care resources are not unlimited and can force services into making diagnostic decisions about intellectual disability under the influence of shifting criteria which aim to control access to specialist services, and so contributing to secondary handicap (Sinason, 1992). In these circumstances shifting focus away from a deficits-based standpoint and towards a recognition of strengths and functional abilities offers the hope of a more holistic understanding of each individual and of their capacity for skill development (Hutchinson, 1995; O'Brien, 2001; Oliver, 1998). An outline of the evidence relating to the mental health needs of the general population, followed by more specifically for individuals with intellectual disabilities, will be outlined in the following sections.

1.2 DEFINITION AND IMPACT OF COMMON MENTAL HEALTH PROBLEMS IN THE UK PRE-IAPT:

Forty percent of all disability is attributed to depression and anxiety (WHO, 1992), both of which have been shown to have a significant impact on an individual's ability to function (Moussavi et al., 2007). The Office for National Statistics estimated that in 2000 six million adults in the UK were suffering from depression and anxiety disorders (Singleton, Bumpstead, O'Brien, Lee, & Meltzer, 2000). Most of these went untreated (Mental Health Policy Group, 2006), partly due to difficulties in accessing psychological intervention. Those who did seek help were usually offered a purely pharmacological intervention (Mental Health Policy Group, 2006), despite evidence and consistent best practice guidance that recommended talking therapies, either alone or in conjunction with medication, as the best treatment plan (National Institute of Clinical Excellence [NICE], 2009, 2011).

The personal and societal burden of depression and anxiety disorders in the UK are well established (Layard, Clark, Knapp, & Mayraz, 2007; Mental Health Policy Group, 2006; Secker, 2009) and the overall cost of depression in England was estimated to be £9 billion in 2000 (Thomas & Morris, 2003). Mental illness is also associated with personal costs including increased distress (Mental Health Policy Group, 2006), reduced life expectancy (Sainsbury Centre for Mental Health [SCMH], 2003), lower employment rates (Social Exclusion Unit, 2004), housing issues (Bassuk, Buckner, Perloff, & Bassuk, 1998; Jones, 2005; Shelter, 2007), increased debt and breakdown of personal relationships (Meltzer et al., 2002). Effective treatment for mental health problems has a positive impact on the health and employment of individuals by mitigating these personal costs (Layard et al., 2007) and promoting their emotional wellbeing. The wider societal gains associated with recovery from mental ill health are confirmed by cost-benefit analyses which highlight a reduction in welfare benefits

expenditure, increased employment retention (Layard et al., 2007), reduced service demands and fewer repeat prescriptions for medication (Lanyard et al., 2007; SCMH, 2003). The disparity between the impact of common mental illness on society and expenditure on services (Mental Health Policy Group, 2006), along with evidence of the effectiveness of discrete interventions such as Cognitive Behavioural Therapy [CBT] (NICE, 2009; NICE, 2011) prompted the UK government to invest in first line services offering high quality, evidence based treatments (HM Government, 2011).

1.3 STRUCTURE OF PSYCHOLOGY SERVICES IN ENGLAND:

IAPT is an NHS initiative to improve accessibility to evidence-based, routine psychological treatments for anxiety disorders and depression in primary care services in England. The implementation plan aimed to improve access to NICE approved psychological treatments (DoH, 2008a) which have demonstrated effectiveness for patients. Launched in 2008, the plan initially targeted working aged adults, but was extended to children and young people in 2010 and adults of all ages by 2015. IAPT represented a key part of the government's strategy to promote recovery from common mental health problems by providing timely access to high quality psychological interventions. IAPT implements a '*stepped care*' approach (Turpin, Richards, Hope, & Duffy, 2008) which provides the least restrictive NICE-compliant intervention to facilitate each service user's recovery (NDTi, 2011). IAPT also provides signposting on such key issues as employment support and debt management.

National guidelines clearly state that public services should be both inclusive (HM Government, 2009) and fair (HM Government, 2011). In pursuit of this statutory requirements embodied in the Equality Act require services to make provisions to safeguard

individuals with nine '*protected characteristics*' against inequality. The characteristics specified include race, disability and age (HM Government, 2010). Providing this more equitable access to mainstream services and informing and giving service users and carers a voice in the decisions which shape policy has led to consultation at both local and national levels. A key principle of this government strategy for the improvement of the mental health of the population has been the empowerment of local services. These have thus been allowed wider choices and greater flexibility when seeking to provide equitable and inclusive access to evidence based psychological treatments (DoH, 2010a). Services' responsibilities in this area constitute a clear legal obligation to ensure that individuals with protected characteristics do not face inequality in access (HM Government, 1995, 1998, 2010), treatment or outcome (HM Government, 2011). Improving equitable access to services is facilitated by services identifying and implementing '*reasonable adjustments*' (DoH, 2008c; HM Government, 2010). *Reasonable adjustments* must anticipate and take into account specific characteristics of protected groups and offer flexibility in such matters as service delivery, staff training and local policies. It is important to recognise that many service users who do not meet diagnostic criteria for intellectual disability but present with some degree of cognitive impairment which may present as difficulty in basic literacy skills or understanding new information, also benefit from the implementation of such reasonable adjustments to access support from services (Dagnan, 2015). IAPT has a mechanism in place to identify and flag patients who are thought to benefit from the implementation of reasonable adjustments (Foundation for People with Learning Disabilities, 2015), which encompasses service users with and without a formal diagnosis of intellectual disability.

Monitoring outcomes is key to the mental health strategy (HM Government, 2011) and IAPT operationalises this via completion of these on a session by session basis (NDTi, 2011) which ensures that data is collected even when patients drop out mid-way through treatment. The minimum dataset data conforms to an NHS '*National Information Standard*' and has a number of important functions: it is, for example, used nationally to track service performance (Clark & Oates, 2014) and locally to improve service delivery, demonstrate the effectiveness of clinicians and promote collaborative treatment planning (NDTi, 2011). The minimum dataset comprises of self-report clinical measures for depression using the Patient Health Questionnaire (PHQ-9; Kroenke, Spitzer, & Williams, 2001), anxiety using the Generalised Anxiety Disorder questionnaire (GAD-7; Spitzer, Kroenke, Williams, & Löwe, 2006), a screening questionnaire for specific phobias and an adjustment scale for work and social issues (Mundt, Marks, Shear, & Greist, 2002). Other assessments include employment status questions, patient experience questions and specific established disorder specific clinical measures where these are appropriate (NDTi, 2011). As a minimum, services must collect the PHQ-9 and the GAD-7 for at least 90% of service users who access treatment (NDTi, 2011) and these measures have been translated into several languages, including Arabic, Polish and Urdu, to improve accessibility for service users. These measures are typically completed independently by service users either online or in the waiting room before each appointment. The PHQ-9 and GAD-7 are brief self-administered measures where items connected to the diagnostic criteria (APA, 2015) are scored on a zero to three Likert scale covering the last two week period ('*not at all*', '*several days*', '*more than half the days*' and '*nearly every day*'). Clinical cut off scores and statistically reliable change are suggested and implemented by IAPT; PHQ-9 = 10, ≥ 6 ; GAD-7 = 8 ≥ 4 (IAPT, 2012; Spitzer, Kroenke, Williams, et al., 1999). These measures are well established and have demonstrated psychometric properties, both

in general (Kroenke et al., 2001; Löwe et al., 2008; Spitzer et al., 2006) and specific populations such as adults receiving treatment for substance misuse (Delgadillo et al., 2012), English and Spanish speaking Latinas (Merz, Malcarne, Roesch, Riley, & Sadler, 2011), British Sign Language users (Rogers et al., 2013;) and Portuguese speakers (Sousa et al., 2015), but not currently for individuals with intellectual disabilities. IAPT '*Key Performance Indicators*' [KPIs] include a measure of recovery which evaluates change in clinical measures as when service users move from above to below a clinical cut off score on each standardised clinical measure or when they produce a statistically reliable reduction in scores which exceeds the measurement error of the questionnaire (NDTi, 2011). The IAPT KPI target for recovery is 50% (NDTi, 2011), based on the '*NHS Mandate Commitment*' (DoH, 2015) and approaching the levels obtained in randomised controlled trials [RCTs] which form the basis of NICE recommendations. This data collection facilitates the monitoring of service equality and inclusion success by measuring adherence to the target of access to services by 15% of the local adult population with common mental health problems (NDTi, 2011).

1.4 MENTAL HEALTH AND INTELLECTUAL DISABILITIES:

Identifying mental health problems in intellectual disability populations can be challenging, due to a range of factors including a lack of standardised clinical assessment tools for this population and a lack of specialised training for professionals and researchers (Irvine & Beale, 2016). Clinical identification is also difficult as individuals with intellectual disability do not always conform to mainstream diagnostic definitions of mental ill-health and so diagnosis often requires indepth clinical assessment (Hermans & Evenhuis, 2010) and those supporting the individual have a crucial role to play in recognising symptoms and facilitating access to assessment (Costello & Bouras, 2006).

Despite these challenges, high rates of mental health problems have been found within intellectual disability populations (Cooper et al., 2015; Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Deb, Thomas, & Bright, 2001; Reid, Smiley, & Cooper, 2011; Taylor, Hatton, Dixon, & Douglas, 2004). Widely differing prevalence rates are reported, and these have been attributed to methodological issues: the use of differing criteria to assess the presence of intellectual disabilities and mental health problems across different studies (Cooper et al., 2007); differing population samples; and/or the case finding methods used (BPS, 2016). The largest UK based population study utilised comprehensive best practice assessment by trained clinicians and this indicated that 40.9% of the sample of 1023 adults with intellectual disabilities presented with mental health problems (Cooper et al., 2007). As in the general population, depression (Cooper et al., 2007) and anxiety disorders (Emerson & Hatton, 2007; Reid et al., 2011) are two of the most prevalent mental health problems experienced by people with intellectual disability. Some individuals with intellectual disabilities display more than one comorbid mental health problem, with 11.6% (n=119) meeting criteria for two or more clinical diagnoses in Cooper and colleagues' sample (2007). Both increased levels of incidence and longer term episodes were shown to account for the greater prevalence of mental ill health within a large cohort intellectual disabilities population sample assessed longitudinally over two years (Smiley et al., 2007). There is evidence that most comorbidities remain untreated for individuals with intellectual disabilities and that this is because many clinical measures struggle to detect mental health problems in this part of the population. Too often symptoms of mental ill health are attributed to an individual's intellectual disability, or '*diagnostic overshadowing*' (Reiss, Levitan, & Szyszko, 1982), especially when individuals exhibit behaviour which presents a challenge to others (Moss et al., 2000). Additionally it

remains unclear whether individuals with intellectual disabilities present with symptoms of mental health problems which are consistent with the phenotypes exhibited by the general population. In this context it is important to note that atypical presentations in adults with mild and severe intellectual disability have been reported in the literature (Meins, 1995). Of note however, is that given such high rates of mental health problems in people with intellectual disabilities, it follows from this this group may well have increased need for intervention.

1.5 HISTORICAL CONTEXT OF ADULTS WITH INTELLECTUAL DISABILITIES ACCESSING PSYCHOLOGICAL INTERVENTION:

In the past adults with intellectual disability have been exposed to iatrogenic injury by psychologists and other professionals; it is well documented that prior to the 1960s individuals with intellectual disability were viewed as immoral social degenerates. In consequence they were routinely confined to asylums, segregated from the wider community in a context of disempowerment and inequality (Baum, 2006). Medical professionals actively aimed to eradicate intellectual disability from the human genome by preventing adults with intellectual disabilities from reproducing using medical and social means. In these circumstances the 1971 White Paper '*Better Services for the Mentally Handicapped*' (DoH, 1971) was of crucial importance. It prompted a shift in thinking about the intellectual disability population, particularly in urging that whenever possible individuals should be helped to integrate with the general population and to lead more active and meaningful lives. Even so, the voices of adults with intellectual disabilities are often subjugated or ignored (Webb-Peploe & Fredman, 2015) and this population remains largely overlooked or excluded from talking therapies (Arthur, 2003). Too often researchers overlook the need to robustly

investigate the effectiveness of psychological interventions (Irvine & Beale, 2016). Bender (1993) posits that therapists' neglect of adults with intellectual disability derives from experiences of *'therapeutic disdain'* arising from a distaste for intimate therapeutic relationships with clients who they perceived as unattractive. Reductionist views permeated the psychological field and difficulties experienced by individuals with intellectual disabilities were presumed to be mediated by organic or environmental factors, an emphasis which focused on behavioural approaches (Stenfert-Kroese, 1997) thus neglecting the emotional experiences of those affected (Irvine & Beale, 2016). I am always shocked by just how recent these views and service structures are in the history of mental health services; it was really not very long ago that mental health problems in the intellectual disability population were accepted as non-pathological and so not requiring intervention. This is particularly striking when compared to the current structure of mental health services for people with intellectual disability in the UK. This at last promotes equality of access to appropriately adapted evidence based interventions across a wide range of talking therapies.

1.6 EFFECTIVELY TREATING MENTAL HEALTH PROBLEMS OF ADULTS WITH INTELLECTUAL DISABILITIES:

The evidence base for applying psychological intervention to the intellectual disability population remains under-developed in comparison to other populations; a situation arising from the historical context detailed above. Methodological limitations in the current research base such as small sample sizes and control groups (Sams, Collins, & Reynolds, 2006) have also impacted on the quality of the evidence base for the intellectual disability population (Sturmey, 2012). Additional inherent difficulties are involved in developing and validating effective psychological interventions for adults with intellectual disabilities. For instance,

service related issues and barriers to research arising from ethical issues are significant. The importance of ensuring that participants are able to provide informed consent and practical constraints such as the paucity of psychometrically sound clinical measures for this population offer clear examples of this. Treatment as usual groups within the intellectual disability population typically consists of community intervention with visits from professionals no more than once a week but the nature and delivery of interventions varies considerably between services (Oliver et al., 2002), which complicates the standardisation of routine treatment for randomisation in research. However, evidence for the efficacy of talking therapies for people with intellectual disabilities has been building and has been boosted by a recent increase in the number of meta-analytic and systematic reviews (BPS, 2016). Although the mechanisms by which treatment is successful remain undetermined (Beail, 1998), the impact of the therapeutic relationship is believed to be a significant factor across all approaches (Martin, Garske, & Davis, 2000; Ramsden, Tickle, Dawson, & Harris, 2016). A broad range of psychological approaches have been adapted, with changes made to assessment, formulation and interventions based on the individual needs of the client and their wider social context (BPS, 2016; Chinn et al., 2014; Jahoda, Dagnan, Stenfert Kroese, Pert, & Trower, 2009). Individual prerequisite skills which are crucial for the successful engagement in talking therapies have been identified (BPS, 2016) and must be addressed to enable clients with intellectual disabilities to successfully engage in cognitive therapy (Willner, 2005). These include memory (Hatton, 2002) and the ability to identify and communicate different emotions (Sams et al., 2006), in addition to the suitability criteria applicable to the general population, such as willingness and readiness to engage (Dodd et al., 2010; Willner, 2006).

Currently the evidence base for the transferability of adapted NICE-compliant treatments for individuals with intellectual disabilities and depression or anxiety disorders is limited (BPS, 2016; Chinn et al., 2014; Dagnan & Jahoda, 2006; Jahoda, Dagnan, Jarvie, & Kerr, 2006). The practical obstacles facing such studies of the intellectual disability populations are considerable and only a few small scale RCTs have been completed (Hatton, 2002; Oliver et al., 2002; Willner, 2005). Additionally, much of the research completed does not discriminate between the presentation of different anxiety disorders, instead using broad classifications (Dagnan & Jahoda, 2006) which severely limit the evidence base for specific anxiety disorders in intellectual disability populations. However, some consistency has been found between the intellectual disability and general populations, with the role of triggering life events and the mediating and cognitive processes associated with common mental health problems providing important examples (Chinn et al., 2014; Dagnan & Sandhu, 1999; Dagnan & Waring, 2004). Initial quantitative enquiry suggests that similar use of appropriately adapted CBT, where adaptations are made to the delivery of the intervention due to the particular cognitive and communication difficulties associated with intellectual disabilities (Jahoda, 2016), may effectively treat depression and anxiety disorders in this population (Hassiotis et al., 2012; Hatton, 2002; Lindsay, 1999). Vereenoghe and Langdon's (2013) recent meta-analysis included 14 intervention studies and provides evidence of the efficacy of CBT in treating anger and depression in adults with intellectual disability but gives insufficient evidence for other therapeutic approaches or for the treatment of younger people with intellectual disability. Positive outcomes for adapted CBT for depression, both directly administered by clinicians (McCabe, McGillivray, & Newton, 2006) and ones administered by staff members (Lindsay, 1999; McGillivray, McCabe, & Kershaw, 2008), have been shown post-intervention and maintained at follow up on self-report measures of depression and anxiety compared to

waiting list controls. Interestingly, it is hypothesised that CBT efficacy for this population may result from a cognitive deficit model which focuses on techniques for improving self-management of symptoms (Beail, 2003; Willner, 2005) rather than from the cognitive distortion model on which CBT is traditionally based (Beck, Rush, Shaw, & Emery, 1979). Thus although emotional difficulties in the general population are attributed to biased ways of thinking about the self and the world, for people with intellectual disabilities it is presumed that any presenting emotional difficulties are caused by their cognitive deficits, resulting in a different approach to intervention. Furthermore, concerns have been raised that clinicians engaging clients with intellectual disability may commonly violate core assumptions of CBT by neglecting to explore the client's internal experiences and not engaging in a truly collaborative relationship (Stenfert-Kroese, 1997). If sustained, this hypothesis would further undermine the evidence base. Evidence about the clinical and cost effectiveness of adapted CBT interventions for depression and anxiety in individuals with intellectual disabilities requires further investigation. Such investigations would need to acknowledge concerns raised about the methodological integrity of some of the RCTs conducted within this population. It is important to stress that the current lack of sufficient evidence for the effectiveness of interventions does not equate to evidence of ineffectiveness. Services and clinicians should thus not be deterred from providing and adapting interventions shown to be effective in the general population.

1.7 PSYCHOLOGY SERVICES WORKING WITH ADULTS WITH INTELLECTUAL DISABILITIES:

Over the past few decades community services have expanded in response to a change of direction in national policy. As a result, specialist local intellectual disability services now exist,

though these usually have high access thresholds and most specifically aim to provide targeted support for individuals with moderate to severe intellectual disabilities. Those with intellectual disabilities who are able to access mainstream services such as IAPT are entitled to do so via the implementation of *reasonable adjustments* appropriate for their needs. This may involve in session adaptations such as simplified formulations, or arise at a wider service level by allowing more treatment sessions (Dodd et al., 2010). IAPT services implement reasonable adjustments based on the needs of the local population and so availability and quality vary between providers (Chinn et al., 2014). These providers are themselves often dependent on the values of clinicians, managers and commissioners (Leyin, 2011). Guidance and support for services to help them anticipate, audit and implement local reasonable adjustments have been developed (DRC, 2006; IAPT, 2009; NDTi, 2016; Royal College of Psychiatrists, 2012). Good practice is actively promoted, as in the following published examples: the development of care pathways (Radcliffe, O'Connor, Pollard, & Coopoosamy, 2011); specific training for staff (Michael, 2008); specialist supervision for 'IAPT LD Champion' clinicians, who work with service users who require reasonable adjustments and joint working between specialist intellectual disability services and IAPT (Heneage, Dhanjal, & Morris, 2009; NDTi, 2012; Theodore et al., 2015); and involving carers to support intervention (Chinn et al., 2014; Goodey & Stirk, 2014).

Despite this, adults with intellectual disabilities still face marked inequalities when accessing healthcare treatment (DoH, 1999; DRC, 2006) and remain under-represented in mainstream psychology services (DoH, 2012) with approximately 20% being known to services (Dagnan, 2015). Individual factors contribute to this discrepancy such as the attitudes and structures of society which impose restrictions on accessibility (IAPT, 2009), the existence of an external

locus of control where individuals perceive that events in their life are controlled by others rather than themselves (HM Government, 2001), and contextual factors at the local and national level such as policies and procedures relating to length or number of sessions offered (IAPT, 2009). The complex interplay between potential service users in vulnerable population groups and the services themselves are highlighted by the construct of '*candidacy*' (Chinn & Abraham, 2016; Chinn et al., 2014; Dixon-Woods et al., 2006) which sees an individual's eligibility to access a service as 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*" (Dixon-Woods et al., 2006, p35). Specific characteristics of the intellectual disability population which impact on candidacy negotiations with IAPT services have been highlighted here. These include requiring support from the wider system to identify the need for intervention for mental health problems and to navigate service pathways (Chinn & Abraham, 2016; Chinn et al., 2014).

The ability of IAPT services to implement successful anticipatory *reasonable adjustments* for individuals with intellectual disabilities is attributed to a supportive and reflective service culture (NDTi, 2016); to higher levels of support from specialist intellectual disability services providing consultation around accessible resources; to ongoing supervision for staff; and to the involvement of individuals with intellectual disabilities (Chinn et al., 2014). Data monitoring is also key; services are required to use the demographic and epidemiological data that they record to assess uptake and provide appropriate treatment for their local intellectual disability population (IAPT, 2009). The effectiveness with which mainstream services provide flexibility and reasonable adjustments which recognise and address the

barriers faced by individuals with intellectual disabilities varies and improvement is essential (Chinn & Abraham, 2016; Chinn et al., 2014; DRC, 2006; Leyin, 2011; NDTi, 2012). Greater consistency in comprehensively and systematically self-auditing their pathways and making required changes in order to provide equitable access is required (Chinn & Abraham, 2016; NDTi, 2016). The development of valid, reliable and accessible service user materials and clinical assessment measures and interventions is important here. (Chinn et al., 2014; IAPT, 2009; NDTi, 2012).

1.8 CHALLENGES IN ENGAGING INDIVIDUALS WITH INTELLECTUAL DISABILITIES WITH MAINSTREAM HEALTHCARE SERVICES:

A range of facilitators and barriers for adults with intellectual disabilities seeking to access support from mainstream services has been identified using qualitative enquiries addressed both to professionals and clients. Addressing the issues facing individual clients was of particular importance here and external factors and intra-personal factors such as the therapeutic relationship were amongst those considered (Ramsden et al., 2016). Overall cognitive ability has been considered as a factor aiding or inhibiting an individual's capability to engage successfully with the conceptual knowledge involved in treatment (Sams et al., 2006). It follows from this that an individual's cognitive capacity to acquire and sustain therapeutic gain could be used to assess suitability for intervention.

Most people with intellectual disability have deficits in expressive and/or receptive communication skills. This provides a salient example of the impact of cognitive deficit and important work has been done in this area. A positive correlation between verbal ability and treatment efficacy for people with intellectual disability has been clearly identified (Rose,

Loftus, Flint, & Carey, 2005). The average reading comprehension ability of adults with mild and borderline intellectual disability is estimated to be comparable to that of a six to eight year old in the general population. Such individuals need more time to read simple written information, make more reading errors and recall information less accurately than others (Karreman, van der Geest, & Buursink, 2007). Communication impairments impact on an individual's ability to access and share information through multiple mediums and this makes accessing psychological intervention difficult. Such access requires an understanding of assessment questions, sharing relevant information, co-developing formulations and processing written information. Since 2016, NHS services in England are legally required to provide written information in various forms, including healthcare leaflets, letters and clinical outcome measures, in a format which are easily accessible for all (NHS England, 2015). Producing written information in a format which is easy to read is thus a major issue and there is some evidence that 'easy read' formats is effective for people with intellectual disabilities (Karreman et al., 2007). The importance of facilitating an understanding of healthcare decisions and informed consent procedures for adults with intellectual disabilities is often stressed (DoH, 2001, 2003, 2010b) and is advocated by service users (Strydom & Hall, 2001). Guidelines for producing easy read documents recommend using short simple sentences with no jargon, text styles which are clear to read, bullet points or boxes to separate points and adding pictures to the left of text which are aligned with the message (DoH, 2010b; MENCAP, 2008). Visual cues can be in a variety of forms, with photographs representing the most accessible for all with intellectual disabilities due to their ability to represent objects concretely, but those with milder impairments are able to employ higher cognitive skills to decode the meanings of line drawings or symbols (Dixon, 1981; Sevcik & Ronski, 1986; Stephenson & Linfoot, 1996). However, it remains unclear whether such recommendations

for the structure of easy read documents is based on evidence (Fajardo et al., 2014) or how compliance can be objectively assessed (Sutherland & Isherwood, 2016). Sutherland and Isherwood's (2016) systematic literature review reveals that the publication of easy read documents aimed at the intellectual disability population is now common practice and there is some evidence that adding visual cues to support the understanding of simple text is helpful (Jones, Long, & Finlay, 2007). Nonetheless problems remain. Even information presented in a style intended to be accessible is not always easy for people with intellectual disabilities to understand, particularly if the reader is overburdened with too much colour, text or abstract visual cues (Buell, 2015; Hurtado, Jones, & Burniston, 2014; Sutherland & Isherwood, 2016). Some evidence suggests that readers with milder intellectual disability may find pictures alone more effective in supporting understanding as this does not require splitting attention between pictures and text, and those individuals with a higher reading ability may not require the visual cues to support understanding of the text (Hurtado et al., 2014). A meta-narrative literature review suggests that individually adapted information is more effective in providing information to people with intellectual disabilities (Chinn & Homeyard, 2016) and it is recommended that easy read documentation be carefully evaluated to ensure that its aims are met (Buell, 2015; Sutherland & Isherwood, 2016) and to ensure that readers' *"cognitive gain outweighs [their] efforts"* (Buell, 2015, p. 89).

External factors and individual deficits in functional skills associated with intellectual disability also impact on the accessibility of healthcare services for this client group. People with intellectual disability require additional support from others, both carers and professionals. Any deficiencies in this regard can make it difficult for individuals to engage with services for reasons as simple as being unable to travel to appointments or to contact the service to

rearrange sessions. Indeed, the importance of the role of a facilitator to support understanding of easy read documents is highlighted by Walmsley (2013), including the facilitators' need for clarity and information to enable them to answer questions to optimise client comprehension and support complex needs (Jones et al., 2007; Sutherland & Isherwood, 2016).

Clinicians report positive attitudes and a willingness to work with clients who have intellectual disabilities, but highlight their need for more support and training if they are to optimise the quality of interventions (Shankland & Dagnan, 2015). Individual therapists' characteristics and perceptions regarding working with individuals with intellectual disabilities have been shown to have an impact on treatment outcome. Lower confidence and enjoyment in therapeutic work results in poorer outcomes both in short-term therapy and in the longer term (Heinonen, Lindfors, Laaksonen, & Knekt, 2012).

1.9 CHALLENGES RELATING TO THE USE OF CLINICAL MENTAL HEALTH MEASURES WITH ADULTS WITH INTELLECTUAL DISABILITIES:

Many of the difficulties associated with people with intellectual disabilities accessing support from healthcare services outlined above are also relevant to the use of clinical outcome measures with this population. This includes difficulties with reading, writing, memory impairments and expressive communication. Despite this, it remains important to use clinical outcome data to inform clinical effectiveness for these service users at an individual, service, population and wider policy level. As in other populations, routinely measuring symptomatology of common mental health problems is a recommended part of clinical assessment (Skelly, 2016). The literature base dealing with the internal experiences of people

with learning disabilities is very poor (Hatton, 2002) and many of the clinical outcome measures relating to this population of necessity focus on the behavioural phenotype of mental ill-health (Cooper et al., 2007). This predominance of third party reporting on clinical measures contrasts with the position in other populations, where self-report measures are very widely employed. Because of this the symptoms associated with the mental health problems of people with intellectual disabilities may well not be fully understood. This situation is made worse when, as sometimes happens, it is assumed that the phenotype for this population is similar to that for the general population, though this is not necessarily the case. For example, it is not always possible to identify key internal cognitive symptoms of depression in people with intellectual disabilities, such as reduced confidence or unwarranted guilt (Marston, Perry, & Roy, 1997) whereas external behavioural symptoms such as increased irritability have been linked to high depression in this population (Marston et al., 1997; Matson et al., 1999; Moss et al., 2000).

1.10 EXISTING CLINICAL MEASURES WHICH ARE USED WITH ADULTS WITH INTELLECTUAL DISABILITIES:

At present there are no 'benchmark' clinical measures for the intellectual disability population and existing measures vary in design, target population and demonstrated psychometric properties (Hatton & Taylor, 2013; McGurk & Skelly, 2014). A range of self-report and third party rated clinical measures covering a wide range of mental health problems have been specifically designed for use with adults with intellectual disabilities, though many of these were generated using small sample sizes and have limited psychometric validation and scale comprehensiveness (McGurk & Skelly, 2014). Within intellectual disability populations the reliability and validity of adapted outcome measures is optimised when adaptations simplify

the language and response choices used and make concepts more concrete (Lindsay & Michie, 1988) such by as using pictures (Lindsay, Neilson, & Lawrenson, 1997) or gestures (Dagnan & Chadwick, 1997).

The Clinical Outcomes in Routine Evaluation – Learning Disabilities [CORE-LD] is a commonly used clinical outcome measure (Brooks, Davies, & Twigg, 2013). It was adapted for use with people with intellectual disabilities in an attempt to detect symptoms of general mental ill-health such as sleep problems, withdrawal from others and thoughts of self-harm and suicide. Each of the 14 items is scored on a three-point Likert scale comprising the responses ‘not at all’, ‘sometimes’ and ‘a lot’ alongside supporting visual cues. The CORE-LD covers a wide range of symptoms of mental ill-health and aims to target the specific experience of the emotional impact of living with an intellectual disability, and as such the original measure was adapted to include experiences such as feeling left out and feeling confused. It is intended to be used as a clinical outcome measure which can be used before and following intervention to measure change over time. Comprehensive psychometric testing was completed on the adapted measure with 324 diverse participants from a range of settings who were accessing a range of interventions, 52 at two time points (Brooks et al). This provided some evidence of good psychometric properties of the CORE-LD, specifically good test-retest reliability ($\rho = 0.64$, $R = 0.64$) and adequate levels of internal consistency ($\alpha = 0.83$), but no assessments of validity have currently been completed (Brooks et al., 2013; Vlissides, Golding, & Beail, 2016).

Two of the most established clinical measures developed to assess specific common mental health problems in the intellectual disability population are the Glasgow scales: the Glasgow Depression Scale (GDS-LD; Cuthill, Espie, & Cooper, 2003) and the Glasgow Anxiety Scale

(GAS-ID; Mindham & Espie, 2003). These self-report measures are lengthy and are scored on a three point Likert scale comprising the responses '*never*', '*sometimes*' and '*always*' for symptoms over the past week. For both measures, a clinical threshold of 13 are suggested by the authors, and completion time is estimated to be ten to 15 minutes for the GDS-LD (Cuthill et al., 2003) and five to ten minutes for the GAS-ID (Mindham & Espie, 2003). Although the authors report that the GAS-ID is easy to use (Mindham & Espie, 2003), the guidance for administrators indicates that a high level of support is often required, with the administrator taking a central role in completion of the measure. The format of the Glasgow Scales is not in line with recommendations for high accessibility to the intellectual disability population (e.g. DoH, 2010b; MENCAP, 2008; Sutherland & Isherwood, 2016). For example, there are no pictures to support understanding of items or responses and there are some inconsistencies in the layouts of the measures, with the GDS-ID requiring respondents to circle their response on the form and the GAS-ID requiring the associated score to be written in each response box. Nevertheless, the GDS—ID has been shown to be a useful clinical tool in the measurement of depression in adults with mild to moderate intellectual disabilities and is recommended as the best currently available self-report instrument (Hermans & Evenhuis, 2010; McGurk & Skelly, 2014; Vlissides et al., 2016). The GDS-LD has demonstrated its status as a high quality clinical outcome measure via good psychometric properties; it is sensitive enough to differentiate between depression and non-depression groups, correlates with the established Beck Depression Inventory (Beck, Steer, & Brown, 1996) ($r = 0.88$), has very good test—retest reliability ($r = 0.97$) and good internal consistency (Cronbach's $\alpha = 0.90$) (Cuthill et al., 2003; Vlissides et al., 2016). The GAS-ID is similarly recommended as the most promising available instrument for measuring anxiety within this population (Hermans, van der Pas, & Evenhuis, 2011; McGurk & Skelly, 2014; Vlissides et al., 2016) and has demonstrated psychometric

properties; it can discriminate anxious from non-anxious participants, has good test–retest reliability ($r = 0.95$) and internal consistency ($\alpha = 0.96$), and correlates quite well with the established Beck Anxiety Inventory (Beck, Epstein, Brown, & Steer, 1988) ($\rho = 0.75$) (Mindham & Espie, 2003; Vlissides et al., 2016). Additionally, the GDS-LD and the GAS-ID have been shown to have clinical utility in assessing recovery (Skelly, 2016).

The majority of clinical measures developed and adapted for people with intellectual disabilities have been validated using small sample sizes (BPS, 2015; McGurk & Skelly, 2014). The GDS was validated using a sample of 38 individuals with intellectual disabilities (Cuthill et al., 2003) and the GAS using a sample of 35 (Mindham & Espie, 2003), with clinical and non-clinical groups in each. It is striking that the ‘gold standard’ measures for this heterogeneous population were established using such small sample sizes. This in itself reflects the current state of the wider intellectual disability evidence base.

Clinical measures developed for the general population are also used with individuals with cognitive impairments, either with (e.g. Lindsay, 1999; Lindsay & Michie, 1988) or without un-standardised and individualised adaptations. As the minimum dataset represents the standard outcome measures used in IAPT, the GAD-7 and PHQ-9 are administered to individuals with intellectual disabilities accessing these services (Chinn et al., 2014; IAPT, 2009; Radcliffe et al., 2011) and other cognitive impairments such as resulting from stroke (Williams et al., 2005) or other age-related cognitive decline (Kroenke, Spitzer, Williams, & Löwe, 2010). However, there is only very limited evidence for the appropriateness of this and clinicians have raised concerns that the items and how the minimum dataset is completed in services require reasonable adjustment. Both the evidence and this researcher’s clinical

experience suggest that these issues currently result in the inconsistent use of minimum dataset measures, with service users with intellectual disabilities accessing IAPT. More support for therapists in administering and using measures with this population is accordingly strongly recommended (Hamilton et al., 2011). Improvements and adaptations are required if common mental health problems in this population are to be monitored effectively and in a way which conforms with IAPT protocols such as KPIs (Lin et al., 2014), and using the existing measures which have been developed or adapted for use with individuals with intellectual disabilities does not allow this. The PHQ-9 and GAD-7 are used within IAPT services nationally to track and monitor recovery data and if these measures are not used with those with intellectual disabilities accessing IAPT, and other clinical measures such as the CORE-LD used instead, these service users may be excluded from national population data regarding the recovery rates of people using IAPT. Additionally the CORE-LD does not specifically target the presentation of depression and anxiety within this population, rather providing a more general screen for the emotional experience of living with an intellectual disability. Both research (Hamilton et al., 2011) and policy (DoH, 2008b) repeatedly highlight the need for adapting the minimum dataset as part of reasonable adjustments designed to allow adults with intellectual disabilities equitable access to mainstream psychology services.

1.11 SUMMARY:

Assessment of mental health problems in intellectual disability populations using self-report clinical measures is well established (BPS, 2015) yet routine outcome measures used in the core IAPT minimum data set are unsuitable for use with clients with intellectual disabilities (Chinn et al., 2014). As yet too little research has considered the advisability or otherwise of using these measures within intellectual disability populations. Adapting the PHQ-9 and GAD-

7 is thought to be clinically important as these measures form the minimum dataset used by many services to track 'recovery' after psychological intervention (DoH, 2008a; Hamilton et al., 2011). At present not having adapted versions of the minimum dataset constitutes a significant barrier for adults with intellectual disabilities seeking equitable access to mainstream services and evidence based treatment. Adapting these is therefore viewed as an important reasonable adjustment for this population (Chinn et al., 2014; IAPT, 2009; NICE, 2016). Existing clinical measures of anxiety and depression for this client group, such as the Glasgow scales (Cuthill, Espie, & Cooper, 2003; Mindham & Espie, 2003), are judged to be unsuitable for use in IAPT services due to their length and to the fact that they do not conform with the minimum dataset measures used to track recovery. This lack of appropriately adapted outcome measures has major repercussions; the PHQ-9 and GAD-7 are used to track recovery and any deficiencies in them may result in individuals with intellectual disabilities not being able to access support from services. This in turn contributes to the frequency and enduring nature of mental health problems in this population (Cooper et al., 2015, 2007; Deb et al., 2001; Reid et al., 2011).

1.12 DEVELOPMENT OF VERSION 1 OF THE ADAPTED MEASURES:

Adapted GAD-7 and PHQ-9 measures have been created which address several of the concerns around the format of the original measures for use with people who require the implementation of reasonable adjustments to access support from IAPT services. The changes came in response to the widespread difficulties experienced by services seeking to use the standardised formats with clients with intellectual disabilities. Both an 'intellectual disabilities champion' working in an IAPT service and clinical psychologists involved with a local specialist intellectual disabilities service devised the adaptations on Version 1 of the adapted measures

which were used in Stage 1.1. These resulted in the following key changes compared to the original versions of the measures used in IAPT services: spacing out the questionnaire to two items per page; adding pictures to provide visual support cues to the individual items and scoring response options; and simplifying the language used in the questions. The initial versions of the adapted measures used in the first stage of the current study can be seen in Appendix 1. Initial feedback on these adapted measures was informally sought from clinicians with differing intellectual disabilities specialisms in the field of Speech and Language Therapy, Psychology and from a small number of service users.

The authors of the original PHQ-9 and GAD-7 measures have given permission for the development of adapted versions of these measures for adults with intellectual disabilities in the current study.

1.13 THE PRESENT STUDY:

It is important to maintain high standards of research comparable with those obtained in the wider literature base if important gaps in our understanding of this specific population sample are to be filled. This involves applying and adapting high quality methodologies in order to contribute to the evidence base for the intellectual disability population and support equitable access to appropriately adapted evidence based interventions. In line with this, the current research project aimed to provide an initial validation of adapted versions of the PHQ-9 and GAD-7 measures including consideration of their application and of whether service users with intellectual disabilities interpret the measures in the way we expect. Key issues included the overall acceptability of the measures and administrative needs and challenges, including how far participants understand and can make use of the two-week time period.

Prior to this research project, no systematic investigation the validity of these adapted measures had been completed, though they have been piloted with service users with intellectual disabilities and anecdotal evidence suggests that they are useful. This project therefore aims to determine if these adapted measures address the main concerns raised about the original PHQ-9 and GAD-7 and assess whether there is evidence that they are appropriate for use with this population.

The primary research aim of this study was to determine if there is preliminary evidence that the adapted PHQ-9 and GAD-7 measures are appropriate for use with adults with intellectual disabilities, using cognitive interviewing methodology. Participants completed a structured interview with a researcher which explored their views about the structure and content of the adapted measures. Recommended modifications to the adapted measures were implemented by the research team with reference to the relevant literature, with further interviews completed with a smaller number of participants to determine if these proposed changes are helpful. An initial step for assessing the appropriateness of a clinical measure for a population was empirically investigating the soundness of the psychometric properties of the measure (Kraus & Castonguay 2010) via reliability and validity (Beck et al., 1988). Thus a second research aim was to assess if initial psychometric investigations support the adapted measures are useful and valid for measuring symptoms of anxiety and depression in adults with intellectual disabilities. This involved participants completing the adapted measures along with established clinical measures for depression [GDS-LD] and anxiety [GAS-ID] for intellectual disability populations.

1.12.1 RESEARCH QUESTIONS:

1. Does cognitive interviewing suggest that there is evidence to indicate that the adapted PHQ-9 and GAD-7 measures are appropriate for use with adults with intellectual disability?
2. Does cognitive interviewing highlight any recommended modifications to these adapted measures and are these helpful?
3. Do initial psychometric investigations support the adapted measures as helpful for assessing symptoms related to depression and anxiety in adults with intellectual disability?

CHAPTER 2: METHODOLOGY

2.1 STUDY DESIGN:

This project aimed to determine whether adapted versions of clinical measures for depression (PHQ-9) and anxiety (GAD-7) are appropriate for use with intellectual disability populations. The issue is of great importance: nationally the two measures provide the standard session-by-session questionnaires used by many psychology services and by most IAPT services to monitor outcomes and track recovery.

The ethos of the study was aligned with the recommendations of a number of recent reports which highlight key areas for future development. (DoH 2008; Foundation for People with Intellectual Disabilities 2015; IAPT 2009).

Guidelines and recommendations detailing best practice for research in intellectual disabilities populations were carefully observed. Special considerations included easy read participant information, consideration of appropriate study design procedures and the development of positive links with specialist services and clinicians.

2.1.1 COGNITIVE INTERVIEWING (STAGE 1):

A cognitive Interviewing approach can be used as a framework for designing and evaluating questionnaire design (Willis, 2005), including the development process for self-administered measures (Schechter, Blair, & Vande Hey 1996). Cognitive interviewing has been shown to be an effective tool with participants with intellectual disabilities (Milne & Bull, 2006),

although there are currently no published examples of how this might be used to evaluate questionnaire design.

The key focus of this study was a preliminary investigation into adapted PHQ-9 and GAD-7 measures to determine their accessibility for individuals with intellectual disabilities. This study employed a concurrent verbal probing cognitive interviewing methodology to investigate if the adapted measures are suitable for use within this population. The benchmarks were those contained in recommendations for good practice (Willis, 2005), but as adapted for the study population.

Given its importance for this study's purposes, the concurrent verbal probing cognitive interviewing method was carefully considered. In Stage 1 it involved immediate probing to identify the sources of any response errors associated with each item of the adapted measures (Priede & Farrall, 2011; Willis, 2005). This was considered the more accessible strategy for participants as it reduced the burden on participants (Willis, 2005) by not relying on an individual's ability to think aloud, by providing structure and by minimising memory processing. On this basis six adults with intellectual disabilities were interviewed about Version 1 of the adapted measures using a Cognitive Aspects of Survey Methodology framework (study Stage 1.1), an established approach for designing and evaluating questionnaire design (Willis, 2005). A four stage model (Tourangeau, 1984) outlines the key cognitive steps necessary if respondents are to answer questions successfully. These are as follows: comprehending the question, retrieving relevant information from memory, completing judgement and estimation processes, and mapping the response. By breaking down the process of comprehension into these discrete and measurable stages this model

makes it much easier to identify the source of errors should they appear in an individual's response to a specific question. The evidence thus produced provides a basis for judging how far a measure is valid for use with a particular population. This use of cognitive interviewing to psychometrically investigate clinical measures has particular value when they are at an early stage in development and optimal effect is best achieved using multiple rounds of interviewing (Willis, 2005). The basic structure of concurrent verbal probing methodology is described by Willis (1999, p. 51) in the following terms:

“a) the interviewer asking the survey question, b) the subject answering the question, c) the interviewer asking a probe question, d) the subject answering the probe question, and e) possibly, further cycles of (c-d)” (p7).

During cognitive interviews, the interviewer primarily focuses questions on the measures with a particular emphasis on how well the target document has been understood. They are thus primarily interested in finding problems. Guidelines accordingly recommend that an interview schedule be prepared in advance, be based on an anticipation of potential response errors and include carefully considered probe questions aimed at these potential problem areas (Willis, 2005). The cognitive interviewer must also, of course, be prepared to use reactive probes triggered when participants describe unanticipated areas of difficulty. It is estimated that cognitive interviews can last for anything from fifteen minutes to two hours (Hunter & Hughes, 2003).

Cognitive interviewing protocols were not devised for use with intellectual disability populations and have only rarely been applied to them. Any attempt to use the cognitive interviewing approach therefore involves adjustments if participants are to engage with the

process successfully. The adjustments made for the purposes of this study included strategies used in other contexts and found to be helpful for engaging and interacting with individuals with intellectual disabilities. Amongst these were ensuring that questions and probes use concrete and simple language; using appropriate pacing; allowing enough time for comprehension and communication of responses; frequent checks on participants' understanding; and providing opportunities for regular breaks. The interview schedule (Appendix 2) involved presenting the adapted measures to participants in the same way they would be administered clinically (i.e. as printed copies) but then immediately administering cognitive interviewing questions about comprehension and the response process. Key examples of these questions included *'What do you think this question is asking about?'* and *'How hard was this question to answer?'*. Accompanying probes included *'What made it easy/difficult?'* and *'Would another picture/word help more?'*. In this way the participant's understanding of individual items and scoring options was monitored. 'Think aloud' cognitive interviewing techniques were not employed as a core part of the cognitive interviewing schedule on the basis that this was judged to require higher level cognitive skills likely to create difficulties for some participants with intellectual disabilities. However, such responses were encouraged using functional remarks and feedback probes whenever participants produced them spontaneously. Feedback about the overall presentation of the measures was also sought from participants and this was used to inform the development of improved adapted versions of the measures.

The results produced by this process were used to make reasonable adaptations to the measures, termed Version 2 of the adapted measures; such adaptations were made with due regard to the relevant literature and to best practice guidelines. The modifications thus

produced were trialled with a further seven adults with intellectual disabilities. These were interviewed in a group using the same interview methodology as before with a view to determining whether or not the modifications were helpful (study Stage 1.2) and to evaluating the impact of the easy read modifications made following Stage 1.1. Final adaptations were made based on input from participants in Stage 1.2 in a similar way to before to produce the final versions of the adapted measures (Version 3).

2.1.2 PRELIMINARY PSYCHOMETRIC ANALYSIS (STAGE 2):

The final stage of the study was an exploratory investigation into the initial psychometric properties of Version 3 of the adapted measures to determine if there is evidence that these are valid for use with this population. In order to complete the initial investigations of the psychometric properties of the adapted GAD-7 and PHQ-9, established self-report measures of depression and anxiety designed for intellectual disability populations were administered alongside the adapted measures. The GDS-LD developed by Cuthill, Espie, and Cooper (2003) and the GAS-ID developed by Mindham and Espie (2003) are both recommended as clinically useful for use with this population (McGurk & Skelly, 2014). Stage 2 utilised an initial empirical statistical investigation of the validity and reliability of the adapted PHQ-9 and GAD-7, in line with guidelines for quality appraisal of outcome measures for this population (Vlissides, Golding, & Beail 2016) and was assessed using established benchmarks for outcome measure standardisation (Cahill et al., 2008; Fitzpatrick, Davey, Buxton, & Jones, 1998). The analysis strategy for Stage 2 prioritised the investigation of the attributes which are most relevant to the specific study when the initial psychometric investigation was designed, thus focussing on concurrent validity and internal consistency of the adapted measures. Practical aspects of administering the measure was also explored, both from the perspective of the participants

in Stage 1.1 and from that of clinicians who used the measure in Stage 1.2. Guidelines were developed to standardise the clinical use of the adapted measures and to support clinicians in non-specialist services who might need to use the adapted measures when dealing with service users with intellectual disabilities.

2.2 ETHICS:

2.2.1 RELEVANT APPROVALS:

This study was ethically reviewed by the Proportionate Review Sub-committee of an NHS Research Ethics Committee and was given a favourable opinion with conditions on the 01/04/2016 (ref: 16/YH/0147). Amended documents and a response to the issues raised by the sub-committee were submitted on 07/07/2016 and these were confirmed to meet the conditions. HRA approval was obtained on 19/7/2016 and letters of access to recruiting NHS trust sites was obtained by the beginning of August 2016. Copies of relevant approval documentation can be seen in Appendix 3.

2.2.2 CAPACITY TO CONSENT:

Participants had to be able to give informed consent to participate in the study and accessible information sheets and consent forms were developed to achieve this (see Appendix 4). An adapted informed consent process was employed together with a structured participation process. This included the researcher talking through the accessible information sheet and consent form with potential participants at numerous times before they became involved in the study. The researcher has more than five years' experience working with people with intellectual disabilities. This period of service included conducting capacity assessments in

clinical settings and made the researcher well qualified to assess the point at which the informed consent of the individual participants had been achieved. It was thus part of the study methodology that those incapable of giving informed consent were excluded. Good practice guidelines for seeking consent in research studies (DoH, 2005; NHS Health Research Authority, 2017) and completing research with adults with intellectual disabilities (DoH, 2001, 2010b) were all consulted in the course of the research.

2.2.3 DISTRESS TO PARTICIPANTS:

As the clinical measures in the study cover symptoms related to mental health problems, the possibility that individuals might find participation distressing had to be considered. However, as these measures are adapted versions of originals routinely administered in non-clinical settings (online or in the waiting area of services, for example) both the research team and the ethics committee judged the risk to be minimal. In Stage 1.1 it was thought that the researcher's experience of working clinically with individuals with intellectual disabilities who are sometimes distressed could be utilised should such situations arise and that signposting for further support could be provided. One participant in this initial stage requested further support from psychology services. Information about sources of local support was therefore provided after the cognitive interview, appropriate consent having been obtained. As Stage 1.2 was completed as part of ongoing and routine clinical intervention, the risk of distress was also judged to be well-managed. In the event, no participant was reported as having become distressed because of their participation in the research, although potential emotional distress was highlighted during Stage 1.2 (see Section 3.2.1).

2.2.4 ANONYMITY:

All data was collected anonymously and personally identifiable information was removed before data entry. Each participant was assigned an identification key upon joining the study and thereafter only the researcher was able to identify individual participants. Details of the services recruited to the study were also kept confidential. In these ways no participants were made identifiable by the research.

2.2.5 CONFIDENTIALITY:

All data collected was kept confidential via restricted access; only the research team had access to the raw data. Anonymised data was stored on a password-protected drive at Royal Holloway University, and will be for 5 years. No third party will be informed of any of the data gathered in the study, except for that contained in the overall published results.

2.2.6 AUTONOMY:

A statement in the Participant Information Sheet made it clear that participants were free to withdraw from the study at any time without giving a reason and without consequence. Participants were reminded of this before participating in the study and confirmation of understanding was sought before involvement. The Participant Information Sheet was reviewed before commencing the research in any case where a participant did not clearly remember the document. Participants were given at least 24 hours to decide whether or not to take part in the research.

Participants were not put at risk of harm as a result of involvement in the study. Participation was voluntary and no incentives were offered for taking part. This research did not involve any invasive procedures or the adaptation of participants' normal treatment plans.

2.3 SERVICE USER INVOLVEMENT:

In line with good practice guidelines consultation with service users took place throughout the project (NIHR, 2013). A small budget for this was obtained from Royal Holloway University and two service user consultation sessions were facilitated at two different time points during the study.

Service users who had an interest in supporting research projects in a similar area and who provided initial feedback about the adapted measures were identified by the NHS services involved in the current project. A local intellectual disability self-advocacy group was consulted and became involved in the recruitment, research design and dissemination stages of the project. This included input at the design stage to ensure that the research title was appropriate, the recruitment strategy and materials well planned and participant information sheets and consent forms fully accessible. The group also helped to ensure that the research team addressed an appropriately wide range of questions and provided support in informing other eligible potential participants about how to be involved in the study. Additional consultation and collaboration input at a later point in the research is intended to maximise the accessibility and relevance of the lay summary of the research.

2.4 RECRUITMENT:

2.4.1 SETTING:

Initially, recruitment for the study was intended to take place in an Adult Community Intellectual Disability Service, an IAPT service with an interest in and pathway to increase access for people with intellectual disabilities and a local self-advocacy organisation for service users. The IAPT NHS service had been one of those involved in producing amendments to the PHQ-9 and GAD-7 measures. The changes were intended to make the measures more suitable for use with adults with intellectual disabilities and, as indicated earlier, they were used in this amended form in the first round of cognitive interviewing (Stage 1.1). However, an audit of this IAPT service revealed that very few of their eligible potential participants were currently accessing the service. Recruitment was therefore expanded to two other IAPT services located in the same NHS Trusts as the primary recruitment sites and to two other non-NHS organisations for adults with intellectual disabilities. Only in this way was it possible to reach the recruitment target in the available time period. The relevant NHS Research and Development Departments authorised this recruitment expansion following local service manager approval. The researcher is independent of the recruitment sites and written consent was obtained from relevant service managers before any individuals were recruited to the research (see Appendix 5). Minimal personal information about participants was collected during recruitment.

Recruitment for the first stage of the project primarily took place via the self-advocacy group. Recruitment for the second stage was initially based in the two primary NHS services only. This was based on the assumption that it was most appropriate for participants in Stage 2 to be individuals who were accessing support for psychological and emotional distress. The key

consideration here was the hope that the final adapted measures would prove suitable for use with this population in similar clinical settings. However, as indicated above, a lack of eligible potential participants accessing the IAPT services led to the extension of Stage 2 recruitment to include non-NHS services; this approach was in conformity with the study's ethical approval conditions.

2.4.2 CHARACTERISTICS OF THE SAMPLE:

Inclusion criteria:

- Adults (18+).
- All participants were either known to the Community Learning Disability Team or to specific intellectual disability service user organisations. This meant that either they had a diagnosed global intellectual disability or a 'working clinical diagnosis' of intellectual disability. They were thus accessing support from IAPT and had been noted by the service as likely to meet the criteria for the intellectual disability service or had intellectual difficulties significant enough to require the service to make such reasonable adjustments as were needed to enable them to access psychological therapies.
- Participants all had the capacity to give informed consent with the support of accessible participant information.

Exclusion criteria:

- Participants who were only able to communicate non-verbally.
- Participants who did not speak English.

2.4.3 RATIONALE FOR THE CHOSEN SAMPLE:

The participant inclusion and exclusion criteria were chosen with clinical utility in mind. If the adapted measures developed by the research are to be used by service users who require reasonable adjustments to access adult psychology services, it seemed most appropriate for the chosen sample to reflect this population.

Unfortunately, due to a lack of funding available for the research, it was not possible to include participants who might not adequately understand verbal explanations or written information given in English. With these exclusions it was possible to produce accessible participation information sheets and consent forms designed to meet the specific communication needs of the target population sample of adults with intellectual disabilities

2.4.4 SAMPLE SIZE:

The sample sizes for the current study were determined using the guidelines for good practice established by the literature. Willis (2005) suggests a sample size of five to ten for the first round of cognitive interviewing and up to five for subsequent stages. The sample size for Stage 1 accords with these guidelines. For the development of outcome measures, cost-benefit analysis recommends a sample size of 24 to 36 for studies without a predetermined level of precision for confidence intervals. The target sample size for Stage 2 of the study was thus established at 30 participants.

2.4.5 IDENTIFICATION OF POTENTIAL PARTICIPANTS:

The current study used a supported and layered recruitment strategy with a focus on

potential participants from within the intellectual disability population. Potential participants were identified locally and were not initially directly approached by the research team. For Stage 1 information about the study was shared with staff members who then discussed the project with potential participants, displayed in waiting rooms and disseminated by a local service user self-advocacy group (see flyer in Appendix 6). Potential participants who expressed an interest in being involved in Stage 1 of the study contacted the researcher about the study. The researcher spoke to them by telephone in order to answer questions about the study and to arrange an appointment to complete the research where appropriate. For Stage 2, most potential participants were approached by a clinician from whichever service was currently working with them. These clinicians explained the research to potential participants, usually using the opportunities afforded by their regular psychology sessions. Other participants in Stage 2 who were recruited from non-clinical settings were approached in a similar way to those recruited in Stage 1.

Once appropriate local Research and Development Department and service management approvals had been obtained it was possible for the researcher to engage with the clinicians who were central to the recruitment strategy outlined above. In particular, the researcher attended team meetings and local 'Learning Disability Champions' meetings and discussed the research project with those clinicians most likely to encounter service users with intellectual disabilities. Research packs containing printed research documents were distributed to the services and time was offered by the researcher in support of the recruitment process. Weekly reminder emails were sent to clinicians and services and these bulletins included updates on the progress being made with recruitment. When recruitment remained slow for several weeks, alternative recruitment strategies were employed; these

were the same as those for Stage 1 described above. Local organisations and advocacy groups run for or by adults with intellectual disability were accordingly contacted with information about the study and offered support with recruitment once approval was forthcoming.

Best practice guidance for applying a proportionate approach to the process of seeking informed consent was consulted and adhered to (NHS Health Research Authority, 2017) to reduce the possibility of potential participants becoming overwhelmed. This consideration was of especial importance in that the process was dealing with individuals with intellectual disability. Information about the research was provided via recruitment material in easy read format. This made clear the aims of the study and what it involved, stressing that participation would have no impact on treatment. The researcher was available to discuss the project with services and potential participants as part of the recruitment process, but no undue influence around participation was exerted.

2.5 PROCEDURE:

2.5.1 COGNITIVE INTERVIEWS (STAGE 1):

Formal coding schemes can be used to analyse cognitive interviewing. These make it possible to identify and consider the problems embedded in questionnaires in a way that is both systematic and objective. One such scheme is Willis et al.'s (1999) system which addresses *Communication/Understanding* problems (i.e. issues affecting the encoding process); *Recall/Computation* problems (i.e. retrieval process issues); *Bias/Sensitivity* problems (i.e. issues affecting the judgement process); and *Response Category* problems (i.e. response process issues). Other non-question specific outcomes such as the ordering and overall

burden of the clinical measure for participants can also be analysed using this approach. However, for the purposes of critically evaluating clinical measures and identifying and seeking to remedy questionnaire problems which reduce their validity it is not necessary to complete formal detailed analysis of probed cognitive interviews using such coding schemes (Willis, 2005). Instead the recommended analysis involves compiling qualitative information about the problems relating to meaning, comprehension and communication raised by participants and using this to make necessary changes to specific items (Willis, 2005).

Prior to the start of research the original adapted PHQ-9 and GAD-7 measures intended for use in Stage 1.1 were trialed with a small number of service users with intellectual disabilities. In addition, existing feedback had been gathered from the developers of the original adapted measures. For purposes of thoroughness this feedback was also considered later when the current research project suggested changes to the adapted versions of the measures.

Participants met with the researcher with considerable flexibility offered as to the places, dates and times for appointments.

2.5.1.1 FIRST ROUND OF COGNITIVE INTERVIEWS (STAGE 1.1):

The participant information sheets were read at the beginning of the appointment unless the participant clearly stated that they had read and remembered them. The purpose of the study was briefly recapped and participants provided informed consent to their involvement by completing the accessible participant consent form. A structured cognitive interview was then conducted to explore the participants' views on Version 1 of the adapted clinical measures. Probe questions were administered when needed to explore views about the

structure and content of the adapted measures. Issues such as visual supports, layout and wording were particularly important in this regard. Finally, participants were thanked for their time and an overview of what would happen following the interview was provided. This explanation included brief details about the remaining stages of the research and expressed the hope that adapted versions of the measures would result and be used by psychology services working with adults who have intellectual disabilities. The value of this was stressed so as to confirm to participants the importance of the assistance they had volunteered. Participants were also able to indicate via the accessible participant consent form whether or not they wished to be considered for participation in future stages of the research and/or receive an easy read summary of the findings once the project had been completed.

2.5.1.1.1 PARTICIPANT DEMOGRAPHIC INFORMATION:

Four female and two male participants with intellectual disabilities all with experience of accessing IAPT services were interviewed during Stage 1.1. Table 1 displays the demographic characteristics of the study population of Stage 1.1. They ranged in age from 23 to 61 years (mean = 37.00, standard deviation = 14.01). Two of the participants were mother and daughter and their request for a joint interview with the researcher was acceded to. The request arose from practicalities in that the daughter required her mother's help to travel to the interview location.

Stage 1.1 participants (n=6)	
AGE	
20 - 29	3
30 - 39	1
40 - 49	1
50 - 59	0
60 - 69	1
GENDER	
Male	2
Female	4
IDENTIFIED ETHNICITY	
White British	5
Black British	1

Table 1: The demographic characteristics of the study population of Stage 1.1

2.5.1.2 SECOND ROUND OF COGNITIVE INTERVIEWS (STAGE 1.2):

Following the completion of Stage 1.1, further adaptations were made to the measures based on the information gathered, discussion in research supervision and consideration of the relevant literature and in alignment with the original measures (Version 2). In line with recommendations for best practice in cognitive interviewing, a second round of cognitive interviews was completed with seven participants. These interviews were similar in structure to the ones already conducted and were used to review and interpret the changes to the adapted measures made as a result of research Stage 1.1. Stage 1.2 was completed in a group format with the researcher facilitating discussion using a cognitive interview approach and questioning. The research team made this decision primarily for practical reasons, as significant issues had arisen when contacting participants in Stage 1.1. Arranging appointments to complete interviews proved far from easy and there were a number of cancellations. The project had a tight timescale and it was essential to leave sufficient time

for Stage 2 recruitment. The group format adopted helped to deal with this and it allowed Stage 1.2 to reach completion on 17/1/2017. Following on from the success of the joint cognitive interview in Stage 1.1, it was hoped that completing Stage 1.2 in a group format would have positive virtues as well as practical advantages. For example, it was hoped that in the group situation would participants with intellectual disabilities would feel empowered to share and discuss ideas and make collaborative decisions about recommended changes.

All participants were part of a local service user organisation which is for and run by adults with intellectual disabilities. The organisation aims to improve services by providing training and consultation, to raise awareness of the needs of the intellectual disability population and to provide advice and advocacy. The research had been initially discussed with the group by a manager and service user advocate. Those interested in taking part in the project were invited to a research session which was held on 17/1/2017 and at which Stage 1.2 of the study took place. The participants were well known to each other and had consented to group participation in Stage 1.2 of the research. At the beginning of the session Stage 1.2 was introduced to participants by showing them the original un-adapted versions of the minimum dataset then in use with psychology services. They were then shown the adapted versions discussed in the cognitive interviews conducted in Stage 1.1. An overview of the purpose of Stage 1.2 was given, including letting participants know the types of questions that would be asked and the information that we were looking for. Particular stress was placed on the fact that the primary interest was in any difficulties that participants experienced either in understanding or in using the measure as distinct from the answers elicited by the questions. The three participants who had been involved in Stage 1.1 were encouraged to help in explaining the aims and methodology of the research to the newly recruited participants.

The second stage of the cognitive interviewing process was supported by two staff members of the service user organisation who knew the participants well and were wholly familiar with the research project methodology. Specifically, these staff members helped to ask and reframe cognitive interview questions in a way which could be widely understood by participants. They also supported efforts directed at making sure that all participants had a voice during the group session. Visuals were available directly in front of participants so that they could readily indicate that they wanted to speak, if there was too much jargon being used or if facilitators needed to stop talking and slow down their speech (see Figure 1 below). Participants had regularly used these visuals in other circumstances, particularly meetings and sessions conducted by their service-user organisation, and were thus already familiar with the arrangement. These visuals were not used by any group members who participated in Stage 1.2, which indicates that the session was well pitched to the participants' level of understanding.



Figure 1: Visual supports available to participants in Stage 1.2

Analysis followed a similar process to that employed in Stage 1.1. Version 3 of the adapted PHQ-9 and GAD-7 measures were developed following the cognitive interviews in Stage 1.2.

2.5.1.2.1 STAGE 1.2 PARTICIPANT DEMOGRAPHIC INFORMATION:

Three female and four male participants with intellectual disabilities completed Stage 1.2 in a group format which used a cognitive interviewing framework. Table 2 below displays the demographic characteristics of the study population of Stage 1.2. They ranged in age from 28 to 45 years (mean = 36.29; standard deviation = 6.42). Three of these participants had participated in Stage 1.1 of the research project.

	Stage 1.2 participants (n=7)
AGE	
20 - 29	2
30 - 39	3
40 - 49	2
50 - 59	0
60 - 69	0
GENDER	
Male	4
Female	3
IDENTIFIED ETHNICITY	
White British	4
Black British	3

Table 2: The demographic characteristics of the study population of Stage 1.2

2.5.2 PRELIMINARY PSYCHOMETRIC ANALYSIS (STAGE 2):

Information about the project, including the required study documents, was shared with clinicians and staff members in the services and specialist organisations. Follow-up support was then offered to services to answer questions about the research and to enable data collection within the recruitment window.

Participants provided informed consent for data collection, and completed the adapted GAD-7 and PHQ-9 measures and established clinical measures for depression (GDS-LD) and anxiety (GAS-ID) designed for intellectual disability populations. This was typically completed in a 1:1 session with either with a clinician who was already working with the participant as part of their psychological treatment sessions or with a staff member working for an organisation supporting people with intellectual disability who knew them well. Data collected in NHS services was used both as part of routine clinical treatment and in the research project. Recruitment for Stage 2 of the research proved challenging, which prompted the expansion of the research to non-clinical settings. Further information about the participants recruited to Stage 2 of the research is provided in Section 3.2.1.

Stage 2 of the research investigated whether or not there is evidence that the adapted measures are useful and valid for measuring symptoms of anxiety and depression in adults with intellectual disabilities. All data was appropriately coded and inputted to IBM SPSS for Mac (version 21). The analysis strategy for Stage 2 utilised an initial empirical statistical investigation of the validity and reliability of the adapted PHQ-9 and GAD-7, in line with recommendations for research (Chinn et al., 2014; Foundation for People with Learning Disabilities, 2015; Hamilton et al., 2011; IAPT, 2009; NICE, 2016) . Validity refers to the ability of an outcome measure to measure what it intends to measure (Rose & Sullivan 1996). The validity of the adapted versions of these measures is assessed in the current study by empirical investigations of content validity and criterion validity. Content validity, referring to the extent that a clinical measure does measure the construct that it intends (i.e. anxiety for the adapted GAD-7 and depression for the adapted PHQ-9), was initially investigated by completing group comparisons for participants recruited from clinical and non-clinical

settings. Criterion validity, refers to how well one measure (i.e. the adapted PHQ-9 or GAD-7) predicts the outcome on another measure (i.e. the GDS-LD or GAS-ID) administered at the same point in time. This involved preliminary investigations of criterion validity via scatterplot graphs to identify any linear relationship between these measures of anxiety and depression, and quantitative investigations of correlations, such as Pearson's correlation analyses which were used to investigate the strength of any identified relationship. Reliability refers to an outcome measure's capacity to yield consistent results from the same respondents in similar conditions (Field, 2014). Initial investigations of the reliability of the adapted versions of these measures is assessed in the current study by an empirical investigation of internal consistency. This involved calculation of Cronbach's α . Nunnally's (1978) threshold for an acceptable Cronbach's α value of 0.70 or above will be used as a benchmark for reliability in the current study

Further empirical investigation is planned into the sensitivity and specificity for the adapted versions of the PHQ-9 and GAD-7 using existing clinical cut-offs for the Glasgow Scales (Cuthill, Espie, & Cooper 2003; Mindham & Espie 2003) and the cut off scores for clinical caseness which are utilised by IAPT on the original PHQ-9 and GAD-7 measures (NDTi, 2011). There is no current guidelines for acceptable standards for levels of sensitivity and specificity in this context so the study will follow the precedent of existing research and aim to achieve a balance of both sensitivity and specificity when identifying potential clinical cut offs, such as in the development of the original PHQ-9 (Kroenke et al., 2001).

2.5.2.1 STAGE 2 PARTICIPANT DEMOGRAPHIC INFORMATION:

Thirty-two participants with intellectual disabilities completed the adapted measures alongside the GAS-LD (Cuthill, Espie, & Cooper 2003) and the GAS-ID (Mindham & Espie 2003),

17 who were recruited from clinical settings and 15 from non-clinical settings. Table 3 displays the demographic characteristics of the study population of Stage 2. Participants in Stage 2 ranged in age from 18 to 76 years (mean = 41.81, standard deviation = 13.98).

	Stage 2 participants n (%) (total n=32)
AGE	
<20	1 (3.13)
20 - 29	6 (18.75)
30 - 39	7 (21.87)
40 - 49	8 (25.00)
50 - 59	7 (21.87)
60-69	2 (6.25)
70-79	1 (3.13)
GENDER	
Male	17 (53.13)
Female	15 (46.87)
IDENTIFIED ETHNICITY	
White British	19 (59.4)
Black British	6 (18.8)
Black Caribbean	3 (9.4)
Pakistani British	1 (3.1)
Asian British	1 (3.1)
Mixed	2 (6.3)

Table 3: The demographic characteristics of the study population of Stage 2

2.5.2.2 STAGE 2 ANALYSIS PLAN:

In order to investigate the initial psychometrics of the adapted versions of the PHQ-9 and GAD-7 measures, the following tests were accordingly carried out:

- i. Assessing the normality of the data sample, including investigations of distribution.
- ii. Investigating any differences between groups in the sample using independent samples t-tests to compare scores on the adapted clinical measures.

- iii. Preliminary investigations of the validity of the adapted measures, specifically concurrent validity via comparison between scores on the clinical measures which were administered concurrently by:
 - a. Completing scatterplot graphs on the measures of depression (adapted version of the PHQ-9 and the GDS-LD) and anxiety (adapted version of the GAD-7 and GAS-ID) to identify any linear relationships and outliers.
 - b. Completing Pearson's correlation analyses to investigate the strength of any identified relationships.
- iv. Preliminary investigations of the reliability of the adapted measures, specifically the internal consistency via Cronbach's alpha analyses, where 0.70 is considered to be a minimally acceptable value (Nunnally, 1978).
- v. Investigations of the sensitivity and specificity of the adapted scales to determine their ability to identify those individuals who present with depression and/or anxiety in the sample.

2.6 RESEARCH QUALITY:

There are no quality guidelines specifically relating to cognitive interviewing. General guidelines specifically designed to optimise the quality of research, notably Elliott, Fischer, and Rennie (1999), were therefore consulted as part of this research project. In particular, efforts were made to situate the sample by collecting basic descriptive demographic data about each participant's gender, age and identified ethnicity. The aim here was to enable the reader to more accurately judge the extent to which the findings might be more generally applicable. Although collecting personal and demographic data and information about the service used by participants served this useful purpose it potentially threatened their

anonymity (Corti et al., 2014). This was especially the case as adults with intellectual disability living in a relatively small geographical area and accessing support from specialist organisations constitute a small target population. Limits were therefore set to the extent of the data collected and this also brought practical advantages. For example, it was easier as well as less intrusive to restrict the collection of descriptive data to that which is routinely collected by NHS services. Thus clinicians reporting in Stage 2 of the study were able use existing data only. Throughout the results write up qualitative data was grounded in examples. These specific examples of each procedure at Stage 1.1 and Stage 1.2 and the outline of extended qualitative notes arising from the first round of cognitive interviews given in Appendix 7 illustrate the process of analysis undertaken.

Throughout the research project the researcher bore in mind and reflected upon her own perspective, influenced as it inevitably was by her background, values and assumptions. In support of this the researcher kept a research log, and this log was discussed with her research supervisor at various stages during the research process. A brief summary of the researcher's background and experience is accordingly relevant. As a thirty-two-year-old, White-British Clinical Psychologist in Training, I became interested in completing research with people with intellectual disabilities as a result of professional and personal experiences. I have a paternal uncle who has intellectual disability and my family was centrally involved in his care during my childhood. This experience provided insight into the challenges faced by adults with intellectual disabilities and the helpfulness of taking time to listen to and fully understand these individual's perspectives. I can recall many times where professionals and members of the public did not do this well enough with my uncle, subjugating his voice intentionally or unintentionally, and I witnessed how this had a detrimental effect on his

ability to be independent and be heard. My pre-training posts involved working for five years to support and enhance the psychological care of children and young adults who have intellectual and developmental disabilities. These experiences as an Assistant Psychologist influenced me to become an advocate of equitable rights for this population. In both capacities I witnessed how difficult it can be for people with intellectual disabilities to have a voice and to have that voice heard by others. Further reflections on the research process as a whole are to be found in the Discussion Chapter (Section 4.7).

CHAPTER 3: RESULTS

This project undertook an assessment of the extent to which the adapted PHQ-9 and GAD-7 measures were comprehensible within the intellectual disability population. The study was based on a two stage process: a cognitive interviewing methodology (Stage 1) was followed by an assessment of the initial psychometric properties of the same measures (Stage 2). It is the main purpose of this chapter to present the data collected in the project, but its later stages also summarise additional information about the processes used to administer the measures to participants with intellectual disabilities. This information was gathered both from those who administered the assessments and the participants who undertook them. Throughout the focus is on the appropriateness or otherwise of the adapted measures for use within this population.

3.1 COGNITIVE INTERVIEWING (STAGE 1):

3.1.1 FIRST ROUND OF COGNITIVE INTERVIEWING (STAGE 1.1):

3.1.1.1 COGNITIVE INTERVIEWING PROCESS:

As detailed in the methodology, consent was obtained from participants, a process which usually took around ten minutes to complete with each. The cognitive interviews in Stage 1.1 lasted between 38 minutes and 50 minutes. Three participants chose to read the items on the measure aloud and three asked for support from the researcher. Five individuals recalled that they had seen these adapted versions of the PHQ-9 and GAD-7 before participation in the research. Recruitment to Stage 1.1 was terminated after consultation of

recommendations made by Willis (2005), including a recognition that no serious problems with the measures had been identified.

Analysis of the data gathered from Stage 1.1 was completed in line with Willis' (2005) guidance. Specifically, extended qualitative notes were made by listening to audio recordings of the cognitive interviews. These notes detailed any difficulties voiced by participants either about item comprehension or about the response options. The notes recorded and organised information by item rather than individual (an example of this can be seen in Appendix 7). This data and relevant literature assisted researchers in formulating and amending questions so that they accessed targeted constructs more effectively and guided discussions with the research team. The resulting insights were used to draft a second version of the adapted measures following Stage 1.1 (see Appendix 8).

The results section includes quotations from participants in the research project. These are provided to ground the results and to enable the reader to interpret them more clearly (Elliott et al., 1999). Irrelevant parts of some of the quotations have been omitted; the resulting gaps are denoted thus: '...'.

3.1.1.2 QUESTION WORDING:

Ensuring that adults with intellectual disabilities understood the wording of the adapted measures was a primary aim of Stage 1.1. Discussion in the cognitive interviews accordingly paid careful attention to the wording of items on the adapted measures. Feedback was sought from intellectual disability participants both about what terminology was readily understood by them and what they considered to be the most accessible terms for their population. In

the example given below the participant describes PHQ-9 item 3 (*'Have you had problems with your sleep?'*) in their own words, with anticipated probes from the researcher used to define specific terms in the question:

"It's asking about have you been not sleeping well....it means like when you are tired but you can't go to sleep,...[waking in the night] is when you went to sleep but you wake up and you are thinking and you can't get back to sleep again!...[sleeping too much] is like if you've been sleeping from night time to all day to night time again" [Participant 4]

Participants were asked for their ideas about how the wording of the items could be made simpler and easier for people with intellectual disabilities to understand. A frequent observation was that too many used multiple but similar questions. The following are representative examples of this particular complaint:

"All the questions [which are part of that item] still link in but they are different. They are all asking about sleeping. Probably [better to] ask one question about sleeping instead of all the questions... examples underneath [would be better as it would give someone] an idea about what [the question] is asking about" [Participant 4]

"It's long and difficult....It should say 'do you sleep alright?'" [Participant 6]

This body of feedback was discussed by the researcher and research supervisor and they consulted other specialist IAPT and intellectual disability clinicians. From these discussions ideas emerged about changes that might usefully be made to items in the measures. It was decided, for example, that wherever possible it would be preferable for each item to consist of a single question using a single term. For example, instead of *'down, depressed or hopeless'* (PHQ-9 item 2) just one term would be used. It was also strongly felt that the single term

should be chosen by the participants as the one most likely to be understood by those with intellectual disabilities. At times the research team had concerns not always shared by participants. For example, the researchers felt that the inclusion of too many concrete examples in the measure might lead people with intellectual disabilities to focus too much on the particular and not enough on a general understanding of a question. One instance of this surfaced when participants suggested that the example about how you might feel before a job interview might support GAD-7 item 1 (*'Have you been feeling anxious? Have you been feeling nervous?'*). However, the research team was concerned that simply using this single example might result in participants failing to register on the item if they were anxious about things other than job interviews. A further concern was that the greater cognitive effort involved in processing long questions might make them less accessible (Buell, 2015). As a result of these considerations it was decided to use relevant examples, alternative terminology and prompts and that these should be located in separate clinician guidance. This guidance was for the use of clinicians who were supporting individuals seeking to complete the measures on an individual basis

Before changes were made to the wording of the items the original PHQ-9 and GAD-7 measures were consulted so as to ensure that any further adaptations were in line with the original questions. For example, on the Version 1 of the adapted measures which were used in Stage 1.1 item 9 on the PHQ-9 read *'Have you wanted to hurt yourself? Have you wanted to kill yourself?'*. This was adapted in Version 2 of the adapted measures to be more in line with the original PHQ-9 item, which specifically asks about whether the individual has had *'Thoughts that you would be better off dead, or of hurting yourself in some way?'*. Thus, to ensure that the current adapted version of the PHQ-9 was closely aligned with the original

PHQ-9, the question wording after Stage 1.1 was changed to *‘Have you had thoughts about: Hurting yourself on purpose? Or killing yourself?’*.

3.1.1.3 PICTURES TO AID UNDERSTANDING OF QUESTIONS:

Another important aim of the first round of cognitive interviews was to assess how well the visual cues intended to increase the accessibility of the adapted measures were understood by people with intellectual disabilities. In Stage 1.1 participants’ feedback on the extent to which the visual cues were aligned with the individual item questions on the adapted measures proved to be mixed. Participants felt that some cues made the focus of questions clearer. PHQ-9 item 3 (see Figure 2 below) which asks about sleep difficulties came into this category:


	<p><i>“The picture is good – there is a lady, I think she is probably thinking that she doesn’t want to get up when her alarm goes off...she wants to stay in bed...Maybe she is really tired.”</i> [Participant 2]</p> <p><i>“The picture makes it easy to understand...she looks tired.”</i> [Participant 1]</p> <p><i>“The picture links in to the question because the woman is trying to go to sleep and can’t!”</i> [Participant 4]</p>
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Figure 2: Picture in Version 1 of the adapted measure discussed in research Stage 1.1 which supports understanding of PHQ-9 item 3 and examples of participant feedback

However, some of the pictures were more difficult for participants to understand and most suggested that these should be changed for ones that more clearly linked to the questions.

PHQ-9 item 9, shown below in Figure 3 was one of those which participants felt could be improved in this way. The item screens for the presence of recent thoughts of suicide or self-harm.


	<p><i>“It’s a box with a sad face – it’s not helpful. Someone has just drawn on a sad face. It doesn’t help me understand.” [Participant 1]</i></p> <p><i>“I think he’s hurt his face and he’s put the bag on his head because he’s embarrassed and he’s upset as he has a sad face on the bag” [Participant 2]</i></p> <p><i>“I don’t like the photo – he looks like he’s trying to hide, that don’t go with the question. It’s like he’s sad that’s all.”</i></p> <p>[Participant 5]</p>
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Figure 3: Picture in Version 1 of the adapted measure discussed in research Stage 1.1. It was intended to support understanding of PHQ-9 item 9. The accompanying examples of participant feedback suggest that it was not effective

Prompts were administered to participants to encourage them to suggest what pictures might be more successful in promoting understanding of this question. They acknowledged that this was a sensitive question and that a picture must be carefully chosen to minimise distress. Nonetheless some helpful suggestions were made:

“[I think it would be] better to have [a picture of] knives or tablets...but a drawing not photograph would be better as a photograph might be upsetting [to see]” [Participant 4]

“I was thinking a gun or a knife but it might be too scary [for people to look at] so I’m not sure”

[Participant 5]

The pictures used in Version 1 of the adapted measures were obtained via google searches and the research team were concerned about copyright restrictions. The pictures were also presented in a range of formats with some as photographs, others as line drawings and yet others as computerised graphics. While completing background information searches for the project a version of the PHQ-9 and GAD-7 measures which had been adapted for use with people with intellectual disabilities was found (Appendix 9). This was a piece of work completed by CHANGE People (<http://www.changepeople.org>), an organisation which aims to empower people with intellectual disabilities. The organisation had been commissioned by a psychology service in Leeds to increase accessibility to the minimum data set in 2012. CHANGE People employs an 'Accessible Information Team' on which designers and illustrators work alongside consultants with intellectual disabilities to develop material suited to this population's needs. The adapted version of the scale produced by CHANGE People retained the original wording of items on the PHQ-9 and GAD-7 but added tailor-made illustrations to support understanding of each item. They also used 'happy' to 'sad' 'smiley' face visual cues to support understanding of the scoring options for the measures. The research team judged that the existing format of the CHANGE People version of the measures were not likely to be the most helpful for the intellectual disability population. The principal weaknesses were the inaccessibility of the wording, the lack of a clear association between the smiley and sad faces visual cues and the scoring options and the overall formatting of the measure. Key problems with the formatting included the fact that the text was not broken down into smaller discrete chunks and there were too many items per page. Guidelines for easy read documentation (DoH, 2010b; MENCAP, 2008) as well as the relevant research literature (Buell, 2015; Hurtado et al., 2014; Sutherland & Isherwood, 2016) were consulted in the course of reaching this decision. Furthermore, although CHANGE People consulted

adults with intellectual disabilities whilst creating the visual cues designed to increase understanding of individual items on the PHQ-9 and GAD-7, there was no evidence to suggest that any research underpinned the development of the measures. The research team nonetheless decided that using the visual cues for the individual items on the measures developed by CHANGE People would be useful, particularly as those who are envisaged to use the adapted measures are thought to have the cognitive ability required to decode visual cues in line drawing form. Two considerations were particularly important here: copyright issues were satisfied; and the images had been developed to reflect the very specific PHQ-9 and GAD-7 measures. Permission for these pictures to be included in the current research project was therefore sought from the service which owns the images and this was granted before these were utilised in Version 2 of the adapted measures.

After sharing and discussing more general ideas about what visual cues might best aid understanding the research team looked closely at each of the CHANGE People illustrations. A key emphasis was on which pictures closely matched the research team's ideal and which required modification. As a result the CHANGE People pictures relating to some items were moved around or edited so that they more closely conformed to the items' concepts and to the ideas both of the researchers and of participants who had been involved in the cognitive interviews undertaken in Stage 1.1.

An example of this process is GAD-7 item 3, which asks if an individual has been '*worrying too much about different things*'. The relevant visual cues from Version 1 of the adapted measure used in Stage 1.1 can be seen below in Figure 4 and the CHANGE People illustration in Figure 5. During the cognitive interviews, participants expressed mixed feelings about the original

adapted visual cue prompt for the GAD-7 item 3 shown in Figure 4. Some understood that the picture represented a person thinking about lots of different worries but others did not:

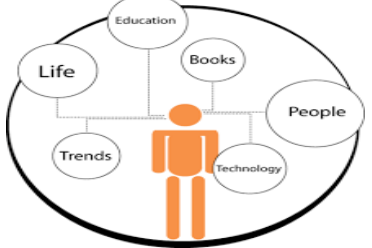



	<p><i>“The picture links in because the man is a person there and he is thinking about lots of things like life and people” [Participant 4]</i></p> <p><i>“It helps a bit, kind of. [But] some of these [worries] I can’t even read. I don’t know what ‘trends’ means – I haven’t heard of that word before” [Participant 3]</i></p> <p><i>“I don’t know what that [picture] is at all” [Participant 2]</i></p>
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Figure 4: Picture in Version 1 of the adapted measure discussed in research Stage 1.1. It aimed to support understanding of GAD-7 item 3, but was very variously received, as the accompanying examples of participant feedback indicate

As with many of the other GAD items, the research team were mindful that the individual visual cues needed to support understanding of the specific symptom of anxiety addressed by the item rather than simply depicting individuals looking generally worried. GAD-7 item 3 in particular highlights this concern and it was judged to be important to more successfully convey the concept of an individual experiencing many different types of worry. The visual cue for Version 2 of the adapted version of the measure (see Figure 4) was changed accordingly. The CHANGE People measure includes a visual cue in support of the item in the IAPT Phobia scale which deals with specific phobias. This visual cue was identified as being aligned with the concept of a single individual experiencing multiple worries (see Figure 6). In contrast to Version 1 of the adapted measures and shown in Figure 4 above it was felt to be preferable to use pictures rather than words. Examples of pictures showing common worries

which were thought likely to aid an understanding of the question were therefore drawn from elsewhere in the CHANGE People adapted measures. The illustration shown in Figure 6 resulted from these considerations and aimed to represent the symptom described in GAD-7 item 3 (see Figure 7). The original CHANGE People picture for GAD-7 item 3 was moved to support understanding of PHQ-9 item 2 of the original version of the measure, which asks if an individual has felt ‘*down, depressed or hopeless*’.

		
<p>Figure 5: CHANGE People GAD-7 item 3 visual cue</p>	<p>Figure 6: CHANGE People visual cue for IAPT Phobia Scale item covering specific phobias</p>	<p>Figure 7: Picture edited as part of the current study to support understanding of GAD-7 item 3 in Version 3 of the adapted measures</p>

The adaptations made to GAD-7 item 3 provide an example to the reader of the process used by the research team to assess the visual cues used in the adapted versions of the PHQ-9 and GAD-7 measures in the light of the first round of cognitive interviews.

3.1.1.4 ITEM SCORING:

Ensuring that users of the measures are able to understand item scoring and to choose amongst item scoring options is crucial if the measures are to be adapted effectively. Item scoring was one area where all participants in Stage 1.1 experienced difficulties, both in

understanding the meaning of the instructions for scoring options and understanding the visual calendar cue provided. Figure 8 depicts the scoring options for each item on the adapted version of the measures as used in the Stage 1.1 cognitive interviews.





Have you felt this way... Please tick one:			
			
0. Not at all	1. Several days?	2. More than half the days?	3. Nearly every day?
.....

Figure 8: Scoring option for Version 1 of the adapted versions of the PHQ-9 and GAD-7

Participants in the cognitive interviews in Stage 1.1 commonly reported confusion about what differentiated the individual scoring options. Whereas many participants understood that ‘not at all’ meant that this symptom was not present and ‘nearly every day’ meant that the symptom was experienced most of the time, the middle two scoring responses were not understood. Three participants stated that they were not sure what ‘several days’ was asking and the others responded as follows:

“Does [several days] mean some of the days or every day?” [Participant 1]

“Is [several days] Monday to Sunday or something?” [Participant 3]

“[Several days] means 2 or 3 days. I’m not really sure other people with learning disabilities would understand this – I think you should put 2 or 3 days instead of several days to help people understand” [Participant 4]

Four participants reported that they did not understand what *'more than half the days'* was asking and the others stated:

"Does that mean half the days? I'm not sure" [Participant 1]

"[It] could be more than several days, like maybe half the days" [Participant 4]

The visual calendar cue to clarify that the measure was covering the last two-week period was also not well understood by participants. Four participants reported in Stage 1.1 that they did not know what the picture was and the other two showed only partial understanding:

"What does it mean? I'm not sure what the pictures mean. It looks like it's a calendar or something. But it's not telling me what it means. The idea of a calendar is helpful but maybe a different picture that is clearer would be better" [Participant 1]

"I can't tell what [the pictures] are...the days I think. The pictures look really small, I can't see them" [Participant 3]

Participants suggested improvements to the scoring options, including making them more specific by stating the number of days covered by each response option and changing the visual cue. Other visual cues which have been developed for use with the learning disability population, such as the CORE-LD (Brooks et al., 2013), utilise shaded-in boxes to provide visual cues about how frequently symptoms have been present over a longer period of time. In line with these suggestions, the research team decided to amend the scoring options as shown in Figure 9 below.





			
0 days	1 – 7 days	8 – 12 days	13 – 14 days

Figure 9: Scoring options developed for Version 2 of the adapted measures

When asked many participants were unable to state what period of time the measures were covering or raised concerns that others with learning disabilities would probably not be able to answer over a two-week period. For example, when asked during the cognitive interviews what period of time the question was asking about two participants were unable to answer and others responded as follows:

“Is it a week?....Maybe one day?” [Participant 2]

“It is asking about afternoons” [Participant 4]

This issue is further explored in the discussion chapter.

3.1.1.5 OVERALL LAYOUT OF THE MEASURE:

Feedback was gathered from participants in Stage 1.1 about the overall layout of the adapted measures. All participants felt that it was important for the measures to be printed in colour and five reported that at two items per page (printed A4) the questions were appropriately sized. All changes made by the research team were informed by best practice guidance for easy read documentation (DoH, 2010b; MENCAP, 2008) and the overall layout of the measure was designed to include a moderate amount of colour, to utilise a clear text style and to employ a large font size. Items were clearly separated on the page and bullet points were

used to separate sub-questions where appropriate. All jargon, unnecessary information and graphics were removed from the adapted versions of the measure to further reduce the burden on the reader. For scoring purposes, total score boxes were inserted at the end of each measure.

3.1.1.7 RECOMMENDATIONS FOR SUPPORT REQUIRED TO FILL OUT THE MEASURES AND CLINICIAN GUIDELINES:

Participants in Stage 1.1 were consulted about the level of support they believed they and others with learning disabilities would need to complete these measures. All participants reported needing support, with five stating that they thought it was a good idea to have someone with them while they completed the measures so that they could clarify the meaning of items, check their understanding of terms and discuss examples. The other participant reported that they would need someone of whom they could ask questions but not necessarily be with them while they completed the measures. Some participants also reported that they felt that over time they would have less need of support in completing the measures. This is in line with the recommendations made in positive practice guidance for those dealing with people with intellectual disabilities (Foundation for People with Learning Disabilities, 2015).

After discussion with the research team a cover sheet was added to the new versions of the adapted measures. This provided easy-read guidance for individuals undertaking to complete the measures. The cover sheet references the two-week rating period covered by the measures and provides guidance for clinicians seeking to explain this to service users. As well

as increasing accessibility for people with learning disabilities, the cover sheet made it possible to remove repetitive information from the body of the measure.

In line with research recommending that clinicians working in mainstream psychology services request (Marwood 2015; Shankland & Dagnan 2015) and indeed require (Chinn et al., 2014; NDTi, 2012, 2016) advice to enable them to work effectively with service users with learning disabilities, a document providing guidance in the use of the adapted measures was produced (see Appendix 10). Many participants mentioned that examples would be helpful to support understanding of individual items and suggested a number of relevant possibilities. However, the research team were concerned that too much information included on the adapted measures themselves might reduce accessibility for service users with learning disabilities. It was therefore decided that this information could more helpfully be included in the clinician document used to guide conversations in ways which aimed to assist the understanding of individual service users. Other information in the document included general guidelines for completing outcome measures with people with learning disabilities, alternative terminology suggested by participants and information about scoring.

Feedback from adults with learning disabilities regularly mentioned that as well as spaces in which to write their answers they would welcome spaces where they could write additional information about matters which impacted on their responses. A pertinent example of this came from respondents whose problems with sleep had arisen from or been aggravated by a recent change in their medication. This very helpful suggestion led us to add a short section at the end of the adapted measure where individuals could record this kind qualitative information.

3.1.2 SECOND ROUND OF COGNITIVE INTERVIEWING (STAGE 1.2):

3.1.2.1 COGNITIVE INTERVIEWING PROCESS:

In what was a diversion from the methodology originally planned, Stage 1.2 was completed in a group format. Prior to the session the service user organisation staff completed participant consent procedures. The group session itself lasted one hour twenty minutes, with a fifteen minute break between discussion of the two measures. Six individuals had seen these adapted versions of the PHQ-9 and GAD-7 before participation in Stage 1.2 of the research.

3.1.2.2 QUESTION WORDING:

Participants were very positive about the wording of items on the further adapted measures, and commented that the questions were *“clear and to the point”*. In particular, PHQ-9 item 2 (*‘Have you felt sad?’*) and item 3 (*‘Have you had problems with your sleep?’*) were highlighted as greatly improved from the previous adapted version of the measure, indicating that the removal of multiple similar terms and examples had been helpful in increasing accessibility. A few minor changes were discussed and agreed. For example, participants suggested that some of the terminology in the measure should be replaced with alternative phrases suggested in the guidelines for clinicians. The consensus was that these alternatives offered terms that were more accessible for the intellectual disability population. The particular recommendations were as follows: that *‘Have you been feeling like you are no good?’* should be changed to *‘Have you been feeling like you have let yourself down or let other people down?’* for PHQ-9 item 6; that *‘Has it been hard to focus on things?’* should be changed to *‘Has it been hard to concentrate on things?’* for PHQ-9 item 7; and that *‘Have you*

felt afraid? should be changed to *'Have you felt scared?'* for GAD-7 item 7. All of these changes had been thoroughly discussed by participants in the group and the decisions arrived at by consensus. The research team approved all the changes suggested for the wording of the item questions.

Difficulties remained with participants' understanding of PHQ-9 item 8 (*'Have you been moving or speaking more slowly or a lot faster?'*), and discussion made it clear that this question was considered particularly confusing. Participants went so far as to say that it was difficult to understand why the question was being asked at all. One participant, for example, expressed this as follows:

"I don't understand why it is being asked? What is the question asking about? What is the concept of it?" [Participant 7]

There are challenges surrounding making any adaptation to the wording of questions on adapted versions of measures, particularly when such drastic changes are required to increase accessibility. Although the original versions of the PHQ-9 and GAD-7 measures were consulted so as to ensure that any further adaptations were in line with the original items, some debate remains as to whether the adapted versions of the questions are really equivalent to the standard wording. In particular, this issue is highlighted by PHQ-9 items 6 (*'Have you been feeling like you have let yourself down or let other people down?'*) and PHQ-9 item 9 (*'Have you wanted to hurt yourself on purpose? Or kill yourself?'*). It could be argued that these adapted wordings may not truly reflect the original questions, as PHQ-9 item 6 also includes screening for feelings of hopelessness or excessive guilt (*'Feeling bad about yourself or that you are a failure or have let yourself or your family down'*), and PHQ-9 item 9 covers recurrent thoughts of death, suicidal ideation without a specific plan, or a suicide attempt or

a specific plan for committing suicide (*Thoughts that you would be better off dead or of hurting yourself in some way*). The implications of this are that the adapted versions of the questions may not pick up on all aspects of these items which are reflected in the diagnostic criteria of DSM-5 (APA, 2015) and so some individuals may present with these symptoms but not score on the adapted versions of the measures. However, as it is of key importance that items are accessible to people with intellectual disability, and the first round of cognitive interviewing in the current project indicated that the standardised wording on the original PHQ-9 and GAD-7 were not well understood by participants, it is judged to be crucial that the wording of questions is adjusted for this population. In line with previously outlined recommendations in the literature, the preference for each question to consist of a single question using a single term which was judged by participants and the researchers to best represent each item is judged to be both acceptable for the integrity of the measure and accessible for individuals with intellectual disabilities.

More positively, participants viewed the front sheet of the questionnaire as clear and accessible in its intention to inform individuals about what the measures are and in providing basic instructions on how to complete them.

3.1.2.3 PICTURES TO AID UNDERSTANDING OF QUESTIONS:

Participants unanimously preferred the new images chosen to support understanding of individual questions. One of those who had been involved in Stage 1.1, for example, considered that they *“now match up much better with the questions”*. Many of the pictures chosen to support understanding of the individual items were singled out in discussion as being very helpful, including PHQ-9 items 3, 4 and 9 and GAD-7 items 3, 5 and 6. It was

suggested that the picture chosen to support PHQ-9 item 2 could be made more clearly sad rather than *'fed up or bored'*. It was felt that adding tears and/or showing the face of the person in the picture more clearly would help to achieve this. To address this, the picture to support understanding of this item was modified by the research team, as shown in Figure 10 below.

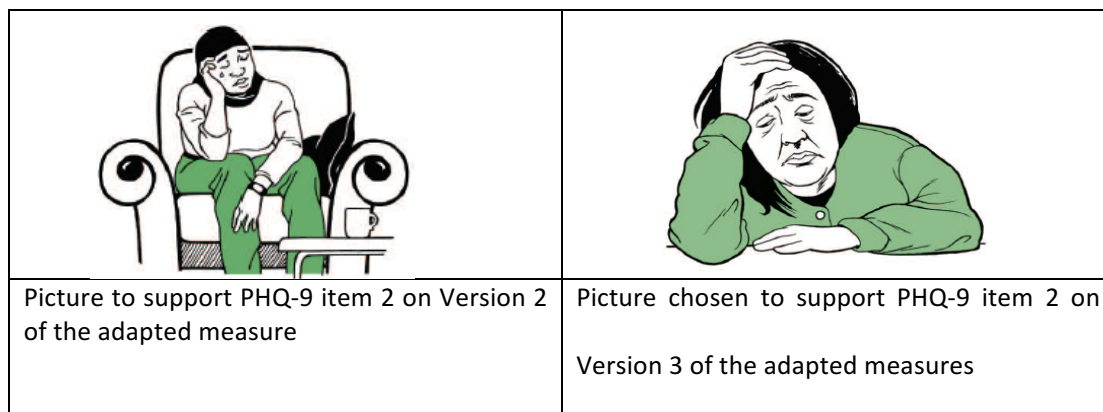


Figure 10: Adapted PHQ-9 item 2 visual cues on Versions 2 and 3 of the adapted measure

Opinion in the group was divided over some aspects of the visual supports for PHQ-9 item 5 (*'Have you been more or less hungry than normal?'*). The main difference of opinion attached to the issue of whether it was better to use one picture or two to clarify this question. There was also some suggestion that an additional picture to depict increased appetite would support the existing picture showing a loss of appetite and would thus make the question more easily read. However, on balance the group felt that the existing picture communicated the idea of changes in appetite well enough. All participants expressed concern that adding an additional picture would result in both pictures being made smaller in order to fit them into the measure and this might make it difficult to see the pictures clearly. This issue was discussed in the research team and it was decided to leave the visual cues for this item unchanged.

The feedback obtained in Stage 1.1. led the research team to consider the desirability of adding a thought bubble depicting self-harm to the existing visual cue created to support item 9 of PHQ-9, which covers thoughts of suicidal and self harm. The existing visual cue on Version 2 of the adapted measure and the proposed addition are shown in Figure 11. The research team felt that the proposed addition to the picture produced by CHANGE would ensure that the visual cue more closely aligned with the question but the participants in Stage 1.2 provided clear feedback that this image should not be added as it could cause distress and the focus of the question was already clear. Participants suggested that an additional thought bubble depicting “a bottle of pills with some on the floor” might be added, though they did not view this as essential to an understanding of the item. The research team decided that it would be difficult to depict parasuicide clearly using this image and resolved to leave the CHANGE People visual unedited.

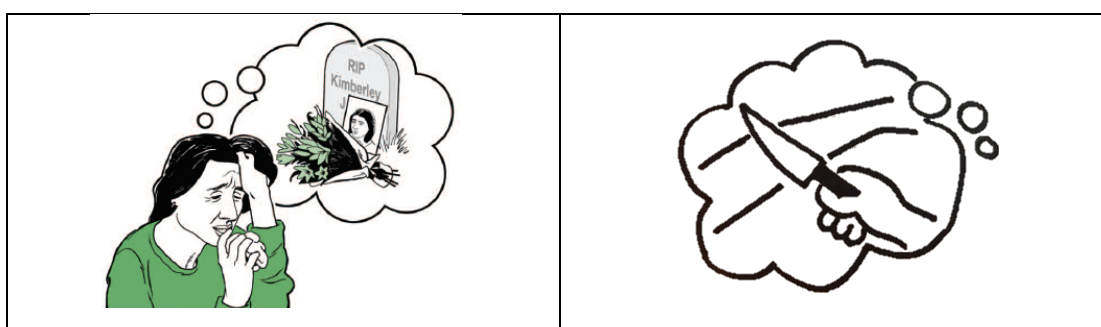


Figure 11: CHANGE People visual supporting PHQ-9 item 9 and research team suggestion for additional thought bubble

The visuals on the cover sheet for the measures were also slightly rearranged to ensure that the cues were more precisely aligned with the statements they were supporting.

3.1.2.4 ITEM SCORING:

An in-depth discussion of item scoring of the kind used in Stage 1.1 was also conducted for Stage 1.2. The modified visual calendar cue used to support understanding of the two-week period covered by the measure was better understood by participants. Most understood immediately that it depicted a calendar, but it was suggested that it should be made bigger and should show the days of the week. Participants also reported that the wording supporting the item scoring was clear and easy to understand, and the group was able to describe what this was asking in their own words:

“It’s asking you to say how you have been feeling in the past couple of weeks” [Participant 2]

In contrast to this easily reached consensus, the scoring options available on the measure prompted a more heated discussion, though some aspects were readily approved. For example, six of the seven participants thought that the visual cues supporting the scoring options were helpful and better aligned with the responses. The remaining participant said that she *“did not like them grey boxes, they annoy me”*, but even with gentle prompting was unable to say why or make any suggestions for a more helpful alternative. Other issues proved less straightforward. In line with suggestions made by participants in Stage 1.1 the scoring options had been made more precise, a change which involved adding the number of days referred to in the scoring period. This caused confusion among participants in Stage 1.2 with many expressing concern that individuals would find it difficult to be specific about the number of days on which they had experienced particular symptoms during the past two weeks:

“To me it’s confusing as it’s like answering a maths question...I like it how it was before” [Participant 1]

“Is it a zero or is it a seven? There’s a big difference between them” [Participant 9]

Further discussion about item scoring was facilitated by probe questions administered by the cognitive interviewer. One change suggested by the group was the addition of numbers to the response options’ visual cues so as to link these more directly. This is shown in Figure 12 below. It was thought that this might be helpful in a way similar to that by which a graph or scale representing the number of days that each option is asking about made things clearer for people with learning disabilities. However, the research team was concerned that adding extra core information to the measures might actually reduce their accessibility. In line with the aim of keeping the adapted measures as straightforward as possible for all, but allowing for individual differences in how people need to receive explanations, it was decided that this suggestion should only be added to the clinician guidelines. In this way it could be used at their discretion when dealing with individuals.

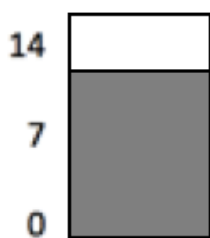


Figure 12: Example of suggestion made by participants in Stage 1.2 to add numbers to the scoring option ‘a lot of days’

It was clear that the response options for the adapted measures remained difficult for participants to understand. To further simplify the scoring options, and to remain as aligned

as possible with the original PHQ-9 and GAD-7 measures, the research team decided to return to a verbal explanation for the response options on the scale and suggested '*no days*', '*some days*', '*a lot of days*' and '*nearly every day*', as shown in Figure 13. Following this discussion, the researcher emailed the proposed updated scoring options to one of the staff members who co-facilitated the cognitive interview group. This staff member collected feedback from several individuals who had participated in Stage 1.2 and sent the information back to the researcher. These participants agreed that this further adaptation to the scoring options made them more accessible for adults with intellectual disabilities.



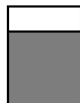

			
No days	Some days	A lot of days	Nearly every day

Figure 13: These scoring options for Version 3 of the adapted measures

3.1.2.5 OVERALL LAYOUT OF THE MEASURE:

Participants reported that they preferred the modified overall layout of the adapted measures. They especially welcomed the new visual cues which supported understanding of the individual items and the response options. In addition to valuing colour printing, participants stressed how important it was for measures to be printed on only one side of the paper:

“double sided can be a bit confusing...if one bit is on this side [of the paper] and the other bit is on the other side, it can be difficult to follow and people lose their place a bit and so it can get confusing” [Participant 7]

The final adapted versions of the PHQ-9 and GAD-7 measures produced in this research project and used in Stage 2 can be seen in Appendix 11.

3.1.2.7 RECOMMENDATIONS FOR SUPPORT REQUIRED TO FILL OUT THE MEASURES AND CLINICIAN GUIDELINES:

The guidelines for clinicians produced to standardise delivery of the adapted measures and to provide support when administering them to adults with intellectual disabilities were updated as outlined above. A copy of this document is provided in Appendix 12.

3.2 PRELIMINARY PSYCHOMETRIC ANALYSIS (STAGE 2):

This section presents the results of the final stage of the research. It was at this stage that the adapted versions of the PHQ-9 and GAD-7 measures were administered to adults with intellectual disabilities alongside the established Glasgow scales of depression (GDS-LD) and anxiety (GAS-ID). This stage of the research aimed to investigate the initial psychometric properties of the adapted measures produced in Stage 1 of the current research project.

3.2.1 STAGE 2 PROCESS:

As previously discussed, it was initially intended that participants for Stage 2 of the current study should be recruited solely from within clinical services, specifically three IAPT services and one Community Learning Disability Team [CLDT]. However, clinicians reported difficulties in recruitment. These difficulties arose from three main factors: a low level of eligible service

users accessing IAPT services; high rates of potential participants not attending offered appointments within the recruitment window; and issues particular to individuals, as when one eligible participant said she was averse to completing questionnaires. Recruitment was accordingly extended to include non-clinical settings. A flow chart providing more specific information about the recruitment of participants in Stage 2 can be seen in Figure 14 below. This indicates the number of participants recruited from different contexts, records the number recruited from the different types of clinical service and gives specific information about how many participants were recruited individually and how many came from groups.

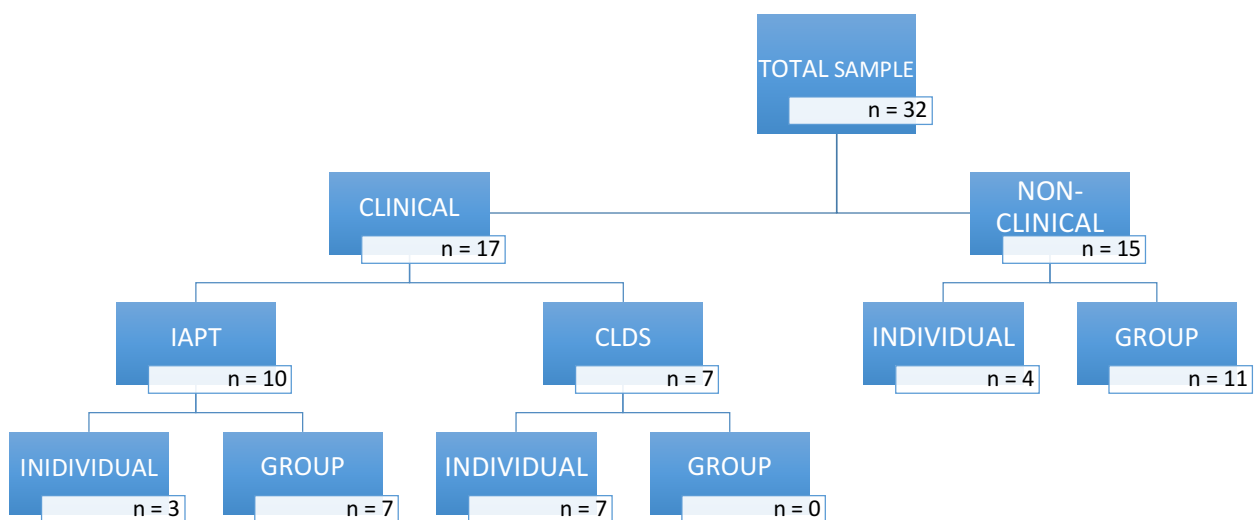


Figure 14: Stage 2 recruitment flowchart

Two groups were used for data collection. One was a clinical group co-facilitated by an IAPT service and a service user organisation. This group was part of a wider programme aiming to provide psychoeducation about topics such as relaxation and sleep for adults with intellectual disability who had been flagged as presenting with some level of mental health difficulty

(n=7). The second group participating in the study was a non-clinical service user advocacy group which was approached towards the end of the recruitment window. This approach was facilitated by the researcher and by an Empowerment Project Co-ordinator, one of whom knew the group well (n=11). The methodology for data collection described above was used with both groups. Feedback about the adapted versions of the measures was sought from clinicians who had supported data collection in Stage 2 via the Administrators Feedback Form (Appendix 13).

The researcher completed some notes following the administration of the adapted versions of the PHQ-9 and GAD-7 to a group of eleven adults with intellectual disabilities in Stage 2. Three participants required individual support to complete the adapted outcome measures, including support reading out the questions, understanding the items by referencing the alternative terms suggested in the clinician guidelines and thinking about the appropriate responses in the two-week timeframe. One of these participants had difficulty reading the text and suggested that it should be increased if possible. Four participants required some support completing the adapted measures, which involved independent completion but occasional checking of their understanding of items or scoring options with a facilitator or another participant. The remaining four participants completed the adapted versions of the PHQ-9 and GAD-7 measures independently. All but one participant had completed both outcome measures within nine minutes, and the remaining participant required a higher level of support but had completed the adapted versions of the PHQ-9 and GAD-7 within 15 minutes. In contrast, the Glasgow Scales took 35 minutes in total for completion and all participants needed much higher levels of support, with seven individuals needing a facilitator to read out each question and help with the scoring for each item. No participant was able to

complete the Glasgow Scales fully independently. All participants were confused by the scoring options for the scales, particularly the inconsistency between the GAS-ID and GDS-LD measures layout and scoring, and most needed a facilitator to help them choose a response each time (for example after the facilitator had read one item, one participant asked “*yes I do, so do I tick this one?*”). The reports from the authors that the response format of the GAS-ID was easy for participants to use as they “*often spontaneously rated their level of symptoms*” in a consistent way to the response options (Mindham & Espie 2003, p. 29) was not replicated here.

The extension of recruitment to non-clinical settings meant that participants might not have been accessing current support from psychology services. The potential risk issues thus created were discussed with the staff members who completed the research and with participants and monitored by the researcher. For example, before setting up the non-clinical service user advocacy group, the researcher contacted the Empowerment Project Co-ordinator who would be co-facilitating the session to discuss an appropriate contingency plan. This plan addressed the possibility of someone in the group being identified as perhaps needing future support from services as, for example, were they to show signs of clinical mental health problems or appear at risk. The planning included checking the availability of support in the local area and considering how participants might be referred. The importance of this consideration was demonstrated when a number of participants noted the presence of suicidal or self-harm thoughts in their responses to item 9 in the adapted PHQ-9 measure. The researcher noted this when she screened the completed clinical measures towards the end of the session and privately raised the issue with the Empowerment Project Co-ordinator. They agreed that she should follow this up with each of these participants the following day to make sure that they were safe and consider whether some or all might need more support.

Looking at the responses of the group as a whole, a number of participants scored quite highly on the clinical measures of anxiety and depression completed together during the session. As it was thought that this might be an indication that the group's members were experiencing a higher level of psychological and emotional distress than was readily apparent, the research team recommended that information about the availability of local psychological support for adults with intellectual disabilities should be shared with the whole group. It was hoped that this signposting would ensure the safety and emotional wellbeing of participants whilst continuing to respect the boundaries of the research project.

3.2.3 STATISTICAL ANALYSIS:

All quantitative analyses completed in Stage 2 were carried out using SPSS; hypothesis testing used a conventional level of significance of 0.05 (Munro, 2005). Appropriate assumptions for parametric tests were checked throughout. It was necessary to complete initial psychometric validation of the adapted PHQ-9 and GAD-7 measures in order to enable assessment of the quality of these measures when compared to recommendations for acceptable criteria for self-report clinical outcome measures (Fitzpatrick et al., 1998; Cahill et al., 2008).

One set of data from the clinical sample was returned with the adapted PHQ-9 incomplete so this was excluded from analyses. No other data was missing from the sample.

3.2.3.1 ASSESSING THE NORMALITY OF THE SAMPLE:

Statistically assessing the normality of the sample is important to ensure that the data complies with the underlying assumptions that underpin parametric statistical tests, specifically that the data are normally distributed and the presence of any outliers detected

so as to ensure that data does not need correction. Outliers are extremely unusual scores, defined as scores between 1.5 and three times the interquartile range (Field, 2014).

Histograms displaying the distribution of the scores on each clinical measure are displayed in Appendix 14. The scores on the GDS-LD appear to be normally distributed and thus acceptable. There is an indication of a slight positive skew to the distribution of the scores on the adapted PHQ-9, GDS-LD and GAS-ID measures, but statistical investigations of skewness and kurtosis indicate that the distributions of the clinical measures can be considered normal as $z < 2.58$ ($p > 0.01$). Outliers, a frequent source of bias, were not evident on the histograms for any of the measures, (Field, 2014). Thus preliminary checks of normality verified that the data were suitable for parametric analysis.

3.2.3.2 INVESTIGATING THE PRESENCE OF BETWEEN GROUP DIFFERENCES:

3.2.3.2.1 CLINICAL AND NON-CLINICAL GROUPS:

Following the expansion of recruitment to the research beyond solely clinical settings, it was decided that the initial psychometric enquiry should check for differences in scores on the measures between those who were recruited in clinical settings (i.e. those participants currently accessing psychological support) and those who were recruited from non-clinical settings. This was based on the presumption that individuals who were recruited in clinical settings were more likely to have a clinical diagnosis of anxiety and/or depression and so would score more highly on the clinical measures of anxiety and/or depression. Thus initial enquiries in Stage 2 focussed on determining the presence of any difference in scores on the

clinical outcome measures between participants who were recruited in clinical and non-clinical settings.

An independent samples t-test was used to compare the adapted PHQ-9 scores of clinical and non-clinical participants. Separate variance estimates were used as homogeneity of variance assumptions was not met ($F = 0.04, p = 0.85$). There was no statistically significant difference in depression scores between groups measured by the adapted PHQ-9 measure ($t(29) = -0.79, p = 0.44$).

An independent samples t-test was also used to compare the adapted GDS-LD scores of clinical and non-clinical participants. Separate variance estimates were used as homogeneity of variance assumptions was not met ($F = 1.15, p = 0.29$). There was no statistically significant difference in depression scores between groups measured by the GDS-LD measure ($t(26) = -1.46, p = 0.16$).

An independent samples t-test was used to compare the adapted GAD-7 scores of clinical and non-clinical participants. Separate variance estimates were used as homogeneity of variance assumptions was not met ($F = 0.06, p = 0.82$). There was no statistically significant difference in anxiety scores between groups measured by the adapted GAD-7 measure ($t(28) = -0.71, p = 0.48$).

Similar comparisons between the adapted GAS-ID scores of clinical and non-clinical participants were completed. Separate variance estimates were used as homogeneity of

variance assumptions was not met ($F = 0.35$, $p = 0.56$). There was no statistically significant difference in anxiety scores between groups measured by the GAS-ID ($t(28) = -0.61$, $p = 0.55$).

There is therefore no evidence that these two groups scored significantly differently on clinical measures of depression (PHQ-9; GDS-LD) or anxiety (GAD-7; GAS-ID). As the same finding was present for both sets of measures, this seems to suggest that there is no difference between these groups and therefore no reason to split the sample according to whether or not participants had been recruited from a clinical or a non-clinical setting.

3.2.3.2.2 PRESENTATION OF CLINICAL SYMPTOMS RELATING TO DEPRESSION AND ANXIETY:

In the absence of between group differences in scores on the clinical measures of depression (PHQ-9; GDS-LD) or anxiety (GAD-7; GAS-ID) based on the type of setting which individuals were recruited from, further statistical investigations were completed to determine if the sample could be re-grouped more meaningfully into groups presenting with 'high' and 'low' levels of depression and anxiety. The authors of the Glasgow Scales suggest a clinical cut off of 13 on the established GDS-LD and GAS-ID (Cuthill et al., 2003b; Mindham & Espie, 2003) and this figure was used to recode each participant as high depression / anxiety (i.e. scoring equal to or above this threshold) or low depression / anxiety (i.e. scoring below this threshold) and to group them accordingly.

Seventeen participants in the sample (53.1%) scored above the suggested clinical cut off for depression on the GDS-LD and 14 (43.8%) scored below this threshold, with one participant representing missing data (3.1%). An independent samples t-test was used to compare the total scores for the adapted PHQ-9 outcome measure for participants who scored above and

below the suggested clinical cut off on the GDS-LD measure. Levene's test for homogeneity of variance indicates that separate variance estimates should be used ($F = 0.34$, $p = 0.56$). Participants who scored above the clinical cut off on the GDS-LD (representing 'high depression' group) scored significantly higher on the adapted PHQ-9 (mean = 11.24, standard deviation = 4.96) than did those who scored below this clinical cut off on the GDS-LD (mean = 4.43, standard deviation = 3.91) ($t(29) = -4.27$, $p < 0.001$).

Twenty-one participants (65.6%) in the sample scored above the suggested clinical cut off for anxiety on the GAS-ID and 11 participants (34.4%) scored below this threshold. An independent samples t-test was used to compare the total scores for the adapted GAD-7 outcome measure for participants who scored above and below the suggested clinical cut off on the GAS-ID measure. Levene's test for homogeneity of variance indicates that separate variance estimates should be used ($F = 3.50$, $p = 0.07$). Participants who scored above the clinical cut off on the GAS-ID (representing 'high anxiety' group) scored significantly higher on the adapted GAD-7 (mean = 9.71, standard deviation = 5.04) than did those who scored below this clinical cut off on the GAS-ID (mean = 3.00, standard deviation = 2.90) ($t(30) = -4.78$, $p < 0.001$).

There was therefore evidence to suggest that it might be more meaningful to re-group the sample into those who score above and below the clinical thresholds on the GDS-LD and GAS-ID. Thus the research team decided that it was justifiable to separate the groups forthwith according to whether participants showed high or low levels of depression or anxiety according to the thresholds of the Glasgow Scales suggested by the authors (Mindham & Espie 2003; Cuthill, Espie, & Cooper 2003).

3.2.3.3 RE-ASSESSING THE NORMALITY OF THE SAMPLE:

Investigations assessing the normality of the sample were repeated separately for the participants who scored above and below the defined thresholds on the Glasgow Scales (i.e. high / low for depression / anxiety). The data file was thus split to enable analyses for separate subgroups. Statistical investigations of skewness and kurtosis indicate that the distributions of the clinical measures can be considered normal as $z < 2.58$ ($p > 0.01$). Thus there is evidence that the distributions of data within clinical and non-clinical groups based on participants scoring above or below the thresholds on the Glasgow Scales are suitable for parametric analysis.

3.2.3.4 PRELIMINARY INVESTIGATIONS OF THE VALIDITY OF THE ADAPTED MEASURES:

The participants in the Stage 2 sample completed clinical measures of depression (adapted PHQ-9; GDS-LD) and anxiety (adapted GAD-7; GAS-ID) on the same occasion. To complete initial investigations of criterion validity, statistical investigation focused on determining whether or not positive linear correlations could be observed between participants' scores on the clinical measures. Cohen's (1988; 1992) suggestions for operational definitions for effect sizes are used to describe findings qualitatively.

Initial investigations of the concurrent validity of the clinical measures for depression in the adult intellectual disability population were assessed via scatterplots. Appendix 15 displays the scatterplots of the total scores on the adapted PHQ-9 and the GDS-LD; these indicated a strong positive correlation with no evident outliers. Further statistical investigation of

possible correlation using Pearson's parametric correlation between these variables reveals a significant positive correlation between total scores on the PHQ-9 and the GDS-LD. In other words, higher scores on the adapted PHQ-9 were associated with higher scores on the GDS-LD ($r(29) = 0.80, p < 0.001$). There is thus evidence for an 80% shared variance between total scores on the PHQ-9 and the GDS-LD, indicating that there is excellent criterion validity between these outcome measures.

Similar investigations of concurrent validity of the clinical measures for anxiety were completed with the scatterplots between total scores indicating a strong positive correlation with no outliers (see Appendix 16). Pearson's parametric correlation between these variables reveals a significant positive correlation between total scores on the adapted GAD-7 and the GAS-ID, that is, higher scores on the GAD-7 were associated with higher scores on the GAS-ID ($r(30) = 0.66, p < 0.001$). Thus there is evidence of a 66% shared variance between total scores on the GAD-7 and the GAS-ID, suggesting excellent criterion validity between these measures for adults with intellectual disability.

The GAS-ID is structured by the authors into three sub-scales: *Worries* comprising ten items; *Specific Fears* comprising nine items; and *Physiological Symptoms* comprising eight items. As the GAD-7 outcome measure is a brief measure which focuses on the more general symptoms associated with anxiety, additional investigations of concurrent validity between the total score on the adapted GAD-7 and the relevant sub-scale scores were completed. Pearson's parametric correlation between these variables reveals a significant positive correlation between total scores on the adapted GAD-7 and the *Worries* subscale of the GAS-ID, that is higher scores on the GAD-7 were associated with higher scores on the *Worries* subscale of

the GAS-ID ($r(30) = 0.80, p < 0.001$). Pearson's parametric correlation between these variables also reveals a significant positive correlation between total scores on the GAD-7 and the *Specific Fears* subscale of the GAS-ID, that is higher scores on the GAD-7 were associated with higher scores on the *Specific Fears* subscale of the GAS-ID ($r(30) = 0.74, p < 0.001$). Pearson's parametric correlation between these variables reveals a weak positive correlation between total scores on the GAD-7 and the *Physiology* subscale of the GAS-ID ($r(30) = 0.36, p < 0.05$). There is therefore evidence that the positive correlations identified between the adapted GAD-7 and the GAS-ID are due to participants scoring highly on the *Worries* and *Specific Fears* subscales rather than on the GAS-ID measure as a whole. There is further discussion of this in the next chapter.

3.2.3.5 PRELIMINARY INVESTIGATIONS OF THE RELIABILITY OF THE ADAPTED MEASURES:

Investigations of the internal consistency of the adapted measures were completed using Cronbach's alpha analyses. Highly satisfactory internal consistency was demonstrated for both the adapted PHQ-9 outcome measure total score ($\alpha=0.85$ $n=31$) and the adapted GAD-7 measure total score ($\alpha=0.91$ $n=32$).

3.2.3.6 INVESTIGATIONS OF THE SENSITIVITY AND SPECIFICITY OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES:

Sensitivity represents the proportion of true positive outcomes that are correctly identified by a diagnostic test and specificity is the proportion of true negative outcomes that are correctly identified by a diagnostic test (Altman & Bland, 1994a). The diagnostic accuracy of an instrument to correctly classify clinical and non-clinical cases within a sample was

evaluated using receiver operating characteristic [ROC] curve analysis using SPSS, including the identification of potential clinical cut offs which provide an appropriate balance of sensitivity and specificity (Altman & Bland, 1994; Metz, 1978; Zweig & Campbell, 1993).

In the current investigation, the Glasgow Scales clinical cut-offs (Cuthill et al., 2003; Mindham & Espie, 2003) and the clinical thresholds suggested for the minimum dataset in the general population (NDTi 2011) were used to quantify the diagnostic ability of the adapted PHQ-9 and GAD-7 measures to identify those individuals in the sample who scored at clinical levels. It is important to note for clarity that it is not the intention here to determine whether the adapted PHQ-9 measure is sensitive to whether participants have clinical levels of depression as we do not have 'clinically diagnosed' and 'non-clinically diagnosed' groups. We are investigating whether participants who score at clinical levels on the Glasgow scales score similarly on the adapted measures.

3.2.3.6.1 CLINICAL MEASURES OF DEPRESSION:

GDS-LD						
ADAPTED PHQ-9		ABOVE CUT OFF		BELOW CUT OFF		TOTAL
	ABOVE CUT OFF	TRUE POSITIVE	N	FALSE POSITIVE	n	14
		65%	13	9.1%	1	
	BELOW CUT OFF	FALSE NEGATIVE	N	TRUE NEGATIVE	n	17
		35%	7	90.9%	10	
TOTAL		20		11		

Table 4: Schematic outcomes of the depression measures used in the current study

Thus there is a demonstrated 65% probability that if an individual scores above the clinical threshold on the Glasgow measure for depression (GDS-LD), that they will also score above the clinical threshold on the adapted PHQ-9 measure of depression. Additionally if an individual scores below the clinical threshold on the Glasgow measure for depression (GDS-LD), there is a 90.9% probability that they will also score below the clinical threshold on the adapted PHQ-9 measure of depression. The likelihood of the adapted PHQ-9 measure not identifying participants who display high scores that reach the clinical threshold on the GDS-LD is 35%. Furthermore 9.1% of participants are indicated to be incorrectly identified as having symptoms of depression reaching a clinical level on the adapted PHQ-9 using the standard clinical thresholds suggested for the measure in the general population. IAPT currently administers these measures in non-adapted form as part of the minimum dataset to clients with intellectual disabilities accessing these services (Chinn et al., 2014; IAPT, 2009; Radcliffe et al., 2011). Thus, there is evidence that the cut offs which are used by IAPT services to indicate clinical presentation of depression in the general population do not provide an appropriate balance of sensitivity and specificity for the adult intellectual disability population.

The ROC curve for the total scores indicates that participants who score at the clinical threshold for depression on the GDS-LD also score highly on the adapted PHQ-9 measure, indicating that both measures are sensitive to identifying symptoms relating to depression in adults with intellectual disabilities (see Appendix 17). The area under the curve is computed as 88.2% and participants scoring at the clinical threshold on the GDS-LD were identified by the total PHQ-9 score at significantly higher than chance ($p < 0.001$). The co-ordinates of the

ROC curve can be examined to suggest a clinical cut-off for the adapted PHQ-9 of between six and nine could be more appropriate in comparison to the standard clinical cut off for the PHQ-9 of ten or higher (IAPT, 2012); around 6.5 could be expected to produce values of 0.94 sensitivity (that is 94.1% of people scoring at a clinically depressed level on the GDS-LD are also correctly identified by the PHQ-9) and 0.21 specificity (that is 21.4% of people who are not scoring as depressed on the GDS-LD would be incorrectly classified as depressed according to the suggested PHQ-9 clinical cut off) and 8.5 could be expected to produce values of 0.65 sensitivity and 0.14 specificity. The validity of these proposed clinical cut offs require further investigation which is beyond the scope of the current study.

3.2.3.6.2 CLINICAL MEASURES OF ANXIETY:

		GAS-ID				TOTAL
		ABOVE CUT OFF		BELOW CUT OFF		
ADAPTED GAD-7	ABOVE CUT OFF	TRUE POSITIVE	n	FALSE POSITIVE	n	11
		55%	11	0%	0	
	BELOW CUT OFF	FALSE NEGATIVE	n	TRUE NEGATIVE	n	21
		45%	9	100%	12	
TOTAL		20		12		

Table 5: Schematic outcomes of the anxiety measures used in the current study

Thus there is a demonstrated 55% probability that if an individual scores above the clinical threshold on the Glasgow measure for anxiety (GAS-ID), that they will also score above the clinical threshold on the adapted clinical measure for anxiety (adapted GAD-7). Additionally if an individual scores below the clinical threshold on the Glasgow measure for anxiety (GAS-

ID), there is a 100% probability that they will also score below the clinical threshold on the adapted clinical measure for anxiety (adapted GAD-7). The likelihood of the adapted measure not identifying participants who display high scores that reach the clinical threshold on the GAS-ID is 45%. Furthermore no participants are indicated to be incorrectly identified as having high symptoms of anxiety reaching a clinical level on the adapted GAD-7 using the standard clinical thresholds suggested for the measure in the general population. Thus, there is evidence that the cut offs which are used by IAPT services to indicate clinical presentation of anxiety in the general population do not provide an appropriate balance of sensitivity and specificity for the adult intellectual disability population.

The ROC curve for the total scores indicates that participants who score at the clinical threshold for anxiety on the GAS-ID also score highly on the adapted GAD-7 measure, indicating that both measures are sensitive to identifying symptoms relating to depression in adults with intellectual disabilities (see Appendix 18). The area under the curve is computed as 89.4% and participants scoring above the clinical threshold on the GAS-ID were identified by the total GAD-7 score at significantly higher than chance ($p < 0.001$). The co-ordinates of the ROC curve can be examined to suggest a clinical cut-off for the adapted GAD-7 of between five and eight could be appropriate in comparison to the standard clinical cut off for the GAD-7 of eight or higher (IAPT, 2012); around five could be expected to produce values of 0.94 sensitivity (that is 94.1% of people scoring as at a clinically anxious level on the GAS-ID are also correctly identified by the GAD-7) and 0.36 specificity (that is 35.7% of people who are not scoring as anxious on the GAS-ID would be incorrectly classified as anxious according to the suggested GAD-7 clinical cut off), and 8.5 could be expected to produce values of 0.65

sensitivity and 0.14 specificity. The validity of these proposed clinical cut offs require further investigation which is beyond the scope of the current study.

3.3 FEEDBACK ABOUT THE ADAPTED VERSIONS OF THE PHQ-9 AND GAD-7 MEASURES:

Feedback was sought from clinicians who completed the adapted PHQ-9 and GAD-7 measures in Stage 2, both formally via an 'Administrators' Feedback Form' and informally by the researcher once data had been collected. The 'Administrators' Feedback Form' was included in the research packs of documents supplied to clinicians at the outset and a copy is supplied in Appendix 13. Informal feedback was also sought from all those involved in recruitment for Stage 2, including those who supported the completion of the research in group and non-clinical settings. The feedback enquiries specifically sought information and opinions about the following: the time taken to complete the adapted measures with participants; how easy it was to administer; how acceptable the adapted measures were to the service user; whether there were any specific items that were difficult to administer; and whether any other general comments occurred to the respondents. Collecting feedback from clinicians and staff members who had supported adults with intellectual disabilities provided valuable information about the appropriateness and validity of the adapted measures, the issues which lie at the heart of this research project. The researcher supported the completion of data collection in the service user advocacy group and thus was able to obtain additional information about the administration and acceptability of the measures. Some service users took up the opportunity afforded by the open text box on the final page of the feedback document and these comments are also considered in this analysis.

3.3.1 ADMINISTRATORS' FEEDBACK FORM RESPONSES:

Seven completed Administrators' Feedback Forms were collected, all of them produced by clinicians working in psychological therapy services. It is important to note that some of the forms might not relate to a single administration of the adapted measures, as some clinicians collected data with more than one participant (e.g. in group settings).

3.3.1.1 ADAPTED PHQ-9 ADMINISTRATORS' FEEDBACK FORM RESPONSES:

The reported time taken for administering this measure in Stage 2 ranged from three to nine minutes (mean = 5.42, standard deviation = 2.07). The 'Administrators' Feedback Form' asked respondents to rate the ease of administration of the adapted measures on a scale of zero to ten, where ten represents very easy to administer. The adapted version of the PHQ-9 was rated to be easy to administer by clinicians (mean = 9.29, standard deviation = 1.12). Similarly, respondents were asked to rate acceptability to participants with intellectual disability, and on this the adapted version of the PHQ-9 was rated as acceptable to participants (mean = 9.14, standard deviation = 1.46). Administrators revealed that participants experienced some difficulty completing items on the adapted PHQ-9 measure and required extra support to do so, specifically item 2 which asks *'Have you felt sad?'* (one occurrence), item 7 which asks *'Has it been hard to concentrate on things?'* (one occurrence) and item 8 which asks *'Have you been moving or speaking more slowly or moving or speaking a lot faster?'* (two occurrences). The general comments section on the feedback form did not detail what specific difficulty the participants experienced but revealed that clinicians used the 'Clinician Guidelines for using the adapted PHQ-9 and GAD-7 clinical measures' (Appendix 12) to support participants' understanding of these items. They also reported that the suggested alternative terms and the prompt examples had proved particularly useful.

3.3.1.2 ADAPTED GAD-7 ADMINISTRATORS' FEEDBACK FORM RESPONSES:

The reported time taken for administering this measure in Stage 2 ranged from three to nine minutes (mean = 6.00, standard deviation = 2.08). Using the same system as previously, clinicians rated the adapted version of the GAD-7 as easy to administer (mean = 9.14, standard deviation = 1.46,) and acceptable to participants (mean = 9.00, standard deviation = 1.73). Administrators revealed that participants experienced some difficulty completing items on the adapted GAD-7 measure and required extra support to do so, specifically item 1 which asks *'Have you been feeling worried?'* (one occurrence), item 2 which asks *'Has it been hard to stop worrying?'* (two occurrences) and item 3 which asks *'Have you been worrying about lots of different things?'* (one occurrence).

3.3.1.3 QUALITATIVE FEEDBACK FROM ADMINISTRATORS:

3.3.1.3.1 POSITIVE FEEDBACK ABOUT THE ADMINISTRATION OF THE ADAPTED MEASURES:

General comments about the use of the adapted measures indicated that it was easier for administrators to support the completion of the adapted measures with adults with intellectual disabilities than was the case with either the standard IAPT measures or the Glasgow Scales. A frequent comment was that participants had an increased understanding of the items on the questions in the adapted versions of the PHQ-9 and GAD-7 and were accordingly able to achieve accurate completion of the measures with less reliance on the support available from the administrators. A number of administrators reported that their clients also expressed a preference for completing the adapted measures or found these easier to complete. One administrator commented that he perceived it to be more

meaningful for participants to complete the adapted PHQ-9 and GAD-7 measures than the Glasgow Scales. The visual cues which supported the understanding of the items and the response options were highlighted by administrators as particularly helpful in aiding participants' understanding.

A particularly supportive view came from the facilitators of the clinical group in Stage 2 of the study who had previously used the original versions of the PHQ-9 and GAD-7 on a session by session basis in order to monitor outcomes in line with IAPT's wider data collection process (NDTi, 2011). These reported that:

"In terms of feedback, I think the amended versions are really user friendly, and definitely a lot quicker for clients to complete...We plan to continue using your version throughout the sessions."

3.3.1.3.2 CHALLENGES REPORTED BY THE ADMINISTRATORS OF THE ADAPTED MEASURES:

Challenges were also reported by the administrators who had supported participants with intellectual disabilities in their completion of the adapted versions of the PHQ-9 and GAD-7 during Stage 2. It was felt that some items were particularly difficult for participants to understand. The administrators therefore noted and reported the individual items on which participants most frequently asked questions and on which support was given. These included items covering a change in appetite [PHQ-9 item 5] and movement [PHQ-9 item 8]. However, these same administrators also reported that the clinician guidelines gave clear guidance on how to support the participants who experienced such difficulties. The administrators particularly welcomed the alternative terms and examples provided.

One administrator reported that the participant they were supporting required reminders that the questions on the adapted measures were asking him/her to report on the last two-week period. It is unclear whether the administrator had followed the advice contained in the clinician guidelines which suggested that participants be orientated on the time scale using a personal point in time as an anchor point.

Another area of difficulty was reported by an administrator who worked as a clinician in an IAPT service. She reported that, although the adapted measures were easier to complete, they required more thought from her as an administrator. She felt that in terms of administration and scoring the standard minimum dataset was easier to implement than were the adapted measures.

3.3.1.5 FEEDBACK FROM PARTICIPANTS ABOUT COMPLETING THE ADAPTED PHQ-9 AND GAD-7:

At the end of the session attended by the researcher, the group provided general feedback about the adapted versions of the measures. They were supported in this by the researcher. In their view the adapted measures were accessible and easy to use; in particular, the pictures were seen as helpful and the wording of the questions as clear. The group feedback included the opinion that the Glasgow Scales were more difficult to understand. Particular criticisms of the Glasgow scales included the view that there was a confusing number of sub-questions for each item and that the lack of pictures created difficulties.

Although some participants chose to write extra information about their answers at the end of the adapted measures, one also wrote feedback about the adapted versions of the PHQ-9 and the GAD-7 measures:

“ I find the pictures help me as a guide and [with] reading. Pictures are more visual and helps”

[Participant 27)

CHAPTER 4: DISCUSSION

This study used a cognitive interviewing approach to investigate the extent to which adaptations to the PHQ-9 and the GAD-7 had addressed the needs of adults with intellectual disabilities. This avowed objective of the original authors of the adaptations is of great importance, given that these two clinical measures are frequently used to assess mental wellbeing as part of IAPT's minimum data set. The study used two rounds of cognitive interviews to test the adapted measures and to generate further adaptations. All those interviewed were adults with intellectual disabilities and all had experience of accessing IAPT services. The final versions of the adapted PHQ-9 and GAD-7 thus produced were then completed alongside clinical measures for depression (GDS-LD) and anxiety (GAS-ID) already established for use in the intellectual disability population. This made possible an initial investigation of the psychometric properties of the adapted measures. The processes thus briefly outlined were dealt with in detail in previous chapters.

This final chapter summarises the study findings as they relate to the research questions before considering in greater detail the existing literature base and the implications for future research and clinical practice. Finally, the strengths and limitations of the current study are discussed and recommendations for future research accordingly outlined.

4.1 SUMMARY OF MAIN FINDINGS:

The PHQ-9 and GAD-7 clinical measures used to assess symptoms of depression and anxiety are part of IAPT's minimum data set and central to tracking recovery after clinical intervention. Devising appropriate adjustments for the measures is therefore crucial if adults

with intellectual disability are to be able to access the measures themselves and, through them, mainstream psychology services (DoH, 2008b; IAPT, 2009; Hamilton et al., 2011; NDTi, 2012; Chinn, Abraham, Burke, & Davies, 2014). The current study used cognitive interviewing to develop adapted versions of the measures and psychometric enquiry to test their validity. The results of this enquiry, conducted with a small sample of adults with intellectual disability (n = 31), were encouraging.

The further changes to the adapted PHQ-9 and GAD-7 clinical measures sought to aid participants' comprehension both of the items themselves and of the response options offered. The research team and participants judged that these changes further improved the adapted measures and increased the validity of the resulting data. Furthermore, participants in Stage 1 of the study provide strong evidence that the adapted PHQ-9 and GAD-7 measures are appropriate for use with adults with intellectual disability.

As indicated above, initial psychometric investigation has proved encouraging. The PHQ-9 measure correlated with the established self-report Glasgow Scale for depression ($r = 0.80$), had good internal consistency ($\alpha = 0.85$) and using a cut-off score of 6.5 yielded 94.1% sensitivity and 21.4% specificity. The GAD-7 measure correlated with the established self-report Glasgow Scale for anxiety ($r = 0.66$) and had good internal consistency ($\alpha = 0.91$). A proposed cut-off score of five representing a clinical threshold for anxiety for adults with intellectual disability yielded 94.1% sensitivity and 35.7% specificity. These demonstrated correlations suggest that the adapted versions of the PHQ-9 and GAD-7 which were developed as part of the current study are potentially useful when assessing depression and anxiety in people with intellectual disabilities, as participants scored similarly on outcome measures developed specifically for the intellectual disability population (i.e. the Glasgow

scales) and on adapted versions of outcome measures developed for the general population (i.e. PHQ-9 and GAD-7). However, as there is also evidence that the clinical cut offs which are used by IAPT to measure depression and anxiety in the general population do not provide an appropriate balance of sensitivity and specificity for people with intellectual disability, the current study also suggests that there may be some differences in the presentation of these mental health problems in the intellectual disability population and the general population as the appropriate clinical cut offs for each may be different.

Following initial quantitative enquiry, it was decided that using the data to identify 'high' and 'low' groups based on whether participants scored above or below clinical cut-offs on established measures for this population was the most meaningful way to split the data sample. This provided an impartial measure of the presentation of symptoms related to depression and anxiety in individuals with intellectual disability.

4.2 INTERPRETATION OF THE KEY RESULTS:

4.2.1 COGNITIVE INTERVIEWING (STAGE 1):

Stage 1 of the study involved completing two rounds of cognitive interviews with adults with intellectual disability. These aimed to support understanding of the PHQ-9 and the GAD-7 measures and were in line with methodological recommendations for the development and initial validation of questionnaires (Willis, 2005). A range of helpful adaptations resulted, suggested by and discussed with adults with intellectual disability. Modifications affected the wording of questions, the use of pictures, response scoring options and the overall layout of the measures. Curtailing the information displayed was a key part of the attempt to minimise

the burden on the reader (Buell, 2015). Maintaining consistency between the original versions of the PHQ-9 and GAD-7 and the adapted versions was a priority. Existing easy read guidance (DoH, 2010b; MENCAP, 2008; NDTi, 2016) and research (Buell, 2015; Hurtado et al., 2014; Sutherland & Isherwood, 2016) was consulted and helped to shape the changes made. The bulk of easy read literature focuses on enabling individuals with intellectual disabilities to make informed healthcare decisions. In this it differs from this study, but many of the concepts and recommendations for good practice are common to both.

The version of the adapted measures used in the initial round of cognitive interviews (i.e. Stage 1.1) largely retained the wording of the original PHQ-9 and GAD-7. A key aim at this stage was to eliminate jargon whilst ensuring that the wording of the questions still clearly accessed the targeted constructs of the items. It was often difficult to decide which terms most clearly and accurately accessed the targeted constructs for people with intellectual disability. For example, participants were split over whether *“focus on”* or *“concentrate”* was their preferred term in PHQ-9 item 7 (*“Has it been hard to concentrate on things?”*). During the two rounds of cognitive interviews, participants spoke at length about which terms they thought most appropriate for themselves and for others with intellectual disability. Stage 1 led to significant changes. These meant that in the final version of the adapted measures (Version 3) each item consisted of a single short question using one term to describe the targeted construct. Questions which required more than one part were broken down using bullet points. Throughout the cognitive interviews participants were encouraged to consider how the items on the questionnaires could be made more accessible. Concrete examples, alternative terms and prompts were amongst the suggestions to emerge and these were noted by the research team. These ideas were usually incorporated into the guidance for

clinicians so as to avoid making the questionnaires themselves too confusing. This decision reflected the belief that overburdening the reader with repeated information was not helpful (Buell, 2015). It also accorded with the views of participants in Stage 1.1, who frequently complained that the use of multiple terms in items created confusion. PHQ-9 item 2 (*Have you felt down? Have you felt depressed? Have you felt hopeless?*) was amongst those thus criticised.

During Stage 1, participants were also prompted to think about whether the pictures used to support understanding were easy to understand and appropriately positioned or instead needed clarification. They overwhelmingly felt that improvement was needed in these matters, a view that led the team to source and incorporate CHANGE People images instead of those contained in the versions of the adapted measures used in Stage 1.1. A further consideration here was the avoidance of potential copyright issues. The replacement images had numerous advantages. They used less colour and this was seen as advantageous given that the literature suggests that it assists comprehension in the intellectual disability population (Buell, 2015). Line drawings in general are judged to be helpful for people with milder intellectual disabilities and this is the population most likely to be accessing support from mainstream services such as IAPT. Even more specifically, there is evidence from other studies suggesting that participants with intellectual disability prefer CHANGE People illustrations over other line drawn illustrations (Strydom, Forster, Wilkie, Edwards, & Hall, 2001). The CHANGE People visual cues had the further recommendation that they were directly aimed at the situations dealt with in the PHQ-9 and GAD-7 measures. Ideally this study would have commissioned and used its own photos as visual cues designed around the feedback offered by participants in Stage 1, but neither time nor funding made this a realistic

possibility.

Having thus decided to use the CHANGE People images the researchers viewed each in turn, judging them in the light of participants' comprehension and concerns raised in Stage 1.1 They also considered their arrangement. These changes fed into Version 3 of the PHQ-9 and GAD-7 measures. Thus this final set of pictures is the one judged by the research team to both reflect the measures' meaning and to be easy to read (Sutherland & Isherwood, 2016). Participants in Stage 1.2 endorsed this opinion, clearly stating that the visual cues supported their understanding of the items on Version 3 of the measures and that by doing so they enabled them to provide more accurate responses.

Standardising the response scoring options for the adapted PHQ-9 and GAD-7 in a format that clear for participants with intellectual disability whilst remaining wholly consistent with the original versions of the measures was one of the most challenging aspects of Stage 1. Participants in Stage 1.1 clearly stated that they had difficulty in understanding the scoring instructions and the response options for the items on Version 1 of the measures. They also felt that the visual cues were not helpful with the calendar, for example, being seen as both unclear and too small. Significant changes were therefore made to the item scoring for Version 2 of the measures. These were discussed in Stage 1.2, with the research team suggesting increased precision about the number of days covered by each response option and a simplified visual cue which was in line with a clinical outcome measure already in use with the intellectual disability population (Brooks et al., 2013). An easy read cover page explaining how to complete the adapted measures was also added with the aim of increasing the accessibility of the response scoring. Participants in Stage 1.2 reported that the changes

left them better able to report on the measures, but issues with the scoring options remained. For example, participants reported that the increase in precision created confusion by apparently requiring them to remember the exact number of days on which they had experienced each symptom. Version 1 of the adapted PHQ-9 and GAD-7 measures mirrored the scoring options of the original versions and was less precise. Instead of asking about the exact number of days being covered within the scoring options it offered vaguer options: *'not at all'*, *'several days'*, *'more than half the days'* and *'nearly every day'*. The research team therefore decided that it was counterproductive to increase the precision of the response option wording by adding the number of days referred to. Version 3 accordingly retained the wording used in the original scoring options. Visual cues provided additional guidance about the proportion of the past two weeks being referred to in each response option. Additional guidance on how to explain the specific number of days referred to in each option was included in the clinician guidelines. These strategies alleviated but did not completely remove concerns about the validity of a two-week report period for the PHQ-9 and GAD-7. This period corresponds to the DSM diagnostic criteria for depression (APA, 2015; Kroenke et al., 2001), but the cognitive impairment experienced by individuals with intellectual disabilities may well mean that they are unable to reliably self-report symptoms occurring over a two-week period. This issue was clearly raised during the cognitive interviews conducted with participants in this study. Interestingly, the authors of the original measures themselves reported that the response period has been shortened to one week in some settings. Telephone surveys in the general population were amongst the settings in which this had been found to be desirable (Kroenke et al., 2010). The diagnostic criteria for particular anxiety disorders specifies that symptom duration must be at least six months (APA, 2015), but recognises that a shorter screen for symptoms remains valid in some populations (Kroenke et al., 2010). It may well

be that reporting on the incidence of symptoms over a one-week period is appropriate for the intellectual disability population. It is in any case unclear whether IAPT services are in practice measuring symptomatology over the past week or fortnight, particularly as clients are typically seen for weekly appointments and may then report changes in their symptoms arising since their previous appointment. Currently, no research has empirically investigated the validity of the two-week report period for these measures. It may well be that we are making assumptions about the accuracy of this report period even for people without intellectual disability. In sum, this may be a wider issue than first appears.

Following Stage 1, changes were also made to the overall PHQ-9 and GAD-7 measures. These involved using large clear text and adjusting the layout. Key considerations included having a maximum of two items per page, using colour where appropriate and employing single sided printing so as to minimise the risk of confusion in readers moving between pages. Although many services put clients' responses into a computer system which automatically scores the measures, a total score box for each of the measures was included. This was done after consultation with the IAPT services involved in the current study so as to help the administrator when scoring and interpreting the adapted measures. The possibility of including additional information about scoring, such as the score associated with each response option, was considered, but on balance the research team decided that it was more important to keep the adapted measures as straightforward as possible. Additional information which might assist some administrators or respondents was therefore provided separately in the clinician guidelines and made available on an individual basis.

Stage 1 of the current study set out to evaluate the adapted PHQ-9 and GAD-7 measures using

a cognitive interviewing methodology. It specifically sought to establish whether or not people with intellectual disability are able to understand and respond appropriately to each item in the measures. This is in line with recommendations made to improve the quality of easy read documents in healthcare settings (Sutherland & Isherwood, 2016). It is important to note here that the study meets the five proposed minimum methodological criteria outlined in the quality appraisal tool relating to its purposes. These are: the inclusion of data; an evaluation component of easy read resources; using easy read to increase understanding; producing the easy read document in written or printed form; and including a description of the design process which produced the easy read document.

Stage 1 also involved the development of guidelines to support clinicians in completing the adapted PHQ-9 and GAD-7 with clients. This was especially important for those who lacked experience of or training in working with people with intellectual disabilities. This provision of assistance for clinicians is in accordance with recommendations arising from research (Shankland & Dagnan, 2015; Walmsley, 2013) and stressing the importance of being able to provide flexible levels of tailored support when working with individuals with intellectual disability (Chinn & Homeyard, 2016). Data gathered from participants in Stage 1 was used to shape the guidelines issued to clinicians, which included the alternative terms and helpful examples discussed during cognitive interviews. The clinicians who supported data collection in Stage 2 of the current study reported that the document had proved helpful but that there were still some challenges to address. In particular they raised questions about three items on the adapted PHQ-9 and three on the adapted GAD-7. They felt that these were still difficult for clients with intellectual disabilities to understand. Two clinicians reported that PHQ-9 item 8 (*'Have you been moving or speaking more slowly? Or moving or speaking a lot faster?'*) and

GAD-7 item 2 (*'Has it been hard to stop worrying?'*) were difficult for participants to grasp, although one reported that information in the clinician guidelines had facilitated understanding. The response rate for the Administrators' Feedback Forms on which such issues were reported was low (n = 7). It therefore remains unclear whether or not the problems thus highlighted are widespread and hence how necessary further attention is. Some items on the measures inevitably deal with quite abstract concepts and it might well be the case that not all items can be made wholly comprehensible for every adult with an intellectual disability.

4.2.2 INITIAL PSYCHOMETRIC ENQUIRY (STAGE 2):

Stage 2 focused on whether or not initial psychometric investigations indicate that the adapted measures are useful and valid for measuring symptoms of anxiety and depression in adults with intellectual disabilities. This question was at the heart of the enquiry, but inevitably led to consideration of the overall quality of the adapted measures. Here the approaches taken in a number of systematic reviews of the outcome measures used in psychological therapies with the intellectual disability population proved extremely useful. These were as follows: Vlissides, Golding, & Beail, 2016; Fitzpatrick and colleagues' criteria (1998); and Cahill and colleagues' rating tool (2008). On this basis, the quality of self-report measures was considered and the current evidence for the quality of the adapted PHQ-9 and GAD-7 measures assessed (see Appendix 19). The quality of outcome measures is considered in its various aspects, with reliability, validity, responsiveness, acceptability, feasibility and precision separately rated as *'adequate'*, *'partially adequate'*, *'inadequate'* or *'unknown'* based on the existing demonstrated evidence (Fitzpatrick et al., 1998; Cahill et al., 2008; Vlissides et al., 2016). As the current investigation constitutes only an initial quantitative

enquiry, the approach highlights the areas of enquiry recommended for more in-depth psychometric research. Information gathered in Stage 1 of the research project is also relevant to an assessment of the quality of the adapted PHQ-9 and GAD-7 measures, and this is included in this chapter where appropriate.

Recruitment for the study was challenging and this resulted in deviations from the planned research protocol described in Section 2.4.1. Most notably, Stage 2 recruitment was expanded to further IAPT services and subsequently to non-clinical sites. Clinicians in the IAPT services reported that poor recruitment was predominantly due to low numbers of eligible participants accessing the services within the recruitment window. It is important to note that there was no suggestion that this indicated low levels of need within this population. The symptomatology related to anxiety and depression evident within the sample used was a further indication of need. All participants seemed entitled to appropriately adjusted talking therapies, as outlined by national policy (DoH, 2008b; HM Government, 2009, 2010).

The absence of demonstrated between-group differences arising from whence participants in Stage 2 were recruited (i.e. 'clinical' as opposed to 'non-clinical') was also interesting, but the reasons for this remain unclear. This could reflect the difficulties faced by individuals with intellectual disabilities seeking to access support from mainstream services. Participants recruited in non-clinical settings may also have been accessing psychological intervention elsewhere. Clinical participants were recruited without reference to the time point reached in their contact with the service and the possibility that individuals who had recovered at the end of treatment were included in the clinical sample was also considered. On balance, the current study supports the suggestion that individuals with intellectual disabilities might well

have high needs for intervention for mental ill-health and yet remain under-represented in mainstream psychology services (DoH, 2012). The importance of removing barriers to access by making appropriate reasonable adjustments is further stressed by such considerations (Chinn et al., 2014).

4.2.2.1 EVIDENCE FOR THE VALIDITY OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES

The current study investigated concurrent validity to assess the extent to which the PHQ-9 and GAD-7 accurately measure the presentation of depression and anxiety in a sample of adults with intellectual disability. The preliminary psychometric investigation provided preliminary support for the validity of the adapted measures in that the adapted PHQ-9 was able to discriminate between participants who scored above and below the clinical threshold on the GDS-LD (established measure of depression for people with intellectual disabilities), and the adapted GAD-7 was able to discriminate between participants who scored above and below the clinical threshold on the GAS-ID (established measure of anxiety for this population). The moderate positive correlation between the two anxiety measures was lower than the very strong relationship demonstrated between the two depression measures, and it is possible that this is related to a difference in the constructs targeted by the two measures. The GAD-7 is intended as a brief screen for Generalised Anxiety Disorder (Kroenke et al., 2010) and indeed the IAPT monitoring system assesses the presence of specific phobias elsewhere in the minimum dataset (NDTi, 2011). Contrastingly, the GAS-ID assesses the presence of more varied symptoms associated with anxiety and indeed the authors reflect this breadth by structuring the measure into three subscales (Mindham & Espie, 2003). The *Worries* subdomain aims to assess symptoms associated with general worry, such as worrying about

family members or the future. The *Specific Fears* subdomain targets symptoms associated with phobias such as nyctophobia or cynophobia. The *Physiology* subdomain targets physical symptoms associated with anxiety, such as dyspnea and increased perspiration. It appears that these two clinical measures may well be measuring different types of anxiety disorder, and it follows that a high total score on the GAS-ID could be the result of a specific phobia which might not produce a high score on a measure of general anxiety such as the GAD-7. For this reason, possible relationships between the total scores for the GAD-7 and the subscale total scores for the GAS-ID were quantitatively investigated, with particular attention to the hypothesis that a stronger positive correlation might exist between the GAD-7 total score and scores on the *Worries* subdomain of the GAS-ID. Pearson parametric correlation revealed a strong positive correlation ($r(30) = 0.80, p < 0.001$), indicating that the adapted GAD-7 measure may be measuring the same type of anxiety. Although a strong positive correlation was also found between the *Specific Fears* subdomain of the GAS-ID and the adapted GAD-7 total score ($r(30) = 0.74, p < 0.001$), it makes little sense to think similarly about how these theoretically link together if, as seems clear, they are measuring distinctly different concepts. However, it is notable that a strong and significant association between generalised anxiety disorders and other Axis I anxiety disorders such as specific phobias has been found in the general population (Carter, Wittchen, Pfister, & Kessler, 2001; Grant et al., 2005; Hunt, Issakidis, & Andrews, 2002; Kessler, Chiu, Demler, Merikangas, & Walters, 2005). The demonstrated weak correlation between total scores on the adapted GAD-7 measure and the *Physiology* subscale of the GAS-ID ($r(30) = 0.36, p < 0.05$) suggests that these individuals with intellectual disability may find it hard to identify and therefore to report physiological arousal connected to anxiety. This is despite the findings of the initial psychometric investigation of the GAS-ID (Mindham & Espie, 2003).

As these measures represent adapted versions of established clinical measures, it could be argued that the content validity is already established, particularly as they mirror the diagnostic criteria for depression and anxiety in DSM-5 (APA, 2015). Furthermore, the demonstrated relationships between these adapted measures and established measures developed to assess depression (GDS-LD) and anxiety (GAS-ID) in the intellectual disability population suggest that we can expect that the items on the adapted measures to represent the constructs of depression and anxiety for adults with intellectual disability. Additionally, the current study provides evidence for the face validity of the adapted measures, particularly as the adapted wording and visual cues chosen to increase the accessibility of the items were developed using both input from specialist professionals and feedback from participants with intellectual disabilities.

Nonetheless, the validity of the adapted PHQ-9 and GAD-7 measures must currently be deemed *'inadequate'* according to the coding instructions for the quality of outcome measures (Fitzpatrick et al., 1998), as only one validity test has been completed during the initial psychometric enquiry undertaken in Stage 2 of the current study.

4.2.2.2 EVIDENCE FOR THE RELIABILITY OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES

In line with recommendations to assess the reliability of a clinical outcome measure (Cahill et al., 2008), the internal consistency of the adapted versions of the PHQ-9 and GAD-7 measures was assessed using Cronbach's alpha. According to the coding instructions for the quality of

outcome measures (Fitzpatrick et al., 1998) applied in the systematic review of the outcome measures used in psychological therapies with the intellectual disability population (Vlissides et al., 2016), the demonstrated values for the total scores of the adapted versions of the PHQ-9 ($\alpha=0.85$, $n=31$) and GAD-7 ($\alpha=0.91$, $n=32$) were notably higher than the minimum threshold of the highest 'adequate' coding rating ($\alpha=0.70$) and above the reliability criteria standard of $\alpha=0.80$ recommended for outcome measures promoted for widespread use (Carmines & Zeller, 1979). Thus there is initial evidence that the adapted PHQ-9 and GAD-7 measures produce reliable results from the same participants when they are applied under consistent conditions (Field, 2014), with the current evidence coded as '*adequate*' according to the criteria established by Fitzpatrick and colleagues (1998).

4.2.2.3 EVIDENCE FOR THE ACCEPTABILITY OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES

The current study provides initial evidence that the adapted versions of the PHQ-9 and GAD-7 measures are acceptable for use with adults with intellectual disabilities. This conclusion is in line with Cahill and colleagues' (2008) criteria, and is especially significant in that the measures were adapted with input from participants thought to be able to access talking therapies with the implementation of reasonable adjustments. Administrators ($n = 7$) in Stage 2 rated the adapted measures as highly acceptable on a rating scale between zero and ten and informal feedback from both administrators and participants was equally positive. Though some participants experienced difficulty in completing items on the adapted measures, only minimal data was missing from the returns collected in Stage 2. This suggests that participants were able to complete the items successfully with support from an

administrator with access to the clinician guidelines, which included alternative terms or examples. Both adapted measures are brief, and the reported time for completion in Stage 2 ranged from three to nine minutes for each measure (PHQ-9 mean = 5.42, standard deviation = 2.07; GAD-7 mean = 6.00, standard deviation = 2.08). This is judged to be acceptable for routine clinical use with this client group. It is also hypothesised that, as findings in positive practice guidelines suggest (Foundation for People with Learning Disabilities, 2015), individuals completing the measures will over time need less support from clinicians. Using the adapted measures over the course of a treatment episode might thus significantly reduce the burden on clinicians.

The original versions of the PHQ-9 and GAD-7 have been translated into a wide variety of languages, but as yet the measures as newly adapted for use with adults with intellectual disabilities exist only in English. In these circumstances, although the participants in both stages of the study identified as ethnically diverse, the acceptability of the newly adapted measures to a sufficiently wide range of adults with intellectual disabilities cannot be considered to have been fully determined. Despite feedback being sought via email from the administrators who supported the collection of this data, which could have provided important information about the acceptability of the adapted measures, this feedback had not been received at the time of writing, hence it is also not known why the one participant did not complete all items on the measure.

According to coding instructions for the quality of outcome measures (Fitzpatrick et al., 1998), the acceptability of the adapted measures can currently be judged '*partially adequate*'. It is important to note that no measure for the adult intellectual disability population reached

adequate levels of acceptability in the systematic review of outcome measures used in psychological therapies with the intellectual disability population (Vlissides et al., 2016). This was largely attributed to too little information relating to this quality standard being reported.

4.2.2.4 EVIDENCE FOR THE FEASIBILITY OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES

The current study provides evidence that the adapted versions of the PHQ-9 and GAD-7 measures are feasible for use when judged on the criteria established by Cahill and colleagues (2008). During the research administrators provided feedback indicating that the adapted measures are easy to administer to clients with intellectual disabilities. Their approval was communicated both formally via the zero to ten rating scale and informally during discussions and in email exchanges. The clinician guidelines in particular were highlighted by administrators as useful when they needed to support participants' understanding of items on the measures or to answer questions in accordance with research findings (Jones et al., 2007; Walmsley, 2013; Sutherland & Isherwood, 2016).

The minimum dataset is routinely administered to individuals with intellectual disabilities accessing IAPT (Chinn et al., 2014; IAPT, 2009; Radcliffe et al., 2011). It is thought that this places an additional burden on clinicians as these clients require increased input to facilitate comprehension (Walmsley, 2013). In these circumstances the use of adapted versions of the PHQ-9 and GAD-7 measures in an easy read format which caters for adults with intellectual disabilities seems a feasible and reasonable adjustment. It is one likely to reduce the burden on clinicians who should find that clients require less support when completing the measures.

The development of clinician guidelines further increases the feasibility of the adapted measures. These are in line with research recommendations (Hamilton et al., 2011), and include general recommendations for completing outcome measures with adults with intellectual disability as well as advice about completing these specific measures. The study's consultations with participants when devising alternative terms and examples is a particular strength in this regard. A further advantage of the adapted measures lies in the changes made to the scoring processes. The changes here are consistent with the original versions in the minimum data set, and thus data can be scored and recorded in electronic patient databases in the same way as for other clients.

According to coding instructions for the quality of outcome measures (Fitzpatrick et al., 1998), the feasibility of the adapted measures can be currently judged to be '*partially adequate*'. It is again relevant to note that Vlissides and colleagues (2016) noted that no clinical measure included in their systematic review met the criteria required for an '*adequate*' rating.

4.2.2.5 EVIDENCE FOR THE PRECISION OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES

The scoring of the adapted measures is dealt with in detail in the clinician guidelines supplied to administrators and is consistent with the original versions of the PHQ-9 and GAD-7 measures. Analyses of precision were completed via the comparison of 'high' and 'low' group data based on whether participants scored above or below clinical cut-offs on the Glasgow scales for depression (GDS-LD) and anxiety (GAS-ID). The appropriateness of various thresholds for clinical cut-offs relating to possible depression and anxiety was investigated to

facilitate the interpretation of individual scores. Although a strong positive relationship was demonstrated between the measures of depression (i.e. PHQ-9 and GDS-LD) and anxiety (i.e. GAD-7 and GAS-ID), preliminary investigations of sensitivity and specificity indicated that the clinical thresholds suggested for the PHQ-9 and GAD-7 in the general population (NDTi, 2011) might not be appropriate for adults with intellectual disability. Further ROC curve investigations indicated that lower cut-off scores might be appropriate, with a reduction from ten to between six and nine for the PHQ-9 and a reduction from eight to between five and eight for the GAD-7 seeming to be the most appropriate. However, the differing scope of the two anxiety measures used in the current study (outlined above in Section 4.2.2.1), raises doubts about the appropriateness of comparing the total scores for the adapted GAD-7 and the GAS-ID. Additional investigation is needed here. According to coding instructions for the quality of outcome measures (Fitzpatrick et al., 1998), the precision of the adapted measures can be currently judged to be '*partially adequate*' as at least one of the components described by Cahill and colleagues (2008) is included in the current study.

4.2.2.6 EVIDENCE FOR THE RESPONSIVENESS OF THE ADAPTED PHQ-9 AND GAD-7 MEASURES:

As a cross-sectional study the current research does not include an investigation of the ability of the adapted PHQ-9 and GAD-7 measures to identify change in the presentation of symptoms across time. The responsiveness of the adapted measures is thus currently undetermined and must thus be judged '*inadequate*' according to coding instructions for the quality of outcome measures (Fitzpatrick et al., 1998).

4.3 STRENGTHS AND LIMITATIONS OF THE STUDY:

A key identified strength of the current study is that the research questions it addresses are closely aligned with seminal published recommendations. Specifically, it relates to recommendations aimed at increasing access to mainstream psychology services for people with intellectual disability and doing so in a way which conforms with IAPT protocols such as Key Performance Indicators (Lin et al., 2014). The key recommendations are those relating to future research (Hamilton et al., 2011; Chinn et al., 2014) and those for policy (DoH, 2008b; IAPT, 2009). The project involved people with intellectual disability considering appropriately adapted versions of the PHQ-9 and GAD-7 and did so in ways which gave participants a major role in developments. Specifically, this involved them in contributing to central decisions about the design and format of the adapted scales. This was achieved by their participation in, and critical assessment of, two discrete cognitive interviewing stages. Thus, for example, changes following Stage 1.1 were checked with participants with intellectual disability. Although this is often recommended for the development of valid and effective easy read information (DoH, 2010b; MENCAP, 2008), it is noted by Buell (2015) that practical issues such as time and cost often impede this process. Too often the development of accessible documents has to be left to staff members. The current study's evaluation of the validity of the adapted measures via qualitative and quantitative enquiry is also something recommended, but often neglected judging by practitioner accounts of the development of easy read documents which figure in the literature (Chinn & Homeyard, 2016).

In common with most research the current study has limitations which need to be borne in mind when interpreting its findings. In particular the very limited precedent for using a

cognitive interviewing methodology with the intellectual disability population occasioned difficulties. This meant, for example, that the use of such an approach for investigating the validity of questionnaires within the specified study population was not dealt with in the literature. The challenge was thus to build from the insights that the literature does provide into largely untried but associated areas. The value of cognitive interviewing for the validation of questionnaire design is well-supported in the literature (Willis, 2005) and this provided a firm foundation. It was also deemed important to contribute to a literature base for the intellectual disability population which makes use of and is consistent with the substantial body of high quality literature already available for the general population. A consideration here was the consciousness that early work in relatively new areas can have a considerable impact on future research. Cognitive interviewing within any population requires participants to employ higher-level cognition skills such as executive functioning. Adaptations to the standard approach were clearly necessary if adults with intellectual disabilities were to engage successfully with the process. Using concurrent probing rather than think aloud techniques was amongst the techniques employed for this. Hitherto, only limited use has been made of the cognitive interviewing approach in addressing the needs of the adult intellectual disability population. The current study strongly indicates that such use is wholly appropriate once adaptations have been made. The design which emerged from this study produced adaptations which were both successful and reasonable when considered in the light of cognitive interviewing protocols, though the lack of involvement of Speech and Language Therapists in both stages constitutes a limitation.

The small sample size of $n=31$ for Stage 2 of the study is a slight concern as studies which use smaller sample sizes are more likely to produce biased results which impact on validity.

However, it is important to note that the sample size used is comfortably within the range recommended by cost-benefit analyses (NICE, 2016) and comparable to other established scale validity studies in this population, such as the Glasgow Scales for depression (Cuthill et al., 2003) and anxiety (Mindham & Espie, 2003).

A more significant limitation to the current study is how participants were recruited once recruitment had to be extended to non-clinical settings. The low recruitment within IAPT services (n = 10) necessitated the recruitment of participants who came from a group programme for individuals flagged as having some degree of mental ill-health. This may well represent a less clinical group than that drawn from those referred to services such as IAPT. There may also be some overlap between the clinical and non-clinical groups as it was not clear whether individuals in either group were presenting with clinical symptoms of depression and/or anxiety at the time they participated in the study. This might mean that overall, despite the overlaps between high scores in groups differently recruited, the scores within the sample may be negatively skewed (i.e. with more people scoring at lower levels of anxiety or depression). It is interesting as a clinician to see no difference in psychological distress between the participants who were recruited in clinical and non-clinical sites, which could highlight the disparity of access to services for people with intellectual disabilities. Although Stage 2 of the current study was intended as an initial investigation into the psychometrics of the adapted measures, the issue of purism in research method is also relevant here. The point at which the adapted measures were completed by clients has an impact on the data collected and it would have been preferable to collect data at the point at which service users entered services as this is when it is likely that the severity of presenting mental health problems is most severe and replicates how the measure is used in clinical practice. The current study was limited by time and other resources, which meant that this

was not possible and resulted in a less purist methodology by recruiting participants from a wide range of settings. Further investigation is required to determine how the adapted measures will perform when being used in services as part of a set of reasonable adjustments for those who require them.

The difference between the report period for the Glasgow scales (one week) and that for the adapted versions of the PHQ-9 and GAD-7 (two weeks) also limits the current study. The GDS-LD and GAS-ID are recommended as the best self-report instruments currently available for the intellectual disability population (Hermans & Evenhuis, 2010; McGurk & Skelly, 2014; Vlissides et al., 2016) and the current study needed them to establish the initial psychometrics of the adapted measures. However, it is currently unclear whether or not participants provided ratings which are sensitive to difference over the time period used.

4.4 THE CLINICAL IMPLICATIONS OF THE RESEARCH:

The current project was developed to address an identified area of clinical need and the implications of its findings are thus of central importance. The adapted versions of the PHQ-9 and GAD-7 measures aim to meet the needs of the intellectual disability population. It may well be that they are also relevant for people presenting to IAPT with no formal diagnosis of intellectual disability but who nonetheless struggle to engage with the 'traditional' IAPT model. Many of those falling into this category are likely to be borderline for inclusion in the intellectual disability range, and may well be ineligible for specialist services. They nonetheless present with significant learning and social difficulties (Dagnan, 2015). These, if not addressed, can lead to significant mental health problems. The inclusion and exclusion criteria of the study were developed with this problem in mind. Rather than being

diagnostically informed the adapted measures aim to meet the needs of clinical practice by providing reasonable adjustments likely to prove accessible to a significant range of intellectually vulnerable adults, not all of whom have been formally diagnosed. The initial evidence suggests that the versions of the adapted measures developed in the current study are indeed appropriate for use with this population. In consequence, it is strongly recommended that they should be used by mainstream services to improve access to services for adults with intellectual disability. It is encouraging to note that several IAPT services, including those who were involved in the research, are now using the adapted versions of the PHQ-9 and GAD-7 as part of their local set of reasonable adjustments. In this way they are facilitating equitable access to talking therapies for adults with intellectual disabilities.

It is thought that a number of different services have made various different adaptations to the minimum dataset to try to make these measures accessible for people with intellectual disabilities, it is likely that these efforts have resulted in an inconsistent use of these different 'accessible' version nationally and no investigations of the psychometrics of such adapted measures have been reported in the literature. Thus there are potential significant clinical implications for having one consistent version of an adapted measure, rather than lots of varied local versions, to track recovery rates for people with intellectual disabilities accessing IAPT services.

4.5 SUGGESTIONS FOR FUTURE RESEARCH:

This study indicates that the internal properties of the adapted PHQ-9 and GAD-7 measures need further assessment. Particular attention needs to be given to the validity of the measures when applied to the assessment of depression and anxiety in the adult intellectual

disability population. Confirmatory factor analysis, for example, would establish whether or not some items might usefully be dropped from the adapted measures.

Further investigations seeking to apply the standards outlined in Fitzpatrick and colleagues' (1998) criteria and Cahill and colleagues' (2008) rating tool are also recommended. Given the central part played by the PHQ-9 and GAD-7 measures in psychometric enquiry this fuller consideration of validity, responsiveness and precision is of great importance. The validity of the adapted measures, rated inadequate (Cahill et al., 2008) needs particular attention, including between-group research design involving two groups of adults both with intellectual disabilities one of which comprises of individuals experiencing depression and anxiety (clinical group) and one of individuals who are not experiencing clinical levels of depression and anxiety (non-clinical group). This would allow an investigation of discriminant validity. Additional investigations of validity could be completed via factor analysis to assess construct validity. Investigations of test-retest reliability are also recommended and could be conducted by administering the adapted measures at the beginning and end of an assessment session with adults with intellectual disabilities, as was done in the initial psychometric investigation of the GDS-LD (Cuthill et al., 2003a).

The adapted measures are used by services to track recovery, making evaluative responsiveness a key consideration. Here it is recommended that future research should assess the measures' ability to track change over the course of psychological interventions dealing with depression and anxiety. Preferably this should be done with service users with intellectual disabilities who are accessing IAPT services. Also relevant here would be a controlled research design comparing changes in mean total PHQ-9 and GAD-7 scores over

the course of an intervention with waiting list controls over the same period. However, the experience of the current study suggests that such a controlled research design approach might well face practical difficulties in the form of recruitment challenges.

The precision of the adapted PHQ-9 and GAD-7 measures could usefully be assessed by examining their ability to detect differences in depression and anxiety between different populations, for example by comparing scores in clinical intellectual disability groups with those in general population clinical groups. Further quantitative investigation of the proposed clinical cut-off scores would also contribute to our understanding of the degree of precision achieved by the adapted PHQ-9 and GAD-7 measures.

The question of how far it is appropriate to compare the total scores for the adapted GAD-7 and the GAS-ID rather than a subscale score also warrants further exploration. At present this remains uncertain and additional investigation, perhaps by comparing scores for clients who meet diagnostic criteria for depression and/or anxiety with those who do not, is recommended.

4.6 DISSEMINATION:

The adapted versions of the PHQ-9 and GAD-7 measures produced as part of the study are freely accessible to services and represent a reasonable adjustment calculated to minimise the barriers to access highlighted by Chinn and Homeyard (2016). Indeed, the permission to adapt the original PHQ-9 and GAD-7 granted by their authors was conditional on the amended versions being made freely available. In fulfilment of this the original authors will be contacted by email and the final versions of the adapted measures forwarded to them, with

a request that these be published online alongside the translated language versions. All such versions can be downloaded by services and clinicians and used to facilitate access to the measures. It is hoped that by thus disseminating single adapted versions of the PHQ-9 and GAD-7 measures catering for adults with intellectual disabilities the potential for inconsistency in nationally submitted data will be minimised. The risks of such inconsistency are inherent in the current position in which individual services develop different versions locally. Consistent with this aim the final versions of the adapted measure have already been disseminated to services via contacts in IAPT, Community Learning Disability Services and other bodies catering for people with intellectual disabilities. The Foundation for People with Learning Disabilities, which has led on previous projects designed to increase IAPT access for people with intellectual disabilities, is also involved in disseminating the adapted measures via links they have with IAPT and specialist learning disability services previously involved with their project work. There are also plans to share the research findings and measures with key individuals in national IAPT, such as Professor David Clark, who chairs the Mental Health Information Network, which publishes detailed data on the outcomes achieved by all IAPT services, to influence the roll out of the adapted measures as part of the minimum dataset where appropriate for individuals with intellectual disabilities accessing IAPT.

The results of the study are felt to be of interest to a range of clinicians, including both professionals in the intellectual disability field and others in the broader psychological therapy community, and they will be shared accordingly. A poster dealing with the preliminary findings of Stage 1 was presented at the 2016 Seattle Club Conference on Research in Intellectual and Developmental Disabilities and a submission has been made proposing to present the full research findings at the European Association for Mental Health in Intellectual Disability conference in Luxemburg in September 2017. Plans to submit a paper to a relevant

leading peer reviewed journal, such as the Journal of Intellectual Disability Research or the British Journal of Learning Disabilities, are also in hand. An abstract of the research will also be submitted to the British Psychological Society Faculty for People with Intellectual Disabilities Bulletin, which is distributed to all Faculty members three times a year, and is a helpful way to highlight the research to a large number of clinical psychologists with interest in working with people with intellectual disabilities. Further opportunities to present the findings will be explored, including considering opportunities to present the research at a conference whose target audience is IAPT professionals or practitioner psychologists who may not be specialists in intellectual disabilities, to attempt to target those who may be encountering people with intellectual disabilities in mainstream psychological therapy services.

Accessibility is at the heart of the study's philosophy. In support of this, a general overview of the findings in layman's language and produced with the assistance of service user consultants with intellectual disability is to be made available. This will be distributed to services and service user groups who were involved in the research to ensure that research findings will be made available to participants and communities who were involved and distributed by others such as via the Foundation for People with Learning Disabilities. A draft of this document can be viewed in Appendix 20. Other formats for presenting the results, such as video, will also be considered to enhance both accessibility for people with intellectual disabilities, and also visibility and impact of the research dissemination amongst professionals (for example video could be produced for use in training IAPT professionals).

4.7 FINAL REFLECTIONS:

The involvement of service users with intellectual disabilities both as participants and as consultants was a key element in the conception and execution of this study. It is therefore appropriate that my principal reflections now that the study has been completed should attach to this aspect of it. Their involvement brought many benefits. At a practical level, they offered an alternative perspective, improved the quality and accessibility of the participant documents and helped with recruitment. By helping in these ways the individuals involved felt more empowered and grew in confidence. These observations arise not only from the experience of the researcher, but also from the comments and conduct of participants and from feedback from staff members, amongst them one who supports people with intellectual disabilities in an advocacy role.

Nonetheless, involving individuals who have intellectual disabilities in the research was challenging at times. A number of factors were at work: the power imbalance of the research; the time pressures involved; and a consultation paradigm which meant that the power to make decisions about the project rested with the research team. However, both service user consultants and the researchers clearly demonstrated a passion for the project and a sense of ownership over the adapted versions of the measures which emerged. There were strong feelings about the decisions made, some of which were taken in active partnership and others of which required the research team to make judgements based on the literature or on broader contextual issues. An example of this came during Stage 1, when many participants felt very strongly that certain items should be removed from the adapted measures on the grounds that no adaptations would make them sufficiently accessible to adults with intellectual disability. The researchers considered that to ensure conformity with IAPT

monitoring protocols it was important to adapt the measures as a whole and they were thus faced with the need to impose this decision on participants. This was done from necessity, reluctantly and with careful explanation, but as an assertion of power was uncomfortable. The impact on adults with intellectual disabilities is unclear, but I am intensely aware of the historical context: the experiences of such individuals have too often involved being subjugated or silenced by people perceived as powerful (Webb-Peploe & Fredman, 2015). I would have much preferred to be able to employ a more collaborative paradigm during the research, with participants with intellectual disabilities having increased ownership of the project and additional input in the interpretation of the data. Given the constraints on the project, including those of time, funding and scale, such an approach was simply impractical. The possibility of further research in this area with greater emphasis on empowering and developing the skills of adults with intellectual disabilities appeals very much to me and, I hope, to others.

4.8 CONCLUSION:

The lack of an appropriate, empirically tested version of the outcome measures used by IAPT services to track 'recovery' after psychological intervention (DoH, 2008a; Hamilton et al., 2011) denies adults with intellectual disabilities equitable access to mainstream psychology services such as IAPT. In this context concerns have been raised about the format of items on the measures and about how the minimum dataset is delivered by services. The current study focused on the two key measures used in the minimum dataset to measure symptoms of depression (PHQ-9) and anxiety (GAD-7), and in particular on adaptations of them aiming to facilitate access for adults with learning disability. The study provides evidence that these adapted versions of the PHQ-9 and GAD-7 measures are appropriate for use with this

population. This conclusion is based on feedback both from adults with intellectual disabilities and from professionals who supported the administration of the measures during the research. Initial investigations of the psychometric properties of the PHQ-9 and GAD-7 measures as here adapted indicate that they are helpful for assessing symptoms of depression and anxiety in adults with intellectual disability. There is thus evidence that the adapted versions of the measure produced during this study could be used by IAPT services as a reasonably adjusted minimum dataset to track recovery from mental ill-health, a need highlighted in the literature (Chinn et al., 2014; IAPT, 2009; NICE, 2016).

Research has also highlighted the need for more support for therapists working in IAPT and seeking to effectively administer and use minimum data set measures with this population (Hamilton et al., 2011). Here too this study is relevant. It involved the development of guidelines designed to assist clinicians working with individuals with intellectual disabilities. It did so by providing information and examples about how to adjust delivery and by affording prompts and examples to help clients. Given that some of the clinicians involved were relatively inexperienced in working with the adult intellectual disability population the guidelines took particular care to maximise the utility of the advice offered. Whilst recognising that every client is an individual requiring individually tailored information (Chinn & Homeyard, 2016), it is nonetheless the firm belief of this study that its guidelines for clinicians support the flexible delivery of the adapted versions of the PHQ-9 and GAD-7 clinical measures very effectively where routine and standardised outcome measures are a requirement and so to completely individually tailored information would be challenging to achieve.

REFERENCES:

- Altman, D. G., & Bland, J. M. (1994). Statistics Notes: Diagnostic tests 1: sensitivity and specificity. *BMJ*, *308*(6943), 1552. <https://doi.org/10.1136/bmj.308.6943.1552>
- APA. (2015). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Arthur, A. R. (2003). The emotional lives of people with learning disability. *British Journal of Learning Disabilities*, *31*(1), 25–30. <https://doi.org/10.1046/j.1468-3156.2003.00193.x>
- Bassuk, E. L., Buckner, J. C., Perloff, J. N., & Bassuk, S. S. (1998). Prevalence of Mental Health and Substance Use Disorders Among Homeless and Low-Income Housed Mothers. *American Journal of Psychiatry*, *155*(11), 1561–1564. <https://doi.org/10.1176/ajp.155.11.1561>
- Baum, S. (2006). The use of the systemic approach to adults with intellectual disabilities and their families: historical overview and current research. In *Intellectual Disabilities – A Systemic Approach* (pp. 21 – 41). London: Karnac.
- Beail, N. (1998). Psychoanalytic psychotherapy with men with intellectual disabilities: A preliminary outcome study. *British Journal of Medical Psychology*, *71*, 1–11.
- Beail, N. (2003). What Works for People With Mental Retardation? Critical Commentary on Cognitive–Behavioral and Psychodynamic Psychotherapy Research. *MENTAL RETARDATION*, *41*(6), 468–472.
- Beck, A., Epstein, N., Brown, G., & Steer, R. (1988). An inventory for measuring clinical anxiety: psychometric properties. *Journal of Consulting and Clinical Psychology*, *56*, 893–897.

- Beck, A., Rush, J., Shaw, B., & Emery. (1979). *Cognitive Therapy of Depression*. New York: Guilford. Retrieved from <http://www.guilford.com/books/Cognitive-Therapy-of-Depression/Beck-Rush-Shaw-Emery/9780898629194>
- Beck, A., Steer, R., & Brown, G. (1996). *Beck Depression Inventory-II*. San Antonio, CA: Harcourt Brace.
- Bender, M. (1993). The unoffered chair: the history of therapeutic distain towards people with a learning difficulty. *Clinical Psychology Forum*, 54, 7–12.
- BPS. (2015). Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood.
- BPS. (2016). Psychological therapies and people who have intellectual disabilities. Retrieved from http://www.bps.org.uk/system/files/Public%20files/Policy/psychological_therapies_and_people_who_have_id_pdf_for_review.pdf
- British Psychological Society. (2001). *Learning disability: Definitions and contexts*. Leicester: BPS.
- Brooks, M., Davies, S., & Twigg, E. (2013). A measure for feelings – using inclusive research to develop a tool for evaluating psychological therapy (Clinical Outcomes in Routine Evaluation – Learning Disability). *British Journal of Learning Disabilities*, 41(4), 320–329. <https://doi.org/10.1111/bld.12020>
- Buell, S. (2015). A commentary on ‘First-hand experience of accessible information’. *Tizard Learning Disability Review*, 20(2), 88–91.
- Cahill, J., Barkham, M., Hardy, G., Gilbody, S., Richards, D., Bower, P., ... Connell, J. (2008). A review and critical appraisal of measures of therapist-patient interactions in mental

health settings. *Health Technology Assessment (Winchester, England)*, 12(24), iii, ix-47.

Carmines, E., & Zeller, R. (1979). Newbury Park, CA: Sage.

Carter, R. M., Wittchen, H. U., Pfister, H., & Kessler, R. C. (2001). One-year prevalence of subthreshold and threshold DSM-IV generalized anxiety disorder in a nationally representative sample. *Depression and Anxiety*, 13(2), 78–88.

Chinn, D., & Abraham, E. (2016). Using 'candidacy' as a framework for understanding access to mainstream psychological treatment for people with intellectual disabilities and common mental health problems within the English Improving Access to Psychological Therapies service. *Journal of Intellectual Disability Research*, 60(6), 571–582. <https://doi.org/10.1111/jir.12274>

Chinn, D., Abraham, E., Burke, C., & Davies, J. (2014). IAPT and Learning Disabilities. Foundation for People with Learning Disabilities. Retrieved from <http://www.learningdisabilities.org.uk/content/assets/pdf/publications/iapt-and-learning-disabilities-report.PDF>

Chinn, D., & Homeyard, C. (2016). Easy read and accessible information for people with intellectual disabilities: Is it worth it? A meta-narrative literature review. *Health Expectations*, n/a-n/a. <https://doi.org/10.1111/hex.12520>

Clark, D., & Oates, M. (2014). Improving Access to Psychological Therapies : Measuring Improvement and Recovery Adult Services. Retrieved from <http://www.iapt.nhs.uk/silo/files/measuring-recovery-2014.pdf>

Clements, J. (1998). Development, cognition and performance. In *In E. Emerson, C. Hatton, J. Bromley & A. Caine (Eds.), Clinical psychology and people with intellectual disabilities*. Chichester: Wiley.

- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2 edition). Hillsdale, N.J: Routledge.
- Cohen, J. (1992). A power primer. *Psychological Bulletin*, *112*(1), 155–159.
<https://doi.org/10.1037/0033-2909.112.1.155>
- Cooper, S.-A., McLean, G., Guthrie, B., McConnachie, A., Mercer, S., Sullivan, F., & Morrison, J. (2015). Multiple physical and mental health comorbidity in adults with intellectual disabilities: population-based cross-sectional analysis. *BMC Family Practice*, *16*(1), 1–11. <https://doi.org/10.1186/s12875-015-0329-3>
- Cooper, S.-A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, *190*(1), 27–35. <https://doi.org/10.1192/bjp.bp.106.022483>
- Corti, L., Van den Eynden, V., Bishop, L., & Woollard, M. (2014). *Managing and Sharing Research Data: A Guide to Good Practice*. Sage Publications Ltd.
- Costello, H., & Bouras, N. (2006). Assessment of mental health problems in people with intellectual disabilities. *The Israel Journal of Psychiatry and Related Sciences*, *43*(4), 241–251.
- Cuthill, F. M., Espie, C. A., & Cooper, S.-A. (2003a). Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability. *The British Journal of Psychiatry*, *182*(4), 347–353. <https://doi.org/10.1192/bjp.182.4.347>
- Cuthill, F. M., Espie, C. A., & Cooper, S.-A. (2003b). Development and psychometric properties of the Glasgow Depression Scale for people with a Learning Disability Individual and carer supplement versions. *The British Journal of Psychiatry*, *182*(4), 347–353.

Dagnan, D. (2015, January). *Core questions for CBT and people with learning disabilities*.

Presented at the Improving Access to Psychological Therapies Services for People with Learning Disabilities. Retrieved from

<https://www.nwppn.nhs.uk/attachments/article/468/Core%20Questions%20for%20CBT%20and%20People%20with%20Learning%20Disabilities%20-%20Prof%20Dave%20Dagnan.pdf>

Dagnan, D., & Chadwick, P. (1997). Using Makaton drawings to assess the ability to recognize facial expression of emotion in people with learning disabilities. In *In B. Kroese, D. Dagnan, & K. Loumidis (Eds.), Cognitive therapy for people with learning disabilities*. London: Routledge.

Dagnan, D., & Jahoda, A. (2006). Cognitive–Behavioural Intervention for People with Intellectual Disability and Anxiety Disorders. *Journal of Applied Research in Intellectual Disabilities*, *19*(1), 91–97. <https://doi.org/10.1111/j.1468-3148.2005.00283.x>

Dagnan, D., & Sandhu, S. (1999). Social comparison, self-esteem and depression in people with intellectual disability. *Journal of Intellectual Disability Research: JIDR*, *43* (Pt 5), 372–379.

Dagnan, D., & Waring, M. (2004). Linking stigma to psychological distress: testing a social–cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology & Psychotherapy*, *11*(4), 247–254. <https://doi.org/10.1002/cpp.413>

Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research: JIDR*, *45*(Pt 6), 495–505.

- Delgadillo, J., Payne, S., Gilbody, S., Godfrey, C., Gore, S., Jessop, D., & Dale, V. (2012). Brief case finding tools for anxiety disorders: Validation of GAD-7 and GAD-2 in addictions treatment. *Drug and Alcohol Dependence*, *125*(1–2), 37–42.
<https://doi.org/10.1016/j.drugalcdep.2012.03.011>
- Dixon, L. S. (1981). A functional analysis of photo-object matching skills of severely retarded adolescents. *Journal of Applied Behavior Analysis*, *14*(4), 465–478.
<https://doi.org/10.1901/jaba.1981.14-465>
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... others. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, *6*(1), 35–48.
- Dodd, K., Joyce, T., Nixon, J., Jennison, J., & Heneage, C. (2010). Improving access to psychological therapies (IAPT): are they applicable to people with intellectual disabilities? *Advances in Mental Health and Intellectual Disabilities*, *5*(2), 29–34.
- DoH. (1971). *Better Services for the Mentally Handicapped*. London: Her Majesty's Stationery Office.
- DoH. (1999). *Facing the Facts. Services for People with Learning Disabilities: A Policy Impact Study of Social Care and Health Services*. Retrieved from <https://www.whatdotheyknow.com/request/110339/response/283514/attach/3/dh%204053632.pdf>
- DoH. (2001). *Good practice in consent implementation guide: consent to examination or treatment*. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4019061.pdf

- DoH. (2003). NHS Toolkit for Producing Patient Information Version 2.0. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4068462.pdf
- DoH. (2005). Research Governance Framework for Health and Social Care. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/139565/dh_4122427.pdf
- DoH. (2008a). Improving Access to Psychological Therapies (IAPT): Best Practice Guidance Commissioning Toolkit. London: Department of Health.
- DoH. (2008b). *Improving access to psychological therapies. Implementation plan: national guidelines for regional delivery*. Department of Health London.
- DoH. (2008c). NHS and Social Care Act 2008. London: Department of Health.
- DoH. (2010a). Liberating the NHS white paper - Publications - GOV.UK. Retrieved 24 May 2016, from <https://www.gov.uk/government/publications/liberating-the-nhs-white-paper>
- DoH. (2010b). Making written information easier to understand for people with intellectual disabilities. Retrieved from http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_121927.pdf
- DoH. (2012). IAPT three-year report The first million patients. Crown Copyright. Retrieved from <http://www.iapt.nhs.uk/silo/files/iapt-3-year-report.pdf>
- DoH. (2015). A mandate from the Government to NHS England: April 2015 to March 2016. Retrieved from <https://www.gov.uk/government/publications/nhs-mandate-2015-to-2016>

- DRC. (2006). Equal treatment: closing the gap: a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems. Retrieved from <http://www.scie-socialcareonline.org.uk/equal-treatment-closing-the-gap-a-formal-investigation-into-physical-health-inequalities-experienced-by-people-with-learning-disabilities-andor-mental-health-problems/r/a11G00000017qeplAA>
- Einfeld, S. L., Ellis, L. A., & Emerson, E. (2011). Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. *Journal of Intellectual & Developmental Disability, 36*(2), 137–143.
<https://doi.org/10.1080/13668250.2011.572548>
- Elliott, R., Fischer, C. T., & Rennie, D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *The British Journal of Clinical Psychology, 38* (Pt 3), 215–229.
- Emerson, E., & Hatton, C. (2007). Mental health of children and adolescents with intellectual disabilities in Britain. *The British Journal of Psychiatry, 191*(6), 493–499.
<https://doi.org/10.1192/bjp.bp.107.038729>
- Emerson, E., & Hatton, C. (2008). Estimating Future Need for Adult Social Care for People with Learning Disabilities in England. Retrieved from http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf
- Fajardo, I., Ávila, V., Ferrer, A., Tavares, G., Gómez, M., & Hernández, A. (2014). Easy-to-read texts for students with intellectual disability: linguistic factors affecting

- comprehension. *Journal of Applied Research in Intellectual Disabilities: JARID*, 27(3), 212–225. <https://doi.org/10.1111/jar.12065>
- Field, A. P. (2014). *Discovering Statistics Using SPSS: (and Sex, Drugs and Rock'n'roll)* (4th ed.). SAGE.
- Fitzpatrick, R., Davey, C., Buxton, M. J., & Jones, D. R. (1998). Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment (Winchester, England)*, 2(14), i–iv, 1-74.
- Foundation for People with Learning Disabilities. (2015). IAPT Learning Disabilities Positive Practice Guide.
- Gacek, M., Smoleń, T., & Pilecka, W. (2017). Consequences of Learned Helplessness and Recognition of the State of Cognitive Exhaustion in Persons with Mild Intellectual Disability. *Advances in Cognitive Psychology*, 13(1), 42–51.
<https://doi.org/10.5709/acp-0205-6>
- Goodey, R., & Stirk, S. (2014). Facilitating access to a local IAPT provider for people with a learning disability: A six month prospective audit. *Clinical Psychology Forum*, 262, 22–27.
- Grant, B. F., Hasin, D. S., Stinson, F. S., Dawson, D. A., June Ruan, W., Goldstein, R. B., ... Huang, B. (2005). Prevalence, correlates, co-morbidity, and comparative disability of DSM-IV generalized anxiety disorder in the USA: results from the National Epidemiologic Survey on Alcohol and Related Conditions. *Psychological Medicine*, 35(12), 1747–1759. <https://doi.org/10.1017/S0033291705006069>
- Hamilton, S., Hicks, A., Sayers, R., Faulkner, A., Larsen, J., Patterson, S., & Pinfold, V. (2011). A user-focused evaluation of IAPT services in London: Report for Commissioning

- Support for London, March 2011. Rethink. Retrieved from
<https://www.rethink.org/.../a/a-user-focused-evaluation-of-iapt-services-in-london>
- Harris, J. G., & Llorente, A. M. (2005). Cultural considerations in the use of the Wechsler Intelligence Scale for Children-Fourth Edition (WISC-IV). In A. Prifitera, D. H. Saklofske, & L. G. Weiss (Eds.), *WISC-IV clinical use and interpretation: Scientist-practitioner perspectives* (pp. 381–413). San Diego, CA, US: Elsevier Academic Press.
<https://doi.org/10.1016/B978-012564931-5/50013-X>
- Hassiotis, A., Serfaty, M., Azam, K., Martin, S., Strydom, A., & King, M. (2012). A Manual of Cognitive Behaviour Therapy for People with Mild Learning Disabilities and Common Mental Disorders: A training guide to help professional therapists in treating people with communication and cognitive problems in CBT. Camden & Islington NHS Foundation Trust and University College London. Retrieved from
<https://www.ucl.ac.uk/psychiatry/cbt/downloads/documents/cbt-id-manual>
- Hatton, C. (2002). Psychosocial interventions for adults with intellectual disabilities and mental health problems: A review. *Journal of Mental Health, 11*(4), 357–374.
<https://doi.org/10.1080/09638230020023732>
- Hatton, C., & Taylor, J. L. (2013). The assessment of mental health problems in adults with intellectual disabilities. In J. L. Taylor, W. R. Lindsay, R. P. Hastings & C. Hatton (Eds.), *Psychological therapies for adults with intellectual disabilities* (pp. 31–54). Chichester: Wiley & Sons.
- Heinonen, E., Lindfors, O., Laaksonen, M. A., & Knekt, P. (2012). Therapists' professional and personal characteristics as predictors of outcome in short- and long-term psychotherapy. *Journal of Affective Disorders, 138*(3), 301–312.
<https://doi.org/10.1016/j.jad.2012.01.023>

- Heneage, C., Dhanjal, K., & Morris, D. (2009). Training 'IAPT' psychological well-being practitioners about learning disabilities- a joint approach: Part 1: Planning and evaluation. *Clinical Psychology & People with Learning Disabilities*, 7, 3–7.
- Hermans, H., & Evenhuis, H. M. (2010). Characteristics of instruments screening for depression in adults with intellectual disabilities: Systematic review. *Research in Developmental Disabilities*, 31(6), 1109–1120.
<https://doi.org/10.1016/j.ridd.2010.04.023>
- Hermans, H., van der Pas, F. H., & Evenhuis, H. M. (2011). Instruments assessing anxiety in adults with intellectual disabilities: A systematic review. *Research in Developmental Disabilities*, 32(3), 861–870. <https://doi.org/10.1016/j.ridd.2011.01.034>
- HM Government. (1995). Disability Discrimination Act [Text]. Retrieved 8 February 2017, from <http://www.legislation.gov.uk/ukpga/1995/50>
- HM Government. (2001). Valuing People. Retrieved from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/250877/5086.pdf
- HM Government. (2009). Valuing People Now: a new three year strategy for people with learning disabilities, making it happen for everyone. Retrieved from http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_093375.pdf
- HM Government. (2011). *No health without mental health: A cross-government mental health outcomes strategy for people of all ages*. Department of Health London.
- HM Government, E. (1998). Human Rights Act [Text]. Retrieved 8 February 2017, from <http://www.legislation.gov.uk/ukpga/1998/42/contents>

- HM Government, E. (2010). Equality Act 2010 [Text]. Retrieved 8 February 2017, from <http://www.legislation.gov.uk/ukpga/2010/15/section/4>
- Hollins, S., Attard, M. T., von Fraunhofer, N., McGuigan, S., & Sedgwick, P. (1998). Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine and Child Neurology*, *40*(1), 50–56.
- Hunt, C., Issakidis, C., & Andrews, G. (2002). DSM-IV generalized anxiety disorder in the Australian National Survey of Mental Health and Well-Being. *Psychological Medicine*, *32*(4), 649–659.
- Hunter, J., & Hughes, K. (2003). *Results and Recommendations from the Cognitive Pretesting of the SIPP Cash Balance Pension Question* (Study Series, Survey Methodology No. 2003–12). Washington DC: US Census Bureau, Statistical Research Division. Retrieved from <https://www.census.gov/srd/www/abstract/ssm2003-12.html>
- Hurtado, B., Jones, L., & Burniston, F. (2014). Is Easy Read information really easier to read? *Journal of Intellectual Disability Research*, *58*(9), 822–829. <https://doi.org/10.1111/jir.12097>
- Hutchinson, T. (1995). The classification of disability. *Archives of Disease in Childhood*, *73*, 91–93.
- IAPT. (2009). Learning Disabilities: Positive Practice Guide. London: Department of Health. Retrieved from <http://www.iapt.nhs.uk/silo/files/learning-disabilities-positive-practice-guide.pdf>
- IAPT. (2012). Guidance note for the HSCIC: Use for Anxiety Disorder Specific Measures (ASDMs) in IAPT. Retrieved from www.iapt.nhs.uk/silo/files/adsm-guidance.pdf
- Irvine, M., & Beale, N. (2016). Identifying and meeting the emotional and mental health needs of people who have intellectual disabilities through psychological therapies. In

Psychological Therapies and People Who Have Intellectual Disabilities. British Psychological Society. Retrieved from http://www.bps.org.uk/system/files/Public%20files/Policy/psychological_therapies_and_people_who_have_id_pdf_for_review.pdf

Jahoda, A. (2016). Cognitive behavioural therapy. In *Psychological therapies and people who have intellectual disabilities* (pp. 29–34).

Jahoda, A., Dagnan, D., Jarvie, P., & Kerr, W. (2006). Depression, Social Context and Cognitive Behavioural Therapy for People who have Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 81–89. <https://doi.org/10.1111/j.1468-3148.2005.00286.x>

Jahoda, A., Dagnan, D., Stenfert Kroese, B., Pert, C., & Trower, P. (2009). Cognitive behavioural therapy: From face to face interaction to a broader contextual understanding of change. *Journal of Intellectual Disability Research*, 53(9).

Jones, A. (2005). Shelter Inclusion Project: two years on. *Shelter*.

Jones, F. W., Long, K., & Finlay, W. M. L. (2007). Symbols can improve the reading comprehension of adults with learning disabilities. *Journal of Intellectual Disability Research: JIDR*, 51(Pt 7), 545–550. <https://doi.org/10.1111/j.1365-2788.2006.00926.x>

Karreman, J., van der Geest, T., & Buursink, E. (2007). Accessible website content guidelines for users with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 20, 510–518.

Kessler, R. C., Chiu, W. T., Demler, O., Merikangas, K. R., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity

- Survey Replication. *Archives of General Psychiatry*, 62(6), 617–627.
<https://doi.org/10.1001/archpsyc.62.6.617>
- King, S. (2011). Clear information can cut inequalities in learning disabilities. *Nursing Times*, 107(4), 22–24.
- Kraus, D., & Castonguay, L. G. (2010). Treatment outcome package (TOP) – development and use in naturalistic settings. In M. Barkham, G. E. Hardy & J. Mellor-Clark (Eds.), *Developing and delivering practice-based evidence: A guide for the psychological therapies* (pp. 155–175). Chichester: Wiley & Sons.
- Kroenke, K., Spitzer, R. L., & Williams, J. B. W. (2001). The PHQ-9. *Journal of General Internal Medicine*, 16(9), 606–613. <https://doi.org/10.1046/j.1525-1497.2001.016009606.x>
- Kroenke, K., Spitzer, R. L., Williams, J. B. W., & Löwe, B. (2010). The Patient Health Questionnaire Somatic, Anxiety, and Depressive Symptom Scales: a systematic review. *General Hospital Psychiatry*, 32(4), 345–359.
<https://doi.org/10.1016/j.genhosppsy.2010.03.006>
- Layard, R., Clark, D., Knapp, M., & Mayraz, G. (2007). Cost-benefit analysis of psychological therapy. *National Institute Economic Review*, 202(1), 90–98.
<https://doi.org/10.1177/0027950107086171>
- Leyin, A. (2011). Improving Access to Psychological Therapies for people with learning disabilities. *Tizard Learning Disability Review*, 16(5), 29–37.
<https://doi.org/10.1108/13595471111185747>
- Lin, J.-D., Lin, L.-P., Kuo, M.-T., Hsu, S.-W., Lee, T.-N., Lai, C.-I., & Wu, J.-L. (2014). Assessment of the 9-item Patient Health Questionnaire (PHQ-9) as a screen tool for symptoms of depression in community caregivers for adults with intellectual disabilities. *Research*

in Developmental Disabilities, 35(1), 178–184.

<https://doi.org/10.1016/j.ridd.2013.10.008>

Lindsay, W. (1999). Cognitive therapy. *The Psychologist*, 12(5), 238–241.

Lindsay, W., Neilson, C., & Lawrenson, H. (1997). Cognitive-behaviour therapy for anxiety in people with learning disabilities. In B. Stenfert Kroese, D. Dagnan & K. Loumidis (Eds.), *Cognitive-Behaviour Therapy for People with Learning Disabilities* (pp. 124–140). London: Routledge.

Lindsay, W. R., & Michie, A. M. (1988). Adaptation of the Zung self-rating anxiety scale for people with a mental handicap*. *Journal of Intellectual Disability Research*, 32(6), 485–490. <https://doi.org/10.1111/j.1365-2788.1988.tb01440.x>

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and Standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the General Population. *Medical Care*, 46(3), 266–274.

Mackintosh, N. (2011). *IQ and Human Intelligence* (2 edition). Oxford ; New York: Oxford University Press.

Marston, G. M., Perry, D. W., & Roy, A. (1997). Manifestations of depression in people with intellectual disability. *Journal of Intellectual Disability Research*, 41(6), 476–480. <https://doi.org/10.1111/j.1365-2788.1997.tb00739.x>

Martin, D. J., Garske, J. P., & Davis, M. K. (2000). Relation of the therapeutic alliance with outcome and other variables: a meta-analytic review. *Journal of Consulting and Clinical Psychology*, 68(3), 438–450.

Marwood, H. (2015). *The Experiences of High Intensity Therapists Delivering Cognitive Behavioural Therapy to Individuals with Learning Disabilities in IAPT Services*.

Retrieved from <http://roar.uel.ac.uk/4532/1/Hayley%20Marwood.pdf>

Matson, J. L., Rush, K. S., Hamilton, M., Anderson, S. J., Bamburg, J. W., Baglio, C. S., ...

Kirkpatrick-Sanchez, S. (1999). Characteristics of depression as assessed by the Diagnostic Assessment for the Severely Handicapped-II (DASH-II). *Research in Developmental Disabilities, 20*(4), 305–313.

McCabe, M. P., McGillivray, J. A., & Newton, D. C. (2006). Effectiveness of treatment programmes for depression among adults with mild/moderate intellectual disability.

Journal of Intellectual Disability Research: JIDR, 50(Pt 4), 239–247.

<https://doi.org/10.1111/j.1365-2788.2005.00772.x>

McGillivray, J. A., McCabe, M. P., & Kershaw, M. M. (2008). Depression in people with intellectual disability: an evaluation of a staff-administered treatment program.

Research in Developmental Disabilities, 29(6), 524–536.

<https://doi.org/10.1016/j.ridd.2007.09.005>

McGurk, K., & Skelly, A. (2014). A quick guide for psychologists working in learning disability on the available clinical outcome measures currently in use. *The Bulletin of the*

Faculty for People with Intellectual Disabilities, 2(1), 28–32.

Meins, W. (1995). Symptoms of major depression in mentally retarded adults*. *Journal of*

Intellectual Disability Research, 39(1), 41–45. [https://doi.org/10.1111/j.1365-](https://doi.org/10.1111/j.1365-2788.1995.tb00912.x)

[2788.1995.tb00912.x](https://doi.org/10.1111/j.1365-2788.1995.tb00912.x)

Meltzer, H., Singleton, N., Lee, A., Bebbington, P., Brugha, T., & Jenkins, R. (2002). The social and economic circumstances of adults with mental disorders. Retrieved 24 May

2016, from

[http://webarchive.nationalarchives.gov.uk/content/20160105160709/http://www.o](http://webarchive.nationalarchives.gov.uk/content/20160105160709/http://www.ons.gov.uk/ons/rel/psychiatric-morbidity/the-social-and-economic-circumstances-of-adults-with-mental-disorders/index.html)

[ns.gov.uk/ons/rel/psychiatric-morbidity/the-social-and-economic-circumstances-of-adults-with-mental-disorders/index.html](http://webarchive.nationalarchives.gov.uk/content/20160105160709/http://www.ons.gov.uk/ons/rel/psychiatric-morbidity/the-social-and-economic-circumstances-of-adults-with-mental-disorders/index.html)

- MENCAP. (2008). Mencap's Make it Clear: a guide to making easy read information.
- MENCAP. (2012). Death by indifference: 74 deaths and counting. Mencap. Retrieved from <https://www.mencap.org.uk/74deaths>
- Mental Health Policy Group. (2006, June). The depression report: a new deal for depression and anxiety disorders [Monograph]. Retrieved 24 May 2016, from <http://cep.lse.ac.uk/>
- Merz, E. L., Malcarne, V. L., Roesch, S. C., Riley, N., & Sadler, G. R. (2011). A multigroup confirmatory factor analysis of the Patient Health Questionnaire-9 among English- and Spanish-speaking Latinas. *Cultural Diversity and Ethnic Minority Psychology, 17*(3), 309–317.
- Metz, C. E. (1978). Basic principles of ROC analysis. *Seminars in Nuclear Medicine, 8*(4), 283–298.
- Michael, J. (2008). Report of the Independent inquiry into access to healthcare for people with learning disabilities. London: Healthcare for All. Retrieved from http://oxleas.nhs.uk/site-media/cms-downloads/Healthcare_For_All_final.pdf
- Mindham, J., & Espie, C. A. (2003). Glasgow Anxiety Scale for people with an Intellectual Disability (GAS-ID): development and psychometric properties of a new measure for use with people with mild intellectual disability. *Journal of Intellectual Disability Research: JIDR, 47*(Pt 1), 22–30.
- Moss, S., Emerson, E., Kiernan, C., Turner, S., Hatton, C., & Alborz, A. (2000). Psychiatric symptoms in adults with learning disability and challenging behaviour. *British Journal of Psychiatry, 177*, 452–456.
- Moussavi, S., Chatterji, S., Verdes, E., Tandon, A., Patel, V., & Ustun, B. (2007). Depression, chronic diseases, and decrements in health: results from the World Health Surveys.

Lancet (London, England), 370(9590), 851–858. [https://doi.org/10.1016/S0140-6736\(07\)61415-9](https://doi.org/10.1016/S0140-6736(07)61415-9)

Mundt, J. C., Marks, I. M., Shear, M. K., & Greist, J. H. (2002). The Work and Social Adjustment Scale: a simple measure of impairment in functioning. *The British Journal of Psychiatry: The Journal of Mental Science*, 180, 461–464.

Munro, B. H. (2005). *Statistical Methods for Health Care Research*. Lippincott Williams & Wilkins.

NDTi. (2011). IAPT Data handbook: Guidance on recording and monitoring outcomes to support local evidence-based practice. NHS. Retrieved from <http://www.iapt.nhs.uk/silo/files/iapt-data-handbook-v2.pdf>

NDTi. (2012). Reasonably Adjusted? Mental Health Services and Support for People with Autism and People with Learning Disabilities. Retrieved from http://www.ndti.org.uk/uploads/files/NHS_Confederation_report_Submitted_version.pdf

NDTi. (2016). Green Light Toolkit: A guide to auditing and improving your mental health service so that it is effective in supporting people with autism and people with learning disabilities (Version 2). Retrieved from http://www.ndti.org.uk/uploads/files/Green_Light_Toolkit_2013_final_word_doc_revised.pdf

NHS England. (2015). Accessible Information: Specification. Retrieved from <https://www.england.nhs.uk/wp-content/uploads/2015/07/access-info-spec-fin.pdf>

NHS Health Research Authority. (2017). Applying a proportionate approach to the process of seeking consent: HRA Guidance. Policy and Public Affairs Directorate. Retrieved from

<http://www.hra.nhs.uk/documents/2017/01/applying-proportionate-approach-process-seeking-consent.pdf>

NHS Health Research Authority. (n.d.). Consent and Participant Information Sheet

Preparation Guidance: Retrieved from <http://www.hra.nhs.uk/resources/before-you-apply/consent-and-participation/consent-and-participant-information/>

NICE. (2009). Depression in adults: recognition and management | Guidance and guidelines

| NICE. Retrieved 8 February 2017, from

<https://www.nice.org.uk/guidance/cg90?unlid=297456067201712171835>

NICE. (2011). Generalised anxiety disorder and panic disorder in adults: management |

Guidance and guidelines | NICE. Retrieved 8 February 2017, from

<https://www.nice.org.uk/guidance/cg113?unlid=95298861520161219132944>

NICE. (2016). Mental health problems in people with learning disabilities: prevention, assessment and management (NG54). Retrieved from

<https://www.nice.org.uk/guidance/ng54/resources/mental-health-problems-in-people-with-learning-disabilities-prevention-assessment-and-management-1837513295557>

Nunnally, J. C. (1978). *Psychometric theory* (2nd ed.). New York: McGraw-Hill.

O'Brien, G. (2001). Defining learning disability: what place does intelligence testing have now? *Developmental Medicine & Child Neurology*, 43(8), 570–573.

<https://doi.org/10.1111/j.1469-8749.2001.tb00763.x>

Oliver, M. (1998). Disability in health practice and research. *British Medical Journal*, 317, 1446–1449.

Oliver, P. C., Piachaud, J., Done, J., Regan, A., Cooray, S., & Tyrer, P. (2002). Difficulties in conducting a randomized controlled trial of health service interventions in

- intellectual disability: implications for evidence-based practice. *Journal of Intellectual Disability Research: JIDR*, 46(Pt 4), 340–345.
- Priede, C., & Farrall, S. (2011). Comparing results from different styles of cognitive interviewing: 'verbal probing' vs. 'thinking aloud'. *International Journal of Social Research Methodology*, 14(4), 271–287.
<https://doi.org/10.1080/13645579.2010.523187>
- Radcliffe, A., O'Connor, J., Pollard, C., & Coopoosamy, Y. (2011). Increasing access to mainstream services for people with a learning disability: Partnership working between a community learning disability partnership and local IAPT service. *Clinical Psychology Forum*, 9(1), 40–48.
- Ramazan Konkan, Ömer Şenormanci, Oya Güçlü, Erkan Aydın, & Mehmet Z. Sungur. (2013). Validity and Reliability Study for the Turkish Adaptation of the Generalized Anxiety Disorder-7 (GAD-7) Scale. *Nöropsikiyatri Arşivi*, 50(1), 53–58.
- Ramsden, S., Tickle, A., Dawson, D. L., & Harris, S. (2016). Perceived barriers and facilitators to positive therapeutic change for people with intellectual disabilities: Client, carer and clinical psychologist perspectives. *Journal of Intellectual Disabilities*, 20(3), 241–262. <https://doi.org/10.1177/1744629515612627>
- Reid, K. A., Smiley, E., & Cooper, S.-A. (2011). Prevalence and associations of anxiety disorders in adults with intellectual disabilities. *Journal of Intellectual Disability Research: JIDR*, 55(2), 172–181. <https://doi.org/10.1111/j.1365-2788.2010.01360.x>
- Reiss, S., Levitan, G. W., & Szyszko, J. (1982). Emotional disturbance and mental retardation: diagnostic overshadowing. *American Journal of Mental Deficiency*, 86(6), 567–574.
- Rogers, K. D., Young, A., Lovell, K., Campbell, M., Scott, P. R., & Kendal, S. (2013). The British Sign Language Versions of the Patient Health Questionnaire, the Generalized Anxiety

- Disorder 7-Item Scale, and the Work and Social Adjustment Scale. *Journal of Deaf Studies & Deaf Education*, 18(1), 110–123. <https://doi.org/10.1093/deafed/ens040>
- Rose, D., & Sullivan, O. (1996). *Introducing Data Analysis for Social Scientists* (2nd Revised edition edition). Buckingham, England ; Philadelphia: Open University Press.
- Rose, J., Loftus, M., Flint, B., & Carey, L. (2005). Factors associated with the efficacy of a group intervention for anger in people with intellectual disabilities. *British Journal of Clinical Psychology*, 44, 305–317.
- Royal College of Psychiatrists. (2012). Enabling people with ID and mental health problems to access health care services. Retrieved from <http://www.rcpsych.ac.uk/usefulresources/publications/collegereports/cr/cr175.aspx>
- x
- Sams, K., Collins, S., & Reynolds, S. (2006). Cognitive Therapy Abilities in People with Learning Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 25–33. <https://doi.org/10.1111/j.1468-3148.2006.00303.x>
- Schechter, S., Blair, J., & Vande Hey, J. (1996). Conducting Cognitive Interviews to Test Self-Administered and Telephone Surveys: Which Methods Should We Use? *Proceedings of the Section on Survey Research Methods Alexandria, American Statistical Association*, 10–17.
- SCMH. (2003). Economic and social costs of mental illness in England. Retrieved 8 February 2017, from <https://www.centreformentalhealth.org.uk/economic-and-social-costs-2003>
- Secker, J. (2009). Mental health, social exclusion and social inclusion. *Mental Health Review Journal*, 14(4), 4–11. <https://doi.org/10.1108/13619322200900022>

- Sevcik, R., & Ronski, M. A. (1986). Representational matching skills of persons with severe retardation. *Augmentative and Alternative Communication*, 2(4), 160–164.
<https://doi.org/10.1080/07434618612331273980>
- Shankland, J., & Dagnan, D. (2015). IAPT practitioners' experiences of providing therapy to people with intellectual disabilities. *Advances in Mental Health and Intellectual Disabilities*, 9(4), 206–214. <https://doi.org/10.1108/AMHID-02-2015-0008>
- Shelter. (2007). Shelter: Homelessness Factsheet. Retrieved from
<http://england.shelter.org.uk/policy/policy-825.cfm/ct/1/sb/15/pg/3/plitem/183>
- Sinason, V. (1992). *Mental Handicap and the Human Condition: New Approaches from the Tavistock*. Free Association Books.
- Singleton, N., Bumpstead, R., O'Brien, M., Lee, A., & Meltzer, H. (2000). Psychiatric morbidity among adults living in private households. Office for National Statistics, Crown Copyright.
- Skelly, A. (2016). Measurement of outcome in psychological therapies for people with ID. In *Psychological Therapies and People Who Have Intellectual Disabilities* (pp. 153–165). British Psychological Society. Retrieved from
http://www.bps.org.uk/system/files/Public%20files/Policy/psychological_therapies_and_people_who_have_id_pdf_for_review.pdf
- Social Exclusion Unit. (2004). *Mental Health and Social Exclusion*. HM Government.
- Sousa, T. V., Viveiros, V., Chai, M. V., Vicente, F. L., Jesus, G., Carnot, M. J., ... Ferreira, P. L. (2015). Reliability and validity of the Portuguese version of the Generalized Anxiety Disorder (GAD-7) scale. *Health and Quality of Life Outcomes*, 13(1), <xocs:firstpage xmlns:xocs=/>. <https://doi.org/10.1186/s12955-015-0244-2>



- Spitzer, R., Kroenke K, Williams JW, & and the Patient Health Questionnaire Primary Care Study Group. (1999). Validation and utility of a self-report version of prime-md: The phq primary care study. *JAMA*, 282(18), 1737–1744.
<https://doi.org/10.1001/jama.282.18.1737>
- Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine*, 166(10), 1092–1097.
- Stenfert-Kroese, B. (1997). Cognitive-behaviour therapy for people with learning disabilities: conceptual and contextual issues. In *Cognitive-Behaviour Therapy for People with Learning Disabilities* (pp. 1–15). Routledge, London.
- Stephenson, J., & Linfoot, K. (1996). Pictures as communication symbols for students with severe intellectual disability. *Augmentative and Alternative Communication*, 12(4), 244–256. <https://doi.org/10.1080/07434619612331277708>
- Sternberg, R., Grigorenko, E., & Bundy, D. (2001). The predictive value of IQ. *Merrill-Palmer Quarterly*, 47, 1–41.
- Strydom, A., Forster, M., Wilkie, B., Edwards, C., & Hall, I. (2001). Patient information leaflets for people with learning disabilities who take psychiatric medication. *British Journal of Learning Disabilities*, 29, 72–76.
- Strydom, A., & Hall, I. (2001). Randomized trial of psychotropic medication information leaflets for people with intellectual disability. *Journal of Intellectual Disability Research*, 45, 146–151.
- Sturmey, P. (2012). Treatment of Psychopathology in People with Intellectual and other Disabilities. *The Canadian Journal of Psychiatry*, 57(10), 593–600.
<https://doi.org/10.1177/070674371205701003>

- Sutherland, R., & Isherwood, T. (2016). The Evidence for Easy-Read for People With Intellectual Disabilities: A Systematic Literature Review. *Journal of Policy and Practice in Intellectual Disabilities, 13*(4), 297–310.
- Taylor, J. L., Hatton, C., Dixon, L., & Douglas, C. (2004). Screening for psychiatric symptoms: PAS-ADD Checklist norms for adults with intellectual disabilities. *Journal of Intellectual Disability Research: JIDR, 48*(1), 37–41.
- Theodore Tapp, K., Chatters, K., Bexley, K., Blundell, R., Healey, L., Eyre, N., & Powell, S. (2015). Reasonable Adjustments for People with Learning Disabilities accessing Improving Access to Psychological Therapies services. *Bulletin of the Faculty for People with Intellectual Disabilities, 13*(3), 5.
- Thomas, C., & Morris, S. (2003). Cost of depression among adults in England in 2000. *British Journal of Psychiatry, 183*, 514–519.
- Tourangeau, R. (1984). Cognitive science and survey methods: A cognitive perspective. In *Cognitive aspects of survey design: Building a bridge between disciplines* (pp. 73–100).
- Turpin, G., Richards, D., Hope, R., & Duffy, R. (2008). Delivering the IAPT programme. *Healthcare Counselling and Psychotherapy Journal, 8*(2), 2–7.
- Vereenoghe, L., & Langdon, P. E. (2013). Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. *Research in Developmental Disabilities, 34*(11), 4085–4102.
<https://doi.org/10.1016/j.ridd.2013.08.030>
- Vlissides, N., Golding, L., & Beail, N. (2016). A systematic review of the outcome measures used in psychological therapies with adults with ID. In *Psychological Therapies and People Who Have Intellectual Disabilities* (pp. 166–203). British Psychological Society.

- Walmsley, J. (2013). Commentary on 'Enabling access to information by people with learning disabilities'. *Tizard Learning Disability Review*, 18, 16–19.
- Webb-Peploe, H., & Fredman, G. (2015). Systemic empathy with adults affected by intellectual disabilities and their families. *Journal of Family Therapy*, 37(2), 228–245. <https://doi.org/10.1111/j.1467-6427.2012.00605.x>
- Whitaker, S. (2004). Hidden learning disability. *British Journal of Learning Disabilities*, 32(3), 139–143. <https://doi.org/10.1111/j.1468-3156.2004.00264.x>
- WHO. (1992). The ICD-10 classification of mental and behavioural disorders: Clinical descriptions and diagnostic guidelines. Geneva: World Health Organisation.
- Williams, L. S., Brizendine, E. J., Plue, L., Bakas, T., Tu, W., Hendrie, H., & Kroenke, K. (2005). Performance of the PHQ-9 as a Screening Tool for Depression After Stroke. *Stroke*, 36(3), 635–638. <https://doi.org/10.1161/01.STR.0000155688.18207.33>
- Willis, G. B. (1999). *Cognitive Interviewing: A 'How To' Guide*. Meeting of the American Statistical Association.
- Willis, G. B. (2005). *Cognitive interviewing: a tool for improving questionnaire design*. Thousand Oaks, Calif: Sage Publications.
- Willner, P. (2005). The effectiveness of psychotherapeutic interventions for people with learning disabilities: a critical overview. *Journal of Intellectual Disability Research*, 49(1), 73–85. <https://doi.org/10.1111/j.1365-2788.2005.00633.x>
- Willner, P. (2006). Readiness for Cognitive Therapy in People with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 19(1), 5–16. <https://doi.org/10.1111/j.1468-3148.2005.00280.x>
- Zweig, M. H., & Campbell, G. (1993). Receiver-operating characteristic (ROC) plots: a fundamental evaluation tool in clinical medicine. *Clinical Chemistry*, 39(4), 561–577.

APPENDICIES:



Appendix 1: Version 1 of the adapted measures used in Stage 1.1 of the current study


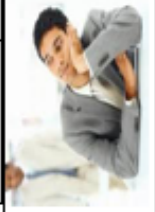
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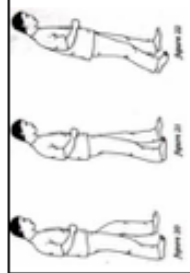

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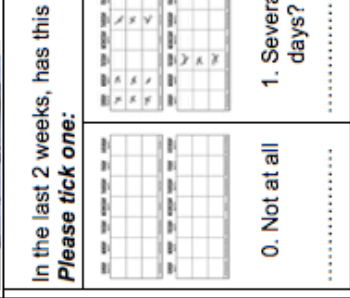
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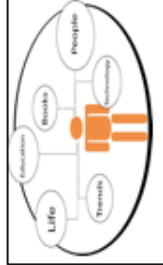
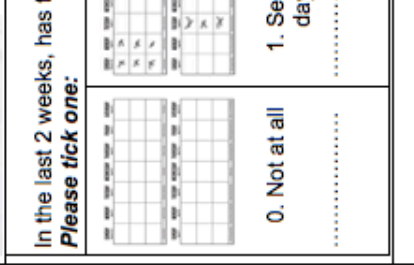
	<p>6.</p> <p>-Do you think you are a failure? -Do you think that you have let people down?</p>																														
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	<p>7.</p> <p>-Do you find it hard to concentrate on things, for example, watching TV?</p>																														
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	<p>8.</p> <p>-Have you been moving or speaking more slowly? <u>Or</u></p> <p>-Have you been moving or speaking a lot faster?</p>																																																																										
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<p>9.</p> <p>-Have you wanted to hurt yourself?</p> <p>-Have you wanted to kill yourself?</p>																																																																											
																																																																											
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	<p>5. -Have you been fidgety or restless? -Do you find it hard to stay still?</p>																																																																																																																																																																										
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	<p>3. -Have you been worrying lots about lots of different things?</p>																																																																																																																																																																										
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	<p>7. -Have you been worrying or scared that something bad is going to happen?</p>																																																																																																																																																																
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Appendix 2: Cognitive interview schedule used in Stage 1 of the study

Check familiarity with project, refer participant to information sheet again & ask if they have any questions about the research.

1) Study background & introduction to cognitive interviewing process:

Questionnaires are used by psychology services to help us understand how sad and worried people feel and measure if they get well after treatment. Two questionnaires have been changed to be used with people with learning disabilities. Today I will ask you questions about your views about these questionnaires and whether you think that people with learning disabilities will understand them, as you know what it is like to have a learning disability. This will help us to think about whether we need to make any more changes to the questionnaires.

For each question, I want to know 3 things. First I want to know whether the question makes sense to you. This means if you understand what it is asking. I also want to know whether you think we could change the words to help people with learning disabilities understand it better.

Next I want to know what you think about the pictures that help support a person's understanding of each question. I want to know if you think they make sense and if there is any thing we could change to make them easier to understand.

Lastly, I want to know if you think how you answer each question makes sense and if we can change the words or the pictures to help people with learning disabilities understand this more easily.

Even though I am asking you questions, I am not looking for information about you or assessing your mental health. I want to find out about if the questionnaires are useful for people with learning disabilities. I will ask you questions as you look at and talk about the questionnaires.

If there is anything you are not sure about or if you need a break, please let me know.

2) Presentation of the adapted measures to participants:

Present the adapted measures (PHQ-9 then GAD-7) to participants in the same way they would be administered clinically (i.e. printed copies).

Interviewer or participant (dependent on their preference/ability to do so) to read aloud instruction *"In the past 2 weeks...."* and check understanding:

- *What is this asking you to do?*
 - *Is this clear / confusing?*
 - *Does the picture [point] help?*
 - *Would another picture help more?*

Then proceed through items on the adapted measures, interviewer or participant to read each aloud before administering cognitive interviewing questions for each:

- *What do you think this question is asking about? / Can you repeat this question in your own words?*
- *What does [insert word from question] mean to you?*
- *Does the picture [point] help you understand the question?*
 - *What made it easy/difficult?*
 - *Does the picture help?*
 - *Would another picture help more?*
- *How many days or weeks is the question asking about?*
 - *How sure are you of your answer? [to determine overall level of confidence]*
 - *How hard was this to answer? [to determine the level of difficulty & likelihood of estimation/guessing]*
- *What are the choices for answering in your own words?*
- *Is it easy or difficult to decide what answer to give?*
 - *What made it easy/difficult?*
 - *Does the picture [point] help?*
 - *Would another picture help more?*

3) Examples of probe questions:

Anticipated probes: Scripted questions based on anticipated problems

- *Would another picture help more?*

Conditional probes: Scripted probes to be used in response to something that a participant says

- *Is this clear / confusing?*
- *What made it easy/difficult?*

General probes for more information

- *Tell me more about what you think about that?*
- *Can you explain what you mean by that?*

Functional remarks: To be used to encourage the participant to keep talking

- *Ah-ha*
- *I see*
- *That's interesting*

Feedback probes: To be used to provide feedback to participants

- *Thanks, that's very helpful*
- *That's just what I'm looking for*

Appendix 3: NHS Ethics and HRA approval documents



Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Room 001
Jarrow Business Centre
Viking Industrial Park
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0207 1048081

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

01 April 2016

Miss Jennifer Breen
Researcher/Postgraduate Student
Camden & Islington NHS Foundation Trust
Clinical Psychology Department
Royal Holloway - University of London
Egham Hill, Egham
TW20 0EX

Dear Miss Breen

Study title: An investigation of the validity of the adapted GAD-7 and PHQ-9 clinical measures for adults with learning disabilities
REC reference: 16/YH/0147
Protocol number: n/a
IRAS project ID: 202468

The Proportionate Review Sub-committee of the Yorkshire & The Humber - Bradford Leeds Research Ethics Committee reviewed the above application on 29 March 2016.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager



Health Research Authority

Yorkshire & The Humber - Bradford Leeds Research Ethics Committee

Jarrow Business Centre

Rolling Mill Road

Jarrow

NE32 3DT

Telephone: 0207 1048081

07 July 2016

Miss Jennifer Breen
Researcher/Postgraduate Student
Camden & Islington NHS Foundation Trust
Clinical Psychology Department
Royal Holloway - University of London
Egham Hill, Egham
TW20 0EX

Dear Miss Breen

Study title: An investigation of the validity of the adapted GAD-7 and PHQ-9 clinical measures for adults with learning disabilities
REC reference: 16/YH/0147
Protocol number: n/a
IRAS project ID: 202468

Thank you for your letter of 7th July. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 01 April 2016

Documents received

The documents received were as follows:

Document	Version	Date
Copies of advertisement materials for research participants [Advert/flyer for participants]	1	21 March 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Royal Holloway confirmation of indemnity]		21 March 2016
Interview schedules or topic guides for participants [Draft Cognitive Interview Schedule (Stage 1)]	1	21 March 2016
IRAS Checklist XML [Checklist_07072016]		07 July 2016
Letters of invitation to participant [Contact letter to services]	1	21 March 2016
Non-validated questionnaire [Adapted GAD-7 & PHQ-9 measures]	1	21 March 2016
Other [Confirmation of approval from the Research Ethics Sub-committee]		21 March 2016

Miss Jennifer Breen
Researcher/Postgraduate Student
Camden & Islington NHS Foundation Trust
Clinical Psychology Department
Royal Holloway - University of London
Egham Hill, Egham
TW20 0EX

Email: hra.approval@nhs.net

19 July 2016

Dear Miss Breen

**Letter of HRA Approval for a study
processed through pre-HRA
Approval systems**

Study title: An investigation of the validity of the adapted GAD-7 and PHQ-9 clinical measures for adults with learning disabilities
IRAS project ID: 202468
Sponsor: Royal Holloway University

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **HRA Approval**. This has been issued on the basis that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).



Appendix 4: Accessible information sheets and consent forms - n.b. two per page









18/10/16



Information about the research (Stage 1)



Title: Are these questionnaires easy for people with learning disabilities to understand?



	<p>My name is Jenny.</p>
	<p>I am doing some research. Research is when we talk to people and ask questions to find out new information. This research is just talking.</p>
	<p>I am asking if you would like to help me.</p>
	<p>You don't have to take part in the research. It's your choice.</p>






 	<p>What is the research about? Questionnaires are often used by psychology services to help us understand how people feel. Questionnaires also help us see if people get well after they see us. There are two questionnaires that are used with people with learning disabilities. <ul style="list-style-type: none"> • One questionnaire measures how sad people feel. • One questionnaire measures how worried people feel. </p>
	<p>We want to make sure the questionnaires we use are easy for people with learning disabilities to use. We want to find out if we need to make some changes to make them better.</p>
	<p>This research does not involve any operations or injections or medication. Taking part only involves talking.</p>
	<p>Why are you asking me to take part? You know what it is like to have a learning disability</p>



	You can tell us what you think about the questionnaires.
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Do I have to take part in the research?	
	Taking part in the research is your choice.
	Even if you agree to take part in the research, you can change your mind at any time and we will stop.


How do I take part in the research?	
	You need to let Jenny know that you want to talk to her about being involved in the research.
	You can call and leave a message for Jenny Breen on: 01784 414 012 Jenny will call you back.




	You can email Jenny at: jennifer.breen.2014@liverpool.ac.uk
	Jenny will call you to talk about taking part in the research.




What will happen if I take part in the research?	
	You will meet to talk with Jenny.
	You will talk to Jenny for about 1 hour.
	Jenny will show you the questionnaires. Jenny will ask you questions about what do you think about the questionnaires.
	Jenny will use a tape recorder to record what you tell her. This will be stored safely and deleted at the end of the research.
	What you tell Jenny will be kept: <ul style="list-style-type: none"> • Private • In a safe place • And it will not have your name on it


	You choose how much to say. You can choose not to answer any question. You can stop talking to Jenny at any time you want to.
	We don't think that taking part will make you feel upset. But if you do get upset when talking to Jenny, she will ask you how you would like to be helped.




Is taking part in the research private?	
	Yes.
	I will not tell people that you took part in the research. Or information about you like your name.
	But if you tell me something that makes me worried about your safety or someone else's safety, I will have to talk to my supervisor. This is to make sure that everyone is safe.

Who is running the research?	
	Jenny is the researcher.

	Royal Holloway University is running the research
	The IAPT service and the Learning Disability Service in Hammersmith & Fulham are helping with the research.
	The NHS has checked that the research is safe and that you will be treated well.

What will happen to the results of the research?	
	Jenny will write a report about the research.
	This will be sent to Royal Holloway University The new questionnaire will be shared with other researchers and other psychology services who may want to use it.
	I can send you an easy read report about the research if you want me to.

Can I talk to someone about the research?	
	Yes

	<p>You can call and leave a message for Jenny Breen on: 01784 414 012 Jenny will call you back.</p>
	<p>You can email Jenny at: jennifer.breen.2014@live.rhul.ac.uk</p>
	<p>You can talk to Kate Theodore (Jenny's supervisor) if you are unhappy with anything about the research</p>



Research stage 1: Consent form

Title: Are these questionnaires easy for people with learning disabilities to understand?

Researcher: Jenny Breen (jennifer.breen.2014@live.rhul.ac.uk)

Please tick boxes and sign below:

		✓ or X
	I have read the Participant Information sheet (version 1.0)	
	Jenny has checked if I have any questions about the research and answered them.	
	I am happy for my talk with Jenny to be recorded. This will be stored safely and deleted at the end of the research.	

	I understand that information about me will be kept: <ul style="list-style-type: none"> • Private • In a safe place • And it will not have my name on it 	
	I know that it is my choice to take part in this research and I can change my mind at any time.	
	I would like to be involved in the research	
	I would like you to send me an easy read report about the research.	

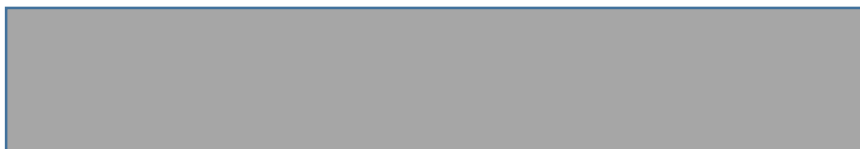
Name of Participant:

Signature of Participant: Date:

Name of Researcher:

Signature of Researcher: Date:

Appendix 5: Consent form for services involvement in the research



Consent form for Services – v1.0

Title: An investigation of the validity of the adapted GAD-7 and PHQ-9 clinical measures for adults with learning disabilities

Researcher: Jenny Breen (jennifer.breen.2014@live.rhul.ac.uk)

Please tick boxes and sign below:

I confirm that I have read both of the participant information sheets (v1.0) for the above study and have had the opportunity to answer questions. All my questions have been answered satisfactorily.

I understand that our service's participation in this study is voluntary and can be withdrawn at any time without consequence or having to give a reason.

I agree for my service to take part in the above study

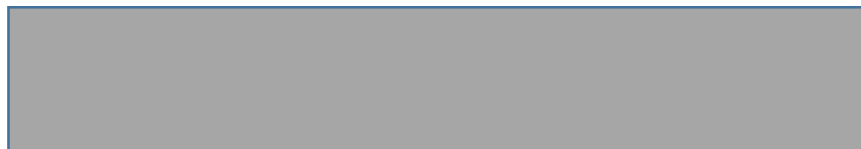
Signed: Print name: Date:

(Manager of service)




Signed: Print name: Date:

(Researcher)

Appendix 6: Accessible flyer to advertise the research to potential participants



How helpful are two questionnaires for people with learning disabilities?






We are looking for adults with learning disabilities to take part in some research.

Research is when we ask people questions to find out new information.

We want to find out what people with learning disabilities think about two questionnaires.

The questionnaires are about feeling sad and feeling worried.

Taking part involves talking to Jenny about the questionnaires for about an hour.



Jenny is the researcher.

If you are interested in taking part in the research, let Jenny know.

You or someone you know can call and leave a message for Jenny Breen on:

01784 414 012


Jenny will call you back.

You or someone you know can email Jenny at:

jennifer.breen.2014@live.rhul.ac.uk

Study flyer v1 15.3.16



Appendix 7: Example of extended notes taken following the cognitive interviews

	PHQ	
		<p>1. -Have you felt less interested in doing things as you used to?</p>
AF (28)	<p>"Why does he have a hat on? Looks like he's going to a party."</p>	<p>"It's ok, I understand it – it's asking if you are less interested in doing things that you really like to do like going out. Other people might not understand it though – maybe giving an example or a few examples might help them understand what the question is answering."</p>
RB (36)	<p>"Helps a little to understand – he looks fed up."</p>	<p>Understands after a Probe that the question is asking about the last 2 weeks. "Maybe it's asking about the things that you do usually, when you feel upset you don't do it anymore because you have other things on your mind. Maybe not too easy for other people with a learning disability to understand" – needed help from Hana to complete this to understand, talking through an example. Unable to answer how long the period is that is being asked about – tentatively suggested 1 week but seemed unsure.</p>
CM (29)	<p>"He's feeling a bit down or something."</p>	<p>"This question is asking about well when you are feeling down, you don't feel like doing anything like hang out with your mates"</p>
JW (45)	<p>"He looks fed up" Maybe thinks another picture might help more but no suggestions about what this could be</p>	<p>"It's asking if you've been less interested in doing things like if you are wanting to stay in your flat. Like you don't want to do things that you usually do like go to Mencap or see friends or go to café or the pub" Probe re meaning of less interested – "like just wanting to stay at home" Tricky to understand "doing things like you used to" – not sure how we could rephrase.</p>

†

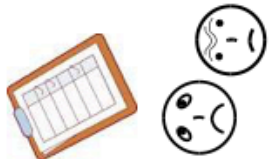



Appendix 8: Version 2 of the adapted measures which were developed following Stage 1.1

and discussed in Stage 1.2 - n.b. two per page

1	<p>FEELING SAD (PHQ-9)</p>  <p>Have you felt less interested in doing things?</p>	<table border="1"> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;">0 days</td> <td style="text-align: center;">1 – 7 days</td> <td style="text-align: center;">8 – 12 days</td> <td style="text-align: center;">13 – 14 days</td> <td></td> </tr> </table>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	0 days	1 – 7 days	8 – 12 days	13 – 14 days	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>								
0 days	1 – 7 days	8 – 12 days	13 – 14 days									
2	 <p>Have you felt sad?</p>	<table border="1"> <tr> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> <td style="text-align: center;"><input type="checkbox"/></td> </tr> <tr> <td style="text-align: center;">0 days</td> <td style="text-align: center;">1 – 7 days</td> <td style="text-align: center;">8 – 12 days</td> <td style="text-align: center;">13 – 14 days</td> <td></td> </tr> </table>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	0 days	1 – 7 days	8 – 12 days	13 – 14 days	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>								
0 days	1 – 7 days	8 – 12 days	13 – 14 days									


ADAPTED PHQ-9 & GAD-7 QUESTIONNAIRES

How to fill in these questionnaires:

	<p>These questionnaires are used by psychology services to help us understand how people feel.</p> <ul style="list-style-type: none"> One questionnaire measures how sad people feel. One questionnaire measures how worried people feel. <p>Questionnaires also help us see if people feel better after they see us.</p>
	<p>These questionnaires ask you about how you have been feeling in the past 2 weeks.</p> <p>It might help you to think about something that you did 2 weeks ago to answer these questions</p>
	<p>For each question, tick one of the boxes to show how you have been feeling in the past 2 weeks.</p>
	<p>If you need help or have questions, you can talk to your therapist.</p>

3


Have you had problems with your sleep?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days

4


Have you been feeling tired?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days

5


Have you been more or less hungry than normal?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days


6


Have you been feeling like you are no good?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days

7	 <p>Has it been hard to focus on things?</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	0 days	1 – 7 days	8 – 12 days	13 – 14 days		

8	  <p>Have you been</p> <ul style="list-style-type: none"> • moving or speaking more slowly than normal? <p>OR</p> <ul style="list-style-type: none"> • moving or speaking a lot faster than normal? 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	0 days	1 – 7 days	8 – 12 days	13 – 14 days		


9	 <p>Have you had thoughts about:</p> <ul style="list-style-type: none"> • Hurting yourself on purpose? • Killing yourself? 	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	0 days	1 – 7 days	8 – 12 days	13 – 14 days		

PHQ-9	TOTAL

1

FEELING WORRIED (GAD-7)


Have you been feeling worried?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 – 7 days	8 – 12 days	13 – 14 days

2


Has it been hard to stop worrying?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 – 7 days	8 – 12 days	13 – 14 days

3


Have you been worrying about lots of different things?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 – 7 days	8 – 12 days	13 – 14 days

4


Has it been hard to relax?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 – 7 days	8 – 12 days	13 – 14 days

5


Has it been hard to sit still?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days	

7

Have you felt afraid?




<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days	

GAD-7	
TOTAL	

6

Have you felt angry?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
0 days	1 - 7 days	8 - 12 days	13 - 14 days	

Is there anything you want to tell us about your answers?

.....






.....





.....

.....

.....

.....

PHQ-9 Depression questions continued...		Not at all	Several days	More than half the days	Nearly every day
		0	1	2	3
	5. Poor appetite or overeating	0	1	2	3
	6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down	0	1	2	3
	7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
	8. Moving or speaking more slowly than usual. Or being fidgety and moving around a lot	0	1	2	3
	9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3
					PHQ-9 Total: <input type="text"/>

PHQ-9 Depression questions		Not at all	Several days	More than half the days	Nearly every day
		0	1	2	3
	1. Little interest or pleasure in doing things	0	1	2	3
	2. Feeling down, depressed, or hopeless	0	1	2	3
	3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
	4. Feeling tired or having little energy	0	1	2	3

GAD-7 | Anxiety questions

Over the last 2 weeks, how often have you been bothered by any of these problems?

Not at all
 Several days
 More than half the days
 Nearly every day

1. Feeling nervous, anxious or on edge

0

1

2

3



2. Not being able to stop or control worrying

0

1

2

3



3. Worrying too much about different things

0

1

2

3



4. Trouble relaxing

0

1

2

3



5. Being so restless that it is hard to sit still

0

1

2

3



6. Becoming easily annoyed or irritable

0

1

2

3



7. Feeling afraid as if something awful might happen

0

1

2

3



GAD-7 Total:

Appendix 10: Clinician guidance for the adapted measures (Version 1) – n.b. two per page

Clinician Guidelines for using the adapted PHQ-9 and GAD-7 clinical measures

General guidelines:

The adapted versions of the PHQ-9 and GAD-7 measures are intended for use with clients who require reasonable adjustments to access psychology services, namely those with learning disabilities. They were developed?

Some useful general points for using the measures with clients include:

- Using the term “questionnaires” rather than “clinical measures”
- Introducing the measures to clients and explaining why you are asking them to do these
 - E.g. *“We ask everyone who is seen in this service to do these questionnaires. This is important as it helps us to understand how people feel and gives us an idea if people get well after seeing us”*
- Orientating them to the scale, particularly the response options. It may be helpful to think with them about something they did two weeks earlier and using this as an anchor in time
 - E.g. *“Today is Tuesday. Can you remember something that you did two Tuesdays ago? OK, when answering these questions, I want you to think about how you have felt between now and when you did X”*
- People with learning disabilities are likely to need a higher level of support to complete these questionnaires than other clients. This may involve completing the questionnaires with the client in sessions at first, to make sure that they are able to report their symptoms accurately. It may be that over time, clients need less support to complete these measures.

The following tables provide suggested alternatives for terms used and examples of prompts which you could use with clients which may help them understand the individual items on the PHQ-9 and GAD-7 measures. Many of these have been suggested by adults with learning disabilities who were involved in the development of the adapted versions of the clinical measures.

PHQ-9 ITEM NUMBER	PHQ-9 ITEM WORDING	ADAPTED WORDING	SUGGESTED ALTERNATIVE HELPFUL TERMS	EXAMPLES OF PROMPTS
1	Less interest or pleasure in doing things	Have you felt less interested in doing things you normally like to do?	None	<ul style="list-style-type: none"> • Like just wanting to stay at home • Not wanting to hang out with your friends • Not wanting to watch your favourite soaps/tv shows • Not wanting to do your favourite hobbies
2	Feeling down, depressed or hopeless	Have you felt sad?	<ul style="list-style-type: none"> • Depressed 	<ul style="list-style-type: none"> • Wanting to be on your own more • Crying a lot
3	Trouble falling or staying asleep or sleeping too much	Have you had problems with your sleep?	None	<ul style="list-style-type: none"> • Like finding it hard to fall asleep at night • Sleeping too much like not wanting to wake up in the morning • Waking up in the night a lot
4	Feeling tired or having little energy	Have you been feeling tired?	<ul style="list-style-type: none"> • No energy to do things 	<ul style="list-style-type: none"> • Feeling tired all the time • Like when you don't want to do much • Wanting to sleep all the time


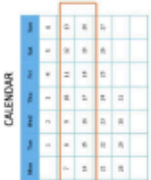
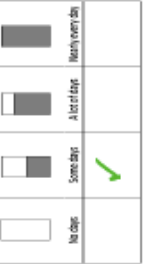

5	Poor appetite or overeating	Have you been more or less hungry than normal?	<ul style="list-style-type: none"> • Appetite 	<ul style="list-style-type: none"> • Eating less/more food than normal
6	Feeling bad about yourself or that you are a failure or have let yourself or your family down	Have you been feeling like you're no good?	<ul style="list-style-type: none"> • Letting yourself r other people down 	<ul style="list-style-type: none"> • Feeling like you've let people down • Feeling like you've let yourself down
7	Trouble concentrating on things, such as reading the newspaper or watching television	Has it been hard to focus on things?	<ul style="list-style-type: none"> • Finding it hard to concentrate • Getting bored easily 	<ul style="list-style-type: none"> • Like when watching your favourite tv programme
8	Moving or speaking so slowly that other people could have noticed or the opposite being so fidgety or restless that you have been moving around a lot more than usual	Have you been moving or speaking more slowly or a lot faster than normal?	<ul style="list-style-type: none"> • Fidgeting a lot • Feeling restless 	
9	Thoughts that you would be better off dead or of hurting yourself in some way	Have you wanted to <ul style="list-style-type: none"> • Hurt yourself on purpose? • Kill yourself? 	<ul style="list-style-type: none"> • Self harming 	<ul style="list-style-type: none"> • Using a knife to cut yourself • Taking lots of tablets • Feeling like you don't want to live anymore • Wanting to end your life

GAD-7 ITEM NUMBER	GAD-7 WORDING	ADAPTED WORDING	SUGGESTED ALTERNATIVE HELPFUL TERMS	EXAMPLES OF PROMPTS
1	Feeling nervous, anxious or on edge	Have you been feeling worried?	<ul style="list-style-type: none"> • Nervous 	
2	Not being able to stop or control worrying	Has it been hard to stop worrying?	None	<ul style="list-style-type: none"> • Worrying a lot
3	Worrying too much about lots of different things	Have you been worrying about lots of different things?	None	<ul style="list-style-type: none"> • Money, bills, getting a job, friends, family, passing exams
4	Trouble relaxing	Has it been hard to relax?	<ul style="list-style-type: none"> • Chill out 	<ul style="list-style-type: none"> • Thinking with the person how they normally relax
5	Being so restless that it is hard to sit still	Has it been hard to sit still?		<ul style="list-style-type: none"> • Feeling restless • Fidgeting a lot
6	Becoming easily annoyed or irritable	Have you felt angry?	<ul style="list-style-type: none"> • Annoyed 	
7	Feeling afraid as if something awful may happen	Have you felt afraid?	<ul style="list-style-type: none"> • Worried 	<ul style="list-style-type: none"> • Worrying that something bad might happen to you or someone else • Not feeling safe • Worrying that you might get hurt • Being mugged or having your bag or phone taken

Appendix 11: Version 3 of the adapted PHQ-9 and GAD-7 measures – n.b. two per page

ADAPTED PHQ-9 & GAD-7 QUESTIONNAIRES


How to fill in these questionnaires:

	<p>These questionnaires are used by psychology services to help us understand how people feel.</p> <ul style="list-style-type: none"> • One questionnaire measures how sad people feel. • One questionnaire measures how worried people feel. <p>Questionnaires also help us see if people feel better after they see us.</p>
	<p>These questionnaires ask you about how you have been feeling in the past 2 weeks. It might help you to think about something that you did 2 weeks ago to answer these questions</p>
	<p>For each question, tick one of the boxes to show how you have been feeling in the past 2 weeks.</p>
	<p>If you need help or have questions, you can talk to your therapist.</p>

1

FEELING SAD (PHQ-9)


Have you felt less interested in doing things?



<input type="checkbox"/>	No days	<input type="checkbox"/>	Some days	<input type="checkbox"/>	A lot of days	<input type="checkbox"/>	Nearly every day
--------------------------	---------	--------------------------	-----------	--------------------------	---------------	--------------------------	------------------

2


Have you felt sad?



<input type="checkbox"/>	No days	<input type="checkbox"/>	Some days	<input type="checkbox"/>	A lot of days	<input type="checkbox"/>	Nearly every day
--------------------------	---------	--------------------------	-----------	--------------------------	---------------	--------------------------	------------------

3


Have you had problems with your sleep?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

5


Have you been more or less hungry than normal?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

4


Have you been feeling tired?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

6


Have you been feeling like you have let yourself down or let other people down?







<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

7

Has it been hard to concentrate on things?








	No days		Some days		A lot of days		Nearly every day
---	---------	---	-----------	---	---------------	---	------------------

9

Have you had thoughts about:

- Hurting yourself on purpose?
- Killing yourself?



	No days		Some days		A lot of days		Nearly every day
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8





Have you been

- moving or speaking more slowly?

OR

- moving or speaking a lot faster?


	No days		Some days		A lot of days		Nearly every day
---	---------	---	-----------	---	---------------	---	------------------

PHQ-9 TOTAL	
----------------	--

1

FEELING WORRIED (GAD-7)


Have you been feeling worried?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

2


Has it been hard to stop worrying?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

3


Have you been worrying about lots of different things?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

4


Has it been hard to relax?



<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No days	Some days	A lot of days	Nearly every day

5


Has it been hard to sit still?



No days	Some days	A lot of days	Nearly every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7


Have you felt scared?



No days	Some days	A lot of days	Nearly every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6

Have you felt angry?



No days	Some days	A lot of days	Nearly every day
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

GAD-7	
TOTAL	

Is there anything you want to tell us about your answers?

.....

.....

.....

.....

.....

.....

Appendix 12: Updated clinician guidance following Stage 1.2 (Version 2) - n.b. two per page

Clinician Guidelines for using the adapted PHQ-9 and GAD-7 clinical measures

General guidelines:

The adapted versions of the PHQ-9 and GAD-7 measures are intended for use with clients who require reasonable adjustments to access psychology services, namely those with learning difficulties or disabilities. They were developed with service users with learning disabilities as well as professionals working in specialist Learning Disability and IAPT services. The literature suggests that ideally information for people with learning difficulties or disabilities should be tailored to the individual and so it is important for clinicians to think about the individual’s needs and adapt the administration and choice of outcome measures used accordingly. Some people will have a preference for visual prompts, others prefer easy read English only, some will require support with administration and others be able to complete the measures themselves independently.

The easy read guidelines for service users on the first page of these adapted measures offer some support for clinicians to cover some of these points. Some additional useful general points for using the measures with clients include:

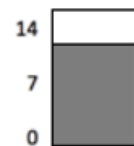
- Using the term “questionnaires” rather than “clinical measures”
- Introducing the measures to clients and explaining why you are asking them to do these
 - E.g. “We ask everyone who is seen in this service to do these questionnaires. This is important as it helps us to understand how people feel and gives us an idea if people get well after seeing us”
- People with learning disabilities are likely to need a higher level of support to complete these questionnaires than other clients. This may involve completing the questionnaires with the client in sessions at first, to make sure that they are able to report their symptoms accurately. It may be that over time, clients need less support to complete these measures.

Response Options & Scoring:

When introducing the scale, it is helpful to orient clients to the scale, particularly the response options. It may be helpful to think with them about something they did two weeks earlier and using this as an anchor in time:

- E.g. “Today is Tuesday. Can you remember something that you did two Tuesdays ago? OK, when answering these questions, I want you to think about how you have felt between now and when you did X”

Some people may need additional support to understand the response options. If so, it may be helpful explain the visuals by drawing numbers onto the visual cues like a scale to represent the number of days that each option is asking about so people can understand this more clearly. For example – the visual here shows ‘a lot of days’ (which corresponds to the original PHQ-9 and GAD-7 response item ‘more than half the days’, hence the numbers written on the visual scale item.



The adapted versions of the PHQ-9 and GAD-7 measures are scored in exactly the same way as the original measures:

Adapted Response option	Original Response option	Score
No days	<i>Not at all</i>	0
Some days	<i>Several days</i>	1
A lot of days	<i>More than half the days</i>	2
Nearly every day	<i>Nearly every day</i>	3

Individual item scores in each measure should be totalled to obtain overall scores for each of the measures. The total scores for the PHQ-9 and GAD-7 measure can be written in the total score box at the end of each measure.

Alternative item explanations:

The tables on the following pages provide suggested alternatives for terms used and examples of prompts which you could use with clients which may help them understand the individual items on the PHQ-9 and GAD-7 measures. Many of these have been suggested by adults with learning disabilities who were involved in the development of the adapted versions of the clinical measures.

PHQ-9 ITEM NUMBER	PHQ-9 ITEM WORDING	ADAPTED WORDING	SUGGESTED ALTERNATIVE HELPFUL TERMS	EXAMPLES OF PROMPTS
1	Less interest or pleasure in doing things	Have you felt less interested in doing things you normally like to do?	None	<ul style="list-style-type: none"> Like just wanting to stay at home Not wanting to hang out with your friends Not wanting to watch your favourite soaps/<u>tv</u> shows Not wanting to do your favourite hobbies
2	Feeling down, depressed or hopeless	Have you felt sad?	<ul style="list-style-type: none"> Depressed 	<ul style="list-style-type: none"> Wanting to be on your own more Crying a lot
3	Trouble falling or staying asleep or sleeping too much	Have you had problems with your sleep?	None	<ul style="list-style-type: none"> Like finding it hard to fall asleep at night Sleeping too much like not wanting to wake up in the morning Waking up in the night a lot
4	Feeling tired or having little energy	Have you been feeling tired?	<ul style="list-style-type: none"> No energy to do things 	<ul style="list-style-type: none"> Feeling tired all the time Like when you don't want to do much Wanting to sleep all the time
5	Poor appetite or overeating	Have you been more or less hungry than normal?	<ul style="list-style-type: none"> Appetite 	<ul style="list-style-type: none"> Eating less/more food than normal

6	Feeling bad about yourself or that you are a failure or have let yourself or your family down	Have you felt like you have let yourself down or let other people <u>down</u>	<ul style="list-style-type: none"> Have you been feeling like you're no good? Failure 	<ul style="list-style-type: none"> Feeling like you've let people down Feeling like you've let yourself down
7	Trouble concentrating on things, such as reading the newspaper or watching television	Has it been hard to concentrate on things?	<ul style="list-style-type: none"> Finding it hard to focus Being distracted Getting bored easily 	<ul style="list-style-type: none"> Like when watching your favourite <u>tv</u> programme
8	Moving or speaking so slowly that other people could have noticed or the opposite being so fidgety or restless that you have been moving around a lot more than usual	Have you been moving or speaking more slowly or a lot faster?	<ul style="list-style-type: none"> Fidgeting a lot Feeling restless 	
9	Thoughts that you would be better off dead or of hurting yourself in some way	Have you wanted to <ul style="list-style-type: none"> Hurt yourself on purpose? Kill yourself? 	<ul style="list-style-type: none"> <u>Self harming</u> 	<ul style="list-style-type: none"> Using a knife to cut yourself Taking lots of tablets Feeling like you don't want to live anymore Wanting to end your life

GAD-7 ITEM NUMBER	GAD-7 WORDING	ADAPTED WORDING	SUGGESTED ALTERNATIVE HELPFUL TERMS	EXAMPLES OF PROMPTS
1	Feeling nervous, anxious or on edge	Have you been feeling worried?	<ul style="list-style-type: none"> Nervous 	
2	Not being able to stop or control worrying	Has it been hard to stop worrying?	None	<ul style="list-style-type: none"> Worrying a lot
3	Worrying too much about lots of different things	Have you been worrying about lots of different things?	None	<ul style="list-style-type: none"> Money, bills, getting a job, friends, family, passing exams
4	Trouble relaxing	Has it been hard to relax?	<ul style="list-style-type: none"> Chill out Calm down 	<ul style="list-style-type: none"> Thinking with the person how they normally relax
5	Being so restless that it is hard to sit still	Has it been hard to sit still?		<ul style="list-style-type: none"> Feeling restless Fidgeting a lot
6	Becoming easily annoyed or irritable	Have you felt angry?	<ul style="list-style-type: none"> Annoyed 	
7	Feeling afraid as if something awful may happen	Have you felt scared?	<ul style="list-style-type: none"> Worried Afraid 	<ul style="list-style-type: none"> Worrying that something bad might happen to you or someone else Not feeling safe Worrying that you might get hurt Being mugged or having your bag or phone taken

Appendix 13: Administrators Feedback Form

Administrators' Feedback Form				
Administrator initials:			Date completed:	
	If completed, time taken to complete (minutes)	If completed, how easy was it to administer? (rating 1 to 10 where 1 = not very practical and 10 is very easy)	If completed, how acceptable was it to the service user? (rating 1 to 10 where 1 = not acceptable and 10 is very acceptable)	If completed, were there any difficult items? Please specify item number
Adapted PHQ-9				
Adapted GAD-7				

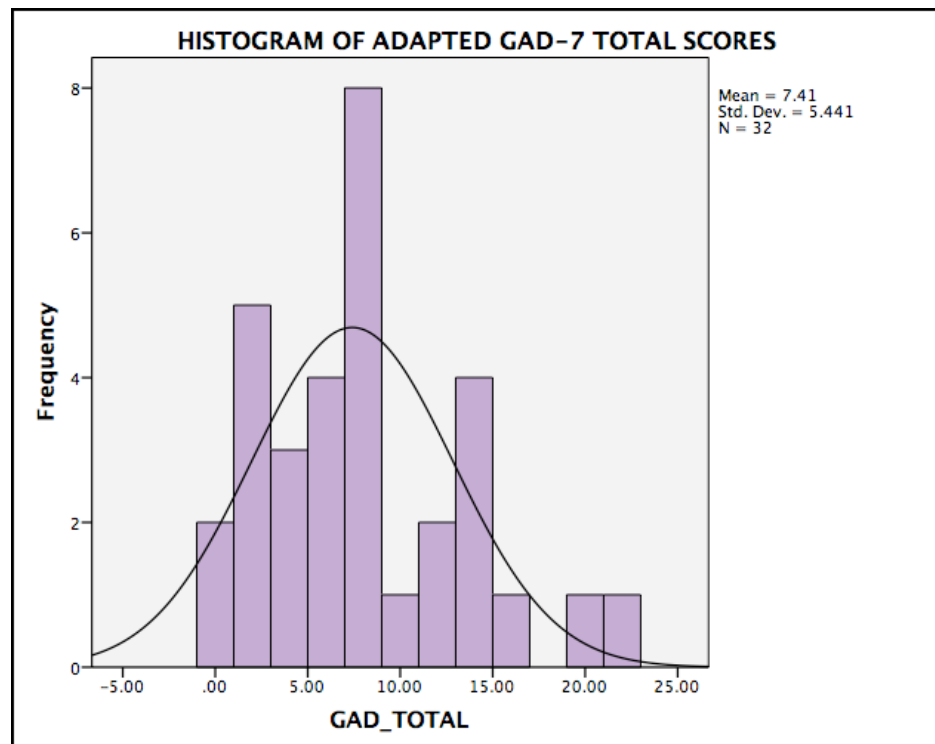
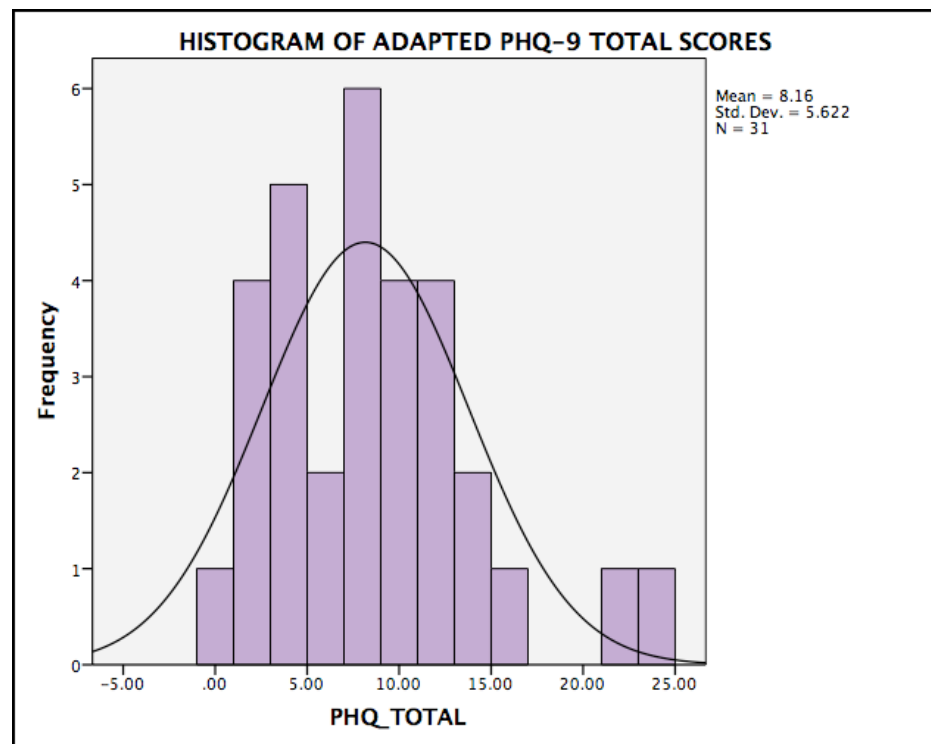
Any other general comments:

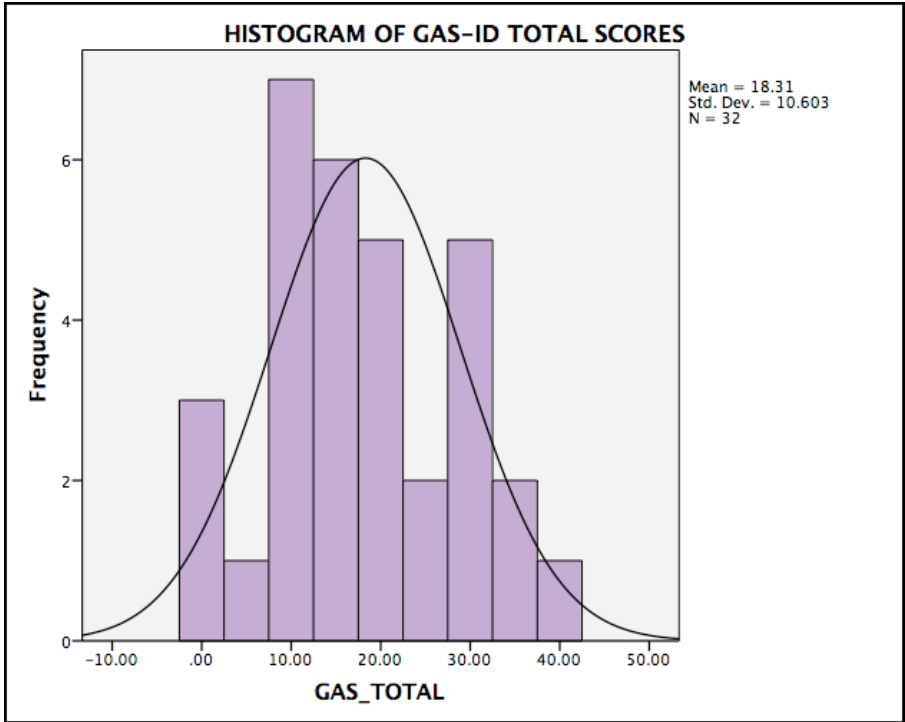
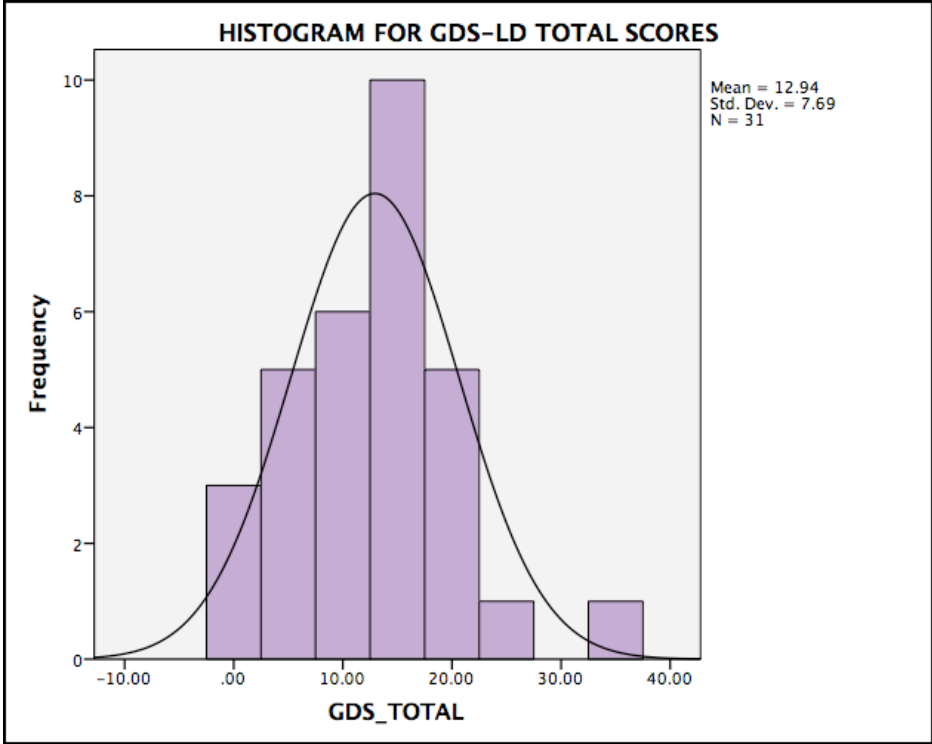
.....

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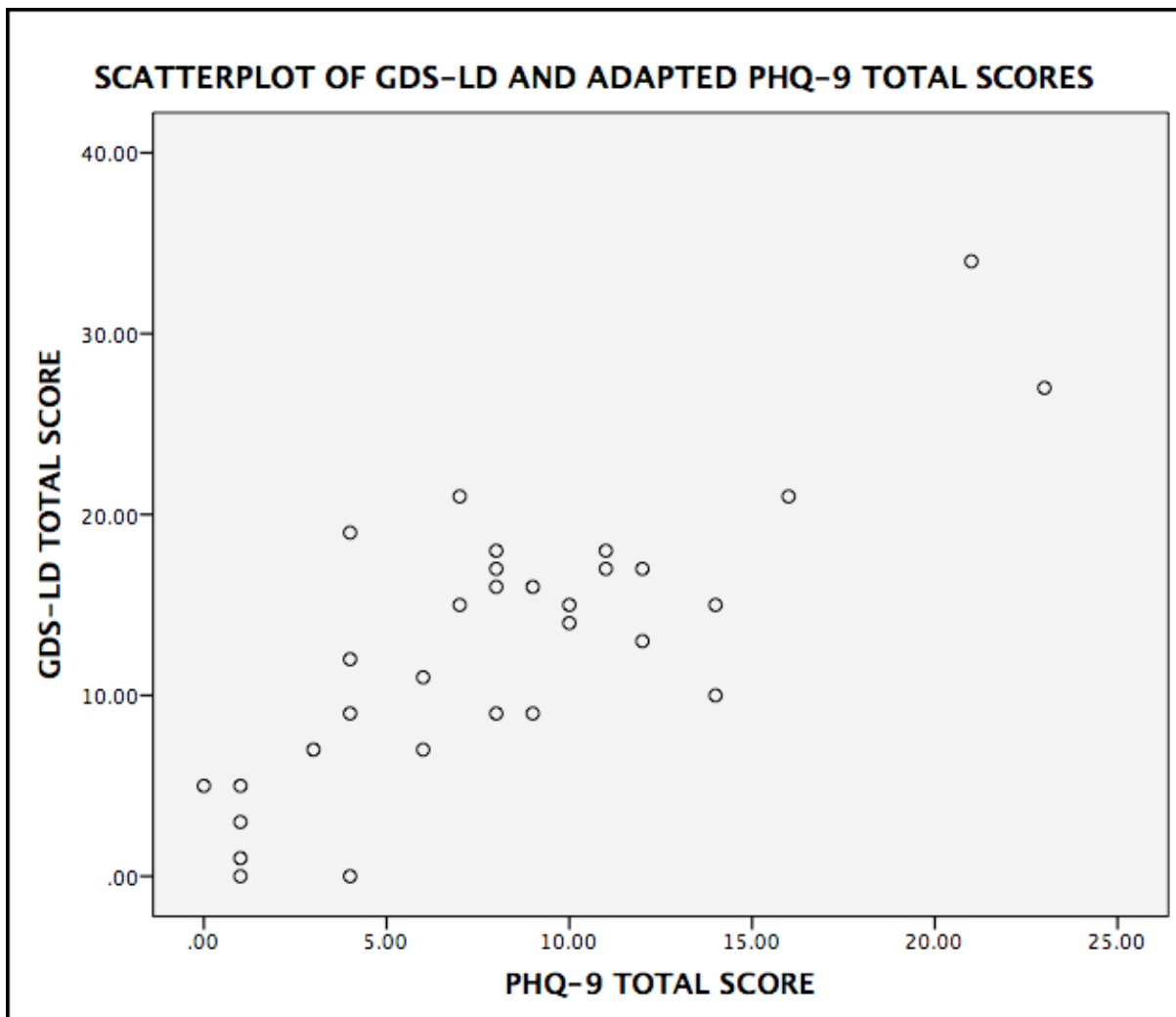
.....

Appendix 14: Histograms of the scores on the adapted PHQ-9 and GAD-7 & Glasgow Scales

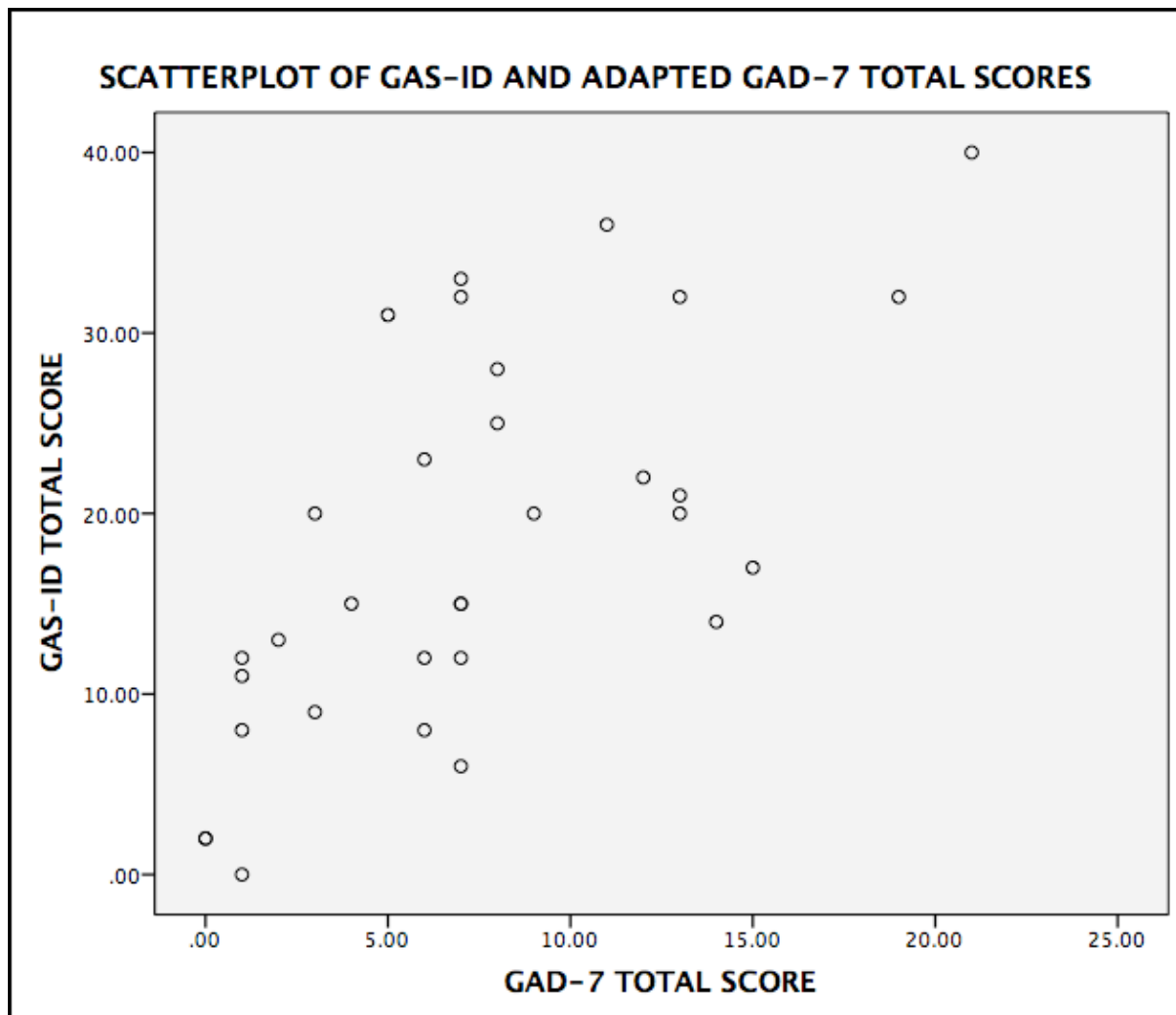




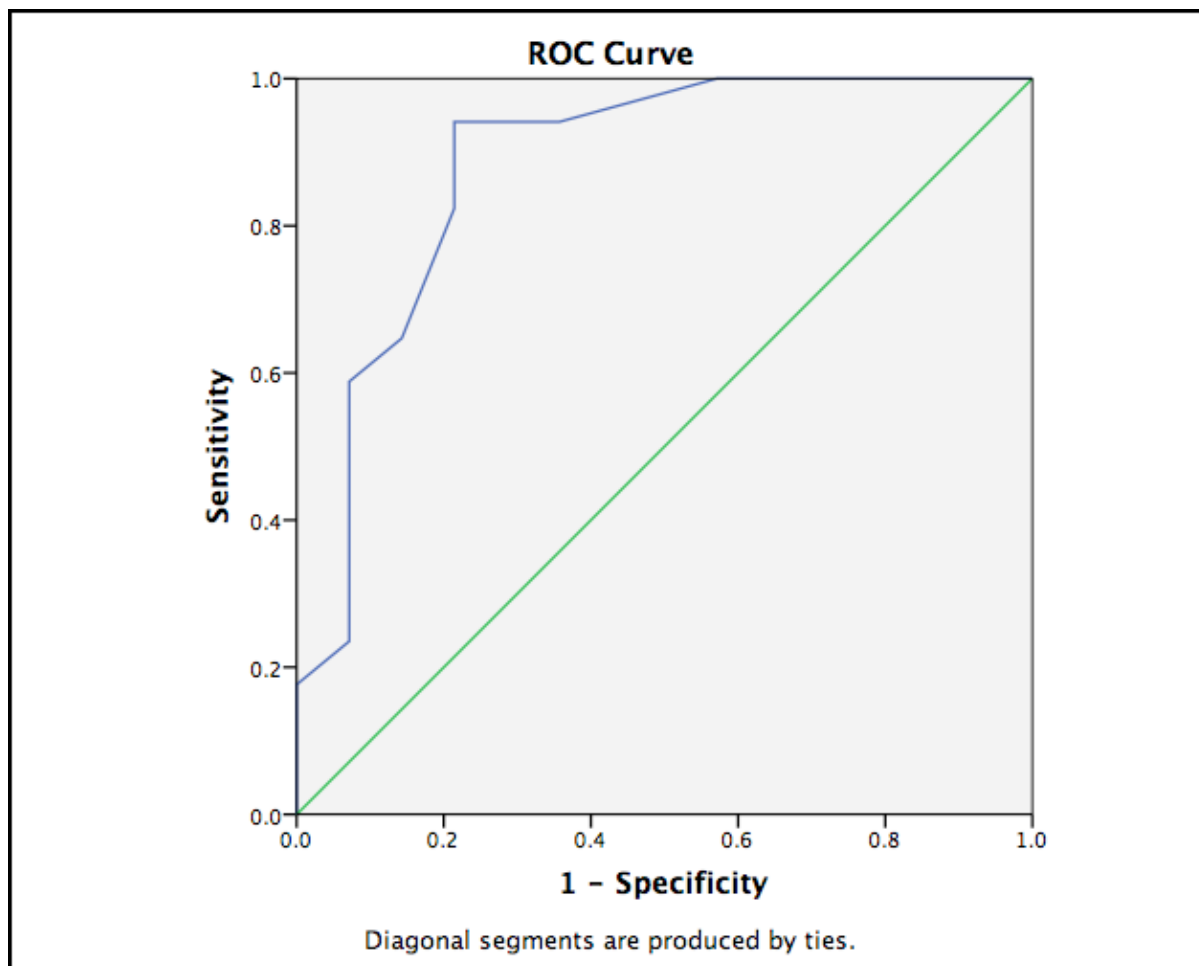
Appendix 15: Scatterplots displaying the total scores between the PHQ-9 AND GDS-LD



Appendix 16: Scatterplots displaying the total scores between the GAD-7 AND GAS-ID



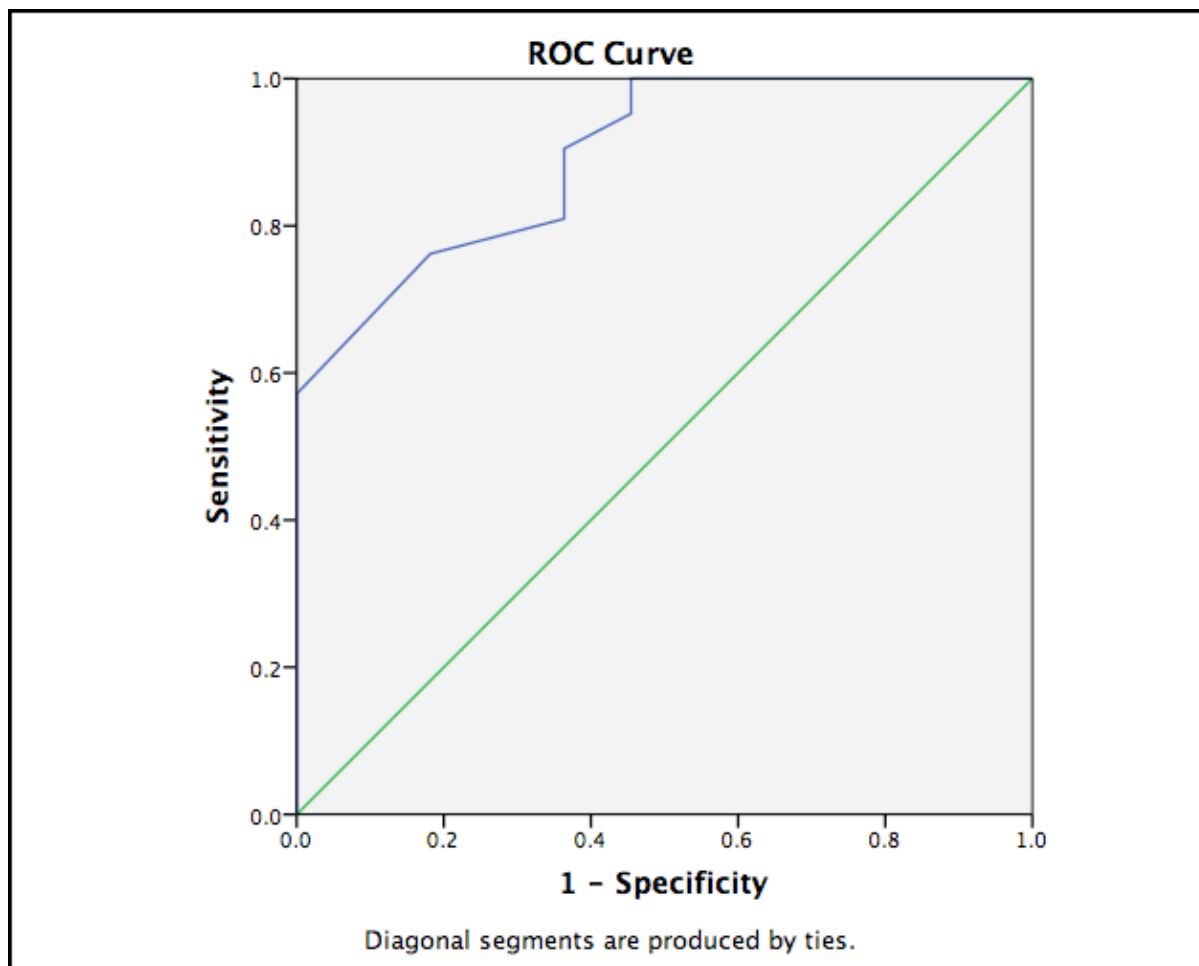
Appendix 17: ROC curve for clinical measures of depression



Area Under the Curve				
Test Result				
Variable(s): PHQ_TOTAL				
Area	Std. Error ^a	Asymptotic Sig. ^b	Asymptotic 95% Confidence Interval	
			Lower Bound	Upper Bound
.882	.066	.000	.753	1.000
The test result variable(s): PHQ_TOTAL has at least one tie between the positive actual state group and the negative actual state group. Statistics may be biased.				
a. Under the nonparametric assumption				
b. Null hypothesis: true area = 0.5				

Coordinates of the Curve		
Test Result Variable(s): PHQ_TOTAL		
Positive if Greater Than or Equal To ^a	Sensitivity	1 - Specificity
-1.00	1.000	1.000
.50	1.000	.929
2.00	1.000	.643
3.50	1.000	.571
5.00	.941	.357
6.50	.941	.214
7.50	.824	.214
8.50	.647	.143
9.50	.588	.071
10.50	.471	.071
11.50	.353	.071
13.00	.235	.071
15.00	.176	.000
18.50	.118	.000
22.00	.059	.000
24.00	.000	.000
<p>The test result variable(s): PHQ_TOTAL has at least one tie between the positive actual state group and the negative actual state group.</p> <p>a. The smallest cutoff value is the minimum observed test value minus 1, and the largest cutoff value is the maximum observed test value plus 1. All the other cutoff values are the averages of two consecutive ordered observed test values.</p>		

Appendix 18: ROC curve for clinical measures of anxiety



Area Under the Curve				
Test Result				
Variable(s): GAD_TOTAL				
Area	Std. Error ^a	Asymptotic Sig. ^b	Asymptotic 95% Confidence Interval	
			Lower Bound	Upper Bound
.894	.056	.000	.785	1.000
The test result variable(s): GAD_TOTAL has at least one tie between the positive actual state group and the negative actual state group. Statistics may be biased.				
a. Under the nonparametric assumption				
b. Null hypothesis: true area = 0.5				

Coordinates of the Curve		
Test Result Variable(s): GAD TOTAL		
Positive if Greater Than or Equal To ^a	Sensitivity	1 - Specificity
-1.00	1.000	1.000
.50	1.000	.818
1.50	1.000	.455
2.50	.952	.455
3.50	.905	.364
4.50	.857	.364
5.50	.810	.364
6.50	.762	.182
7.50	.571	.000
8.50	.476	.000
10.00	.429	.000
11.50	.381	.000
12.50	.333	.000
13.50	.190	.000
14.50	.143	.000
17.00	.095	.000
20.00	.048	.000
22.00	.000	.000
<p>The test result variable(s): GAD_TOTAL has at least one tie between the positive actual state group and the negative actual state group.</p> <p>a. The smallest cutoff value is the minimum observed test value minus 1, and the largest cutoff value is the maximum observed test value plus 1. All the other cutoff values are the averages of two consecutive ordered observed test values.</p>		

Appendix 19: Fitzpatrick and colleagues' (1998) criteria and Cahill and colleagues' (2008)

rating tool – from Vlisides et al., (2016, p. 180)

Criteria to assess the quality of a measures (based on Cahill et al., 2008):

CRITERION	DEFINITION
Reliability	
Internal consistency	As measured by Cronbach's alpha, split-half reliability estimates
Test-retest reliability	
Validity	
Construct validity	Hypotheses are generated and a measure tested to determine whether it actually reflects these prior hypotheses
Concurrent validity	Where a new measure is administered at the same time as a pre-existing one and the two are correlated
Convergent validity	A measure converges with other indications of the same concept
Discriminant validity	A measure demonstrates low levels of correspondence with a measure that represents a different concept
Responsiveness	
	Addresses the question: does the instrument detect changes over time that matter to the patient? It can be discriminative (between individuals) or evaluative (within individuals across time)
Acceptability	
	Addresses the question: is the measure acceptable to users?
	Practicality of administration
	Time taken to complete
	Length of instrument
	Translations
	Access by ethnic minorities
	Reading age
Feasibility	
	Is the measure easy to administer and process?
	Cost and burden to administrative staff
	Electronic scanning options
	Scoring systems
	Training package or manual
	Support from measure developers
Precision	
	Interpretability
	Normative data

Coding instructions for the quality assessment of the outcome measures:

FITZPATRICK CRITERIA	CODING	EXPLANATION
Reliability		
	Adequate	> 0.7
	Partial	> 0.5 < 0.7
	Inadequate	< 0.5
	Unknown	Reliability not supplied
Validity		
	Adequate	Reports more than three types of validity tests
	Partial	Reports two types of validity tests
	Inadequate	Reports one validity test
	Unknown	Validity estimates not supplied
Responsiveness		
	Adequate	Significant differences found between groups or within individuals
	Partial	Non-significant trends found between groups or within individuals
	Inadequate	Not addressed
Acceptability		
	Adequate	All of the components described
	Partially addressed	At least one of the components described
	Not addressed	None of the components described
Feasibility		
	Adequate	All of the components described
	Partially addressed	At least one of the components described
	Not addressed	None of the components described
Precision		
	Adequate	All of the components described
	Partially addressed	At least one of the components described
	Not addressed	None of the components described





Appendix 20: Draft of accessible overview of research findings disseminated to participants and service user organisations






EASY READ RESEARCH SUMMARY:

Research title: Are these questionnaires easy for people with learning disabilities to understand?




Why did we do the research?

	<p>Psychology services use questionnaires to help us understand how people feel.</p>
	<p>These questionnaires were not easy for people with learning disabilities to understand.</p>
	<p>The research wanted to make two questionnaires easier for people with learning disabilities to understand.</p>
	<p>We hoped that this would make it easier for people with learning disabilities to access psychology services.</p>



What did we do?

	<p>In Stage 1 of the research we used something called 'cognitive interviewing'.</p> <p>This means we talked to 6 people with learning disabilities to find out what they thought about the questionnaires.</p> <p>We asked them about:</p> <ul style="list-style-type: none"> • The words • The pictures • How to answer the questions • How the questionnaires looked
	<p>The research team then made some changes to the questionnaires.</p> <p>And talked again with 7 people with learning disabilities to see what they thought.</p> <p>We then made more changes to the questionnaires.</p>
	<p>In Stage 2 of the research we asked therapists to use the questionnaires with people with learning disabilities.</p> <p>32 people with learning disabilities used the measures.</p>

What did we find out?





	<p>People with learning disabilities were able to help us make the questionnaires easy read.</p>
	<p>The easy read questionnaires were quick and easy to use.</p>
	<p>The research suggests that the questionnaires can be used with people with intellectual disabilities. They pick up signs of depression and anxiety.</p>

What happens next?

	<p>We want to let people know about the research. We will present the research results to therapists and researchers at conferences.</p>
	<p>We want therapists in more services to use the easy read questionnaires.</p>

	<p>We will ask services and organisations across the UK to help us.</p>
	<p>We will write a paper about what we found out for clinicians to read and share.</p>
	<p>We want to say thank you to those people who helped us with the research and are helping us to share the results.</p>

Questions?

	<p>Jenny Breen was the researcher</p>
	<p>Kate Theodore was the research supervisor</p>
	<p>You can call and leave a message for Jenny or Kate on: 01784 414 012</p>
	<p>You can email Jenny at: jennifer.breen.2014@live.rhul.ac.uk</p>