COGNITIVE ASSESSMENT: PERSPECTIVES FROM ADULTS WITH INTELLECTUAL DISABILITY

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ABSTRACT

Cognitive assessment is frequently used in the process of the diagnosis of intellectual disability (ID) in adults. However, there is little known about the subjective experience and discourses surrounding this process of assessment. This study therefore aims to explore this experience, and the specific discursive devices utilised by people when describing the experience, from the perspective of adults with ID. Information was gathered using semi-structured interviews with four clients with a recently diagnosed ID. These were analysed using both Interpretative Phenomenological Analysis (IPA) and Discourse Analysis (DA), to examine various aspects of discourse alongside the phenomenological experience.

The IPA results highlighted a variety of experiences that participants had and suggested that they did not experience their tests as emotionally neutral. For example, participants described experiences of disconnected services, namely through having seen various professionals over the assessment period, having experienced multiple similar types of assessment over their lifetime, and through experiencing poor communication from services. Participants experienced their assessors as being nice, empathetic, and listening to them, and were left with a feeling of hope that they would get support. However, there was also confusion about the purpose of the assessment and surrounding what the outcomes would be. DA results examined the language and discursive devices used by participants within the discussions about their experience. This latter part of the analysis revealed four main themes, namely surrounding the system holding the power, reliance on others, resilience, and having to do something versus choosing to do it.

The results of this study are considered in the context of the surrounding literature. Potential implications and suggestions for future research are also discussed.

CONTENTS

INTRODUCTION

1.1. Overview

This chapter will introduce the contexts surrounding cognitive assessment in adults with a diagnosis of an intellectual disability (this term will be referred to from hereon as ‘ID’). I begin with a brief overview of my interest in this research area, which stems both from personal and professional experiences. I then go on to discuss the current definitions of ID and the policy and political climate of ID and cognitive assessment. Following on from this, I contextualise the research in light of policy and the current political climate in which IDs are currently understood.

In the second half of the introduction I focus on literature surrounding the experience of having a cognitive assessment, followed by discourse analysis research involving people with ID. Lastly, I highlight my study aims and research question in the context of the existing research.

1.2. Personal Interest in the Research Area

For a number of years, I have been interested in cognitive testing and processes, and undertook a degree in this area. In parallel to this, I have a more personal interest in ID, as a close family member of mine has significant cognitive difficulties. Through personal experience, and working for a number of years in ID services, I became an advocate of personalisation of care for people with ID, and often felt my frustration of observing things being ‘done to’ rather than ‘done with’ people with ID. During my second year of the clinical doctorate on placement in an ID service I became aware of how frequently cognitive assessments are used as ‘gatekeeper’ instruments for adults in order to access ID services. In my experience, this was particularly when adults appeared to be coping in some areas but struggling in others. People having the cognitive assessment were often aware of areas they struggled in and, in my experience, tended to understand that the results of this assessment would dictate whether the ID service could provide support. However, I noticed that there did not tend to be much, if any, opportunity to give feedback about the assessment process, and this led me towards wanting to explore this area further. My hope for this piece of research is to help services to be providing more informed, person-centred care in relation to cognitive tests for people with suspected ID, and for clinicians to be aware of potential difficulties that the tests themselves may bring up.

1.3. Terminology and Definition of Intellectual Disability

While deciding upon terminology for this research, I initially began to decide between using the descriptions of ‘intellectual disability’ (ID), ‘learning difficulty’ and ‘learning disability’. While the words learning difficulty are preferred by some self-advocacy groups (Kandel & Merrick, 2008), this tends to be a term often defined more broadly and usually in educational settings, such as to describe dyslexia or dyscalculia in the UK (Department of Health, 2001, p.15). Initially I had decided upon the term learning disability, as in my experience this has been the term used commonly in the UK in the context in question. Therefore, my initial title for this research project was ‘The experience of cognitive assessment, views of clients with a learning disability’. However, during my data collection and write up stages, various services told me that ID is now becoming more commonly used. This is because the term learning disability is broadly used in the USA to refer to people with dyslexia (Penney, 2018). In most English-speaking countries, for example the USA, Canada and Australia, the term ID is now most frequently used, and is starting to gain popularity in UK services and research (Anderson, Larson, MapelLentz, & Hall-Lande, 2019). Therefore, I felt that the term ID fitted most closely with the concept I was researching and describing for this project and would aid in minimising ambiguity or confusion. My change of the research study title reflects this thinking (see Appendix A).

There are multiple and varying definitions of ID. The Valuing People Now paper (Department of Health, 2009), a governmental strategy set out to improve the lives of people with ID, uses the definition set out by the Department of Health (2001, p. 14) in that an ID includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning);
- Which started before adulthood, with a lasting effect on development.

Commonly, ID is defined by a certain level of intelligence. Etymologically, the word intelligence comes from the Latin word intelligere, which means to understand or comprehend (Cornoldi, 2006). However, there are multiple and varying definitions of intelligence. Boring coined the definition of intelligence that it is what the tests of intelligence test (Boring, 1923), which neatly highlights the circularity and difficulty of defining such as abstract concept. Similarly, one of the resulting ideas, the construct of 'IQ', or the intelligence quotient, has a number of widely debated limitations (Lezak, 1988). The ICD-11 (World Health Organization, 2018) classifies 4 degrees of ID using IQ; mild (IQ of 50-69), moderate (IQ of 20-34), severe (IQ of 20-34) and profound (IQ less than 20). The British Psychological Society (2015), on the other hand, defines ID as either significant (IQ of 55-69) or severe (IQ of less than 55).

Interestingly, the definitions of ID appear to have little influence over how ID is identified or operationalised. For example, some studies have found the prevalence to be around 1% in the general population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011), while others have estimated it to be at 2% (Emerson & Hatton, 2004). Estimates of prevalence are frequently debated and contested, with rates varying considerably. There are also several well-documented debates surrounding the usefulness and meaning surrounding IQ scores, such as whether these allow us to make accurate predictions about outcomes and about what types of skills and abilities the tests are actually measuring (Kaufman, 2018). Some critics also claim that an IQ score of less than 70 may mean that an individual is significantly less able to cope, whereas generally the majority of people with an IQ of 70 or less can cope well without specialist services (Whitaker, 2004).

In order to fully understand some of the influences which have led to the term ID, it is important to examine not only its relationship with the concept of cognitive assessment, but also the understanding and treatment of people with ID throughout history.

1.4. Policy and Political Climate

1.4.1. A Brief History of the Stigma and Societal Views of ID

Understanding the historical treatment of people with ID is important for several reasons. One of my aims for this research was to create a more informed process of testing and diagnosis and to bring people with ID's voices to the forefront of the cognitive assessment process. The issue of people with ID being treated as inferior and unable to contribute to not only research but society, is one that is well documented (Ryan & Thomas, 1987). Throughout my liaison with ID services, I found I was being asked multiple times by clinicians in the field why parents and carers were not being asked their opinions of the assessment process instead, as they would have been 'easier to ask about their opinions and to get answers easily'. I worried that this was reflective of the passive role that people with ID are often forced into. I feel it is important to discuss the historical understanding and influences that led to the term ID in addition to some of the origins of the views and stigmas.

The origin of words associated with the term ID can be dated as far back as the 4th and 5th centuries AD, which is the first recorded use of the word "idiot" (Ryan & Thomas, 1987). Historically there is evidence even earlier in history of the distinction and oppression of people with differing abilities, both physical and intellectual. Some of this can be dated back as far as Greek mythology. Barnes (1997), for example, noted the significance of only one of the Greek gods, Hephaestes, being physically flawed, and that as a result Zeus practiced a sort of infanticide by banishing Hephastes from heaven.

Strong Christian influences brought with them core values adopted by western society, one of these being charity and caring for the less fortunate. Davis (1989) suggests that these values further contributed to the narrative of people with disabilities being seen as people who should be pitied and helped. Davis discusses how this can have the effect of robbing disabled people of their individuality and identity as a whole person, with the disability becoming all that society sees, and becoming something to pity and/or fix. These views were reflected in the Poor Laws which were introduced in 1834, which led to large swathes of individuals with ID being admitted into asylums for lifelong care, as society regarded them as vulnerable and in need of help (Jackson, 1996)

Following the Second World War, and the formation of the NHS in 1948, changes were seen in policy and laws which affected people with ID. For example, with the introduction of the Mental Health Act in 1959, which allowed compulsory detainment of people with ID, it became common for people with ID to reside in institutions. However, after a series of scandals arose which highlighted widespread abuse of residents in these establishments, this became a key influence in the updating of relevant policies for people with ID, such as the 1971 White Paper “Better Services for the Mentally Handicapped”, which outlined recommendations for people to be cared for in the community rather than institutions. Furthermore, Wolfensberger (1972) introduced the idea of normalisation, which, for the first time, advocated for the rights of people with ID as valued citizens, arguing that people with ID have the rights to dignity, choice and freedoms within their lives. Wolfensberger claimed that by increasing the public’s exposure to ID, stereotypes about people with ID could be challenged, leading to an increase in positive attitudes (Wolfensberger, 1983).

1.4.2. Current Views and Legislation

A number of policies have been put in place to encourage services to provide tailored care and to give people with ID more input into their care. For example Valuing People (Department of Health, 2001) and Valuing People Now (Department of Health, 2009) outline that people with ID should be given choice, rights, independence, empowerment and inclusion as part of every service they receive. In order to keep the aims of this type of policy meaningful, services need to be open to feedback on the care they provide, but also need to provide opportunities for service users to offer their views in an accessible way. Service users will often have a different view of the type of care they need, and the quality of the care they are receiving, to views of the clinicians providing the services

(Perkins, 2001). This makes it even more important for service users' views to be explored and published.

1.5. Historical and Social Context of Cognitive Assessments

This section gives an overview of the origin and development of cognitive assessments – where the perceived need for them arose from and subsequently why they were developed. I then discuss the current instruments which are used in modern-day cognitive assessments within healthcare settings. Following this, I outline some issues surrounding the potential influence and power that cognitive assessments have within defining ID and the associated outcomes for people given a diagnosis of ID.

1.5.1. The Development of Cognitive Assessments

There has been interest in measuring intelligence that dates back millennia (Sternberg, 2012). The first formal test of intelligence was developed in France in 1904 in response to the political climate of the time – the French government had passed a law declaring that all children needed to attend school. For the first time it became necessary to determine which children with "normal intellect" would benefit most from being included in mainstream education and which might need special assistance (Kaufman, 2018). French government officials consulted a psychologist named Alfred Binet to help devise a test which could identify the children who may struggle more in school so that extra help could be given to them (Hally, 2015). Binet asked Theodore Simon to help him create a test which could measure areas like attention, memory and problem solving. Some children were able to answer more difficult questions than their peers, therefore based on this observation the concept of 'mental age' was first brought into use. The resulting intelligence scale, for children aged 3 to 12, was named the Binet-Simon Scale. Binet and Simon believed that intelligence was learnt, and that children have a different type of intelligence to adults (Hally, 2015). The test was the first to use a standardised measure to rank children into certain categories, and levels of classification were; average, if the child's mental age matched their chronological age; advanced, if their mental age was higher than the chronological age; retarded, if mental age was lower than the chronological age.

The Binet-Simon Scale generated a huge amount of interest and started to become widely used throughout France. When the creators took their concept over to America, a psychologist named Lewis Terman became the first to standardise the test on a group of American children in 1916. This led to the development of a revised version of the test – the Stanford-Binet Intelligence Scale, which saw the first use of a number, the ‘intelligence quotient’ (IQ) to measure and scale intellect (Lezak, 1988). A person’s IQ was originally determined by dividing a person’s mental age score by their chronological age, and then multiplying the resulting fraction, or quotient, by 100 to give the IQ score.

In 1917, IQ tests saw further development, with an American psychologist, Robert Yerkes, developing two tests to aid with the screening of potential U.S. army recruits. These were named Alpha and Beta tests – the Alpha, designed as a written test, and the Beta was designed for recruits who did not speak English or were deemed illiterate, and this consisted mainly of pictures. The tests were administered to over two million army recruits, and results were used to allocate people to certain positions of leadership (Hally, 2015). As cognitive testing gained in popularity in the 1910s in America, a psychologist and eugenicist, H. H. Goddard claimed that people with lesser intelligence (a definition which he coined ‘morons’), were more likely to commit crimes (Reddy, 2007). Goddard used a version of the Binet Intelligence Scale to rank people into categories dependent on their intelligence score, these were; idiots (pre-verbal), imbeciles (illiterate) and morons (high functioning). Goddard defined morons as those with mental ages between eight and twelve, and he deemed that they were a risk to society because of the ease with which they could pass for normal and reproduce (Reddy, 2007).

Following the end of the First World War, Yerkes’ tests remained in use to test a variety of individuals. Evidence suggests that these tests were often used to screen people immigrating to the USA at Ellis Island (Hally, 2015). The tests were only available in English, which left the majority of immigrants who were tested at an obvious disadvantage as they could not understand the language. Yet, these tests were used as evidence about people’s mental capacity, which led to sweeping generalisations being made about people, such as to verify claims of low intelligence, particularly of Jewish and Southern European immigrants (Cherry, 2019).

In 1955, The Wechsler Adult Intelligence Scale was first brought into use (Hally, 2015). This went through three revisions and is now used in modern day intelligence testing – see below for further information on its present day use.

1.5.2. Cognitive Assessments in the Present Day

In modern day diagnosis of ID, IQ is commonly used threshold criterion which a person must meet (see 1.4. Definition of Intellectual Disabilities). The most widely used cognitive assessment which gives an IQ score, and the assessment of choice recommended by the BPS (2015), is the Wechsler Adult Intelligence Scale – Fourth UK Edition (WAIS-IV UK) (Wechsler, 2008). In addition to a Full-scale IQ (FSIQ), it produces four index scores – Verbal Comprehension, Perceptual Reasoning, Working Memory and Processing Speed – all from 10 core subtests. This version of the WAIS was standardised on a sample of 270 adults in the UK and it has strong test-retest reliability (BPS, 2015). However, Whitaker (2012) found that results of the UK WAIS may be less accurate for lower ability ranges.

It may not always be possible or practical for psychologists to conduct a full WAIS. The full testing process can take several hours and requires a certain level of concentration and attention from the participant to be able to complete some of the subtests. Therefore, if completion of a WAIS is inappropriate, the BPS (2015) recommends the Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II) (Wechsler, 2011) as an alternative. Both of these tests are conducted in English and require a certain level of receptive and expressive language skills in English to complete. Therefore, an alternative for participants who do not have the required about of English language is the Leiter International Performance Scale, Third Edition (Leiter-3) (Roid, Miller, Pomplun, & Koch, 2013). To meet the current criteria for ID, a person must score two standard deviations below the population mean, i.e. a FSIQ of 70 or below.

1.5.3. The Influence and Power of the Cognitive Assessment

Cognitive assessments, and their associated outcomes, carry a great deal of power, control and influence. They have far reaching impact – not only upon the definition of ID itself, but also in dictating who has access to ID services, and by proxy, certain types of holistic support.

ID has, for centuries, been understood to be something in the world which can be diagnosed and measured (Reddy, 2007), even though factors such as poverty and social deprivation can account for lowered IQ scores (Whitaker, 2004). Indeed, ID is not a politically neutral term, in that it "appears that people who will not, or can not, meet societal expectations about self-sufficiency, employment and normative expectations about the discharge of social responsibilities – of proper conduct – can, potentially, be diagnosable as intellectually disabled" (Rapley, 2004, p. 36). The definitions of ID have changed throughout time (see 1.4.1. A brief history of the stigma and societal views of ID). Therefore, the 'truth' surrounding ID is also ever changing, as is reflected in the constant elaboration and refinement of diagnostic criteria. This can in itself be described as a political and societal move towards controlling and regulating the lives of people given the label of ID, as "if it can be known, then it can be controlled, medicated, treated (Rapley, 2004, p. 44). Cognitive assessments, not only recently but historically too, have been inextricably linked to this diagnostic definition of ID, as a way of labelling and diagnosing ID.

Cognitive assessments have also been criticised for being used as 'gatekeeper' functions for ID services rather than to guide clinical practice (Hare, 2016). This is because test scores are used in conjunction with a need for someone to present with impairment in adaptive functioning, the latter of which can sometimes be more difficult to assess (Leylin, 2010). This brings about ethical difficulties when deciding who can access a service. For example, some people with severe impairments in adaptive functioning, such as people with high functioning autism, would be excluded from accessing an ID service on the basis of their score on a cognitive assessment because they are not 'intellectually disabled', even though on a functional level, they would benefit greatly from the support offered by an ID service. Similarly, someone who is on the borderline for their score, or who perhaps has a spiky profile, may also be excluded from accessing the service. There does not appear to be a clear set of guidelines or answer for questions raised such as this, and the approach taken is likely to vary service to service or to be based on clinical judgement. This is an area that could benefit from further research and clarification within services. Cognitive assessment scores, therefore, hold a great deal of power in being able to dictate who is offered help from a service and who is not.

These assessments also have the power to significantly influence upon the opportunities and social circumstances of people labelled with ID. This comes in the form of what happens after the ID diagnosis is given; people may, or may not, gain access to tangible financial support, such as Disability Living Allowance, or practical support in the form of a social worker or support worker. People may, or may not, be able to apply for affordable council housing on the basis of such a diagnosis, or be able to get subsidised transport, or gain access to an independent advocate. The list goes on concerning the potential support avenues that a diagnosis of ID can open up. Cognitive assessment remains a key element as part of this diagnostic criteria. Consequently, issues such as power differentials, choice, autonomy and identity are therefore all inherently linked to the process of having a cognitive assessment as part of the diagnosis of ID.

1.6. Literature Search Terms and Search Engines

I conducted my literature search for sources between 1980 and 2021 for articles relevant to people with ID and relating to experience of qualitative research and cognitive assessment. This involved an electronic literature search using a variety of psychological databases; ScienceDirect, PsychINFO, ClinPsych, Web of Science, PubPsych, PubMed, PLoS and Directory of Open Access Journals. The search terms I used included:

- Qualitative research
- Intellectual disability
- Learning disability
- Cognitive assessment
- Neuropsychological assessment

- Subjective experience
- Interpretative Phenomenological Analysis
- Discourse Analysis

I used these search terms in a variety of combinations. A small number of key references emerged throughout this search, which enabled me to identify and track further related articles and research within this topic. My literature search also included searching for current definitions and guidelines using internet browsers. I also reviewed the relevant reference lists of various articles in order to source further relevant books and journal articles.

1.7. Experience of Cognitive Testing

To date, there has only been one known published qualitative study investigating the experience of people with ID of having a cognitive test. Therefore, in order to fully explore the potential literature relating to this area, I have broken this section down into several sections. Firstly, I will summarise and comment upon the study involving participants ID. I will then go on to discuss the research involving the experience of cognitive assessment of other participant groups – namely with adult participants, adults with traumatic brain injury, and children and families.

1.7.1. Adults Participants with ID

The literature search only revealed one published study concerning the experience of people with ID of having a cognitive test. This was conducted by Davidson, Smith and Burns (2013), and it explored the potential influence that cognitive assessments had on the identity of people with ID. The authors' rationale for exploring this area was that the label of ID can stigmatise and present an individual as powerless, even when a test is conducted for service eligibility reasons (Gillman, Heyman, & Swain, 2000). Five people with ID were asked about their experiences in a semi-structured interview. Each stage of the testing process was asked about – consent, introduction, administration and feedback. Transcripts were analysed using Interpretive Phenomenological Analysis. Several themes arose from participants' answers, surrounding each stage of the process. At the consent stage, participants generally reported that they thought the assessment was to look at their strengths and weaknesses. This has the effect of minimising conversations about ID, and left some participants feeling unclear as the purpose of the assessment. At the introduction and administration stage interviewees felt that clinicians focused mainly on rapport building, which helped participants to feel comfortable and trust that the clinician was acting in their best interests. The stage which varied the most between participants in terms of experience was the feedback stage. Many participants reported that the clinician focused on patterns of strengths and weaknesses at this point, and while some participants said that they felt they learnt something new about themselves, others were unclear as to how this information would be used. Participants also reported feeling excluded from decisions made about them after the assessment, in addition to feeling that there was lots of waiting involved and that communication mainly happened through letters.

While Davidson et al’s (2013) study revealed some of the impact of cognitive test results on identity, the terms ID or learning disability were never introduced or explored directly. The authors explain that this was due to the study being exploratory, and comment that it may be helpful for future research to ask directly about the experience of the assessment process and the choice of the individual to use the term ID or not. They also suggest that more thought needs to happen surrounding how to give ownership and agency to adults with ID during the testing and feedback process.

1.7.2. Adult Participants

One of the most widely cited studies in the area of cognitive assessment experience was conducted by Bennett-Levy, Klein-Boonschate, Batchelor, McCarter, & Walton, 1994. Their study examined consumer satisfaction with the assessment in three areas; expectations and preparation for assessment, the assessment itself, and discussion and feedback. Most participants (56%) felt that the overall experience had been positive, and 91% reported the experience to be either positive or neutral. Of those patients who had received feedback about their results, 67% of people found the assessment results helpful, and useful in learning about their strengths and difficulties. However, 59% of people asked said that they would have liked more information about their results than they received. The experience of the test was moderated by several factors, such as the expectations relating to assessment, the length of assessment, how detailed the feedback was, and its perceived usefulness.

Bennett-Levy and colleagues discussed two of their findings in terms of how we as practitioners need to be mindful of the quality and quantity of the feedback that we give people. This was due to the fact that almost a third of the participants asked in their study said that they did not understand the feedback that they received and did not remember it. Most people would have also liked more feedback than they received.

While Bennett-Levy's study shed much light on the experiences of assessment, it is not without its limitations. The study was quantitative and responses were collected from questionnaires. Therefore, while it allowed for a relatively large sample size (129 adults), the results from the study lack the depth and richness of data that a qualitative approach may have found. Furthermore, participants were not able to give answers to questions other than those that had been set out, which may have meant that potential areas of the assessment that participants struggled with, or found particularly helpful, were not evaluated.

Feedback following assessment seems to play an important part in the experience of cognitive assessment. Donofrio, Piatt, Whelihan, and DiCarlo (1999) collated data from 60 patients two weeks after they had completed a cognitive evaluation during a one-hour feedback session of the results. People completed a one-page questionnaire that examined the patient's experience of the process of assessment and feedback, as well as the perceived utility of the information provided. Donofrio and colleagues found that the training level of the assessor did not affect satisfaction results. All patients asked either found the feedback session helpful (16.7%) or very helpful (83.3%), and written summaries of the results were reported to be of particular help to patients and their families.

Studies have shown that many factors affect the experience of having a cognitive assessment. One particular factor is test anxiety. Gass and Curiel (2011) investigated this in a sample of 300 predominantly male veterans who were administered cognitive test batteries. The research explored the role of test anxiety and how it related to performance on four components of the WAIS-III; verbal comprehension, perceptual organization, working memory, and speed of information processing. While test anxiety did not appear to affect performance in two of the test domains, it was found that test anxiety was related to performance in the area of working memory. The authors theorised that text anxiety may evoke intrusive thoughts which become a source of distraction, though this proposed mechanism remains untested. Another difficulty with this study's results is the potential confounding variable of level of education. Previous high educational attainment was correlated both with lower test anxiety and better performance on the test battery. Gass and Curiel suggest that poorer working memory caused an increase in test anxiety, but it is not possible to draw a causal relationship and rule out the possibility that the anxiety did not cause poorer working memory.

While studies using questionnaires as measurements of factors that may positively or negatively affect the experience of cognitive testing are helpful to examine relationships between variables, they often lack the depth of detail needed to understand what the subjective experience of having a test is like.

1.7.3. Adults with Traumatic Brain Injury

Owen (2012) reported upon the experience of people with traumatic brain injury of having a cognitive assessment (Owen, 2012). Interviews were conducted with eight individuals, and a number of positive experiences, as well as negative, were reported. In particular, participants valued being treated as equal partners in the assessment process and having a good relationship with the assessor so that the participant could relax. Negative experiences that were reported were based around fatigue of the assessment process itself and poor assessment environments. For example, participants commented on aspects such as rooms being visually distracting, too small, and overly warm.

Owen also discusses the viewpoint from which results of cognitive assessments are fed back, i.e. from a position of highlighting areas of difficulty and weakness. Generally assessments are written from a professional viewpoint, and Owen discusses that this may have the effect of leaving a participant feeling incompetent after reading about areas of perceived failure.

1.7.4. Children and Families

It appears that the experience of testing and feedback is indeed not neutral, and it seems this perception is also shared by families and children too. Griffin and Christie (2008) conducted an audit which revealed that families of children who had completed an assessment were generally pleased to be given the opportunity for their child to have the test. Families did, however, say that the reports were often difficult to read and understand, and many of the children and young people said they did not bother to read the report at all. In addition, Griffin and Christie’s findings showed that nearly a quarter of the referrals to their service for cognitive assessment could have been resolved more effectively through other means, such as through school consultation or through a conversation with the family. This research brings into question the perceived usefulness of cognitive assessments to the participant and their families and highlights the need for careful thought about the testing and feedback process.

Conniff (2008) also conducted qualitative research on the experience of cognitive testing in children. The research highlighted that clinicians were seen as experts in the tests and in giving advice. Some participants described wanting more information than had been given to them, and Conniff suggested that children were often put in a position of diminished power in relation to the adults making decisions for them. This may draw parallels to the feelings and experience of adults with ID, as adults with ID are often positioned as needing to rely on others to make decisions for them that are in their best interests.

1.8. IPA Research on Services Used by People with ID

While there have been a number of large-scale surveys exploring the experience of healthcare for individuals with ID (Band, 1998; Emerson, Davies, Spencer, & Malam, 2005), there have been comparatively few studies which have used IPA. There has, however, been a substantial increase in qualitative research methods being published in journals of intellectual disability over the last few years (Beail &

Williams, 2014). To my knowledge, there is only one study which has used IPA to explore the experience of cognitive assessment using participants with ID, which is Davidson, Smith and Burns (2013). This study is discussed in detail above in section 1.6.1. Adults Participants with ID. Therefore, it is important to explore other IPA research which has focused on people with ID as a population. This can help us to evaluate people with ID's experience of various health services and to be mindfully aware of potential themes that may arise in my research, as well as gaps in the current literature which uses IPA with individuals with ID.

The following sections highlight research that has used IPA as a method of analysis when evaluating people with ID's experience of various health services. Firstly, I discuss IPA studies which have explored the experience of receiving psychological therapy in people with ID. Secondly, I highlight and evaluate IPA studies looking at experiencing of people with ID as inpatients in hospital. I lastly explore studies into the experience of diagnosis and disability. I conclude the section by discussing the relevance of these IPA studies to the research which has been conducted by myself for this thesis.

1.8.1. Experiences of Receiving Psychological Therapy

There is growing evidence that people with ID are more likely to suffer significant life events, such as childhood abuse and trauma, than people without ID (Govindshenoy & Spencer, 2007). However, it has been documented that historically people with ID have been excluded from traditional talking therapies, despite there being no evidence to suggest these therapies would not be helpful (Hollins & Sinason, 2000). Therapeutic disdain of mental health professionals towards patients with ID has been discussed as a potential reason, and barrier, to this lack of offered therapy (Bender, 1993). It appears that, as talking therapies have not been widely offered within the field of ID, they have equally not been explored in research within ID in comparison to the literature within populations without ID (Macdonald, Sinason, & Hollins, 2003). Nevertheless, within the last ten years there has been a growing research base exploring the experience of therapy with adults with ID. IPA also appears to be growing in popularity as an approach within this research area.

Several studies using IPA have explored experiences of therapy of people with ID. Anslow (2014) used this approach to further understand the experience of systemic family therapy, using semi-structured interviews with five adults with ID. This paper differs to some other studies, in that the researchers supplemented their interview questions with DVD clips of the reflecting team in the family therapy in order to help participants recall what their experiences of the therapy were like. Certain difficulties were highlighted by participants in terms of barriers to effective therapy, such as long words being used by their therapists and therapists not using Makaton. Participants also discussed not feeling prepared for what the family therapy process would be like, which heightened their anxiety. Themes surrounding powerlessness also arose – for example, participants discussed not feeling like they could speak up at times or ask questions when they didn't understand something.

Lewis, Lewis and Davies (2016) analysed interviewed with six adults with ID and found that participants' views were a mix of positive and negative about their therapy experience. For example, positive experiences of therapy involved experiences of relief of finally being able to meet with a psychologist, the importance of getting to know their therapist and feeling comfortable, and about how the therapeutic relationship felt different to other relationships in the participants' lives. Some participants also reflected on how the therapy was made more accessible to them, such as through adaptation of language, or through use of creative and visual materials.

Accessibility to therapy is a theme that has been explored in more recent research. Participants in a study conducted by Statham and Beail (2018) discussed important factors to people with ID which can make therapies more accessible, such as therapists being prompt and flexible and the building itself being clearly labelled and easy to enter. The process of referral through to therapy was also discussed by people – with some participants not knowing exactly why they had been referred for therapy, but knowing that there was a 'problem' that they needed help with. The therapeutic process itself was also explored with participants, and people talked about feeling listened to as a key factor in the therapy being effective. Many participants described that the therapy itself was different to their expectations, e.g.

not expecting to feel negative emotions or to discuss certain topics, but that openness and flexibility within their own approaches helped them to access the therapy. Similarly, Merriman and Beail (2009) also found that participants were generally aware of how they were referred to therapy but sometimes had unclear expectations before attending.

Certain therapist factors also appear to have an impact on people's perceptions of their care. Kroese, Rose, Heer and O'Brien (2013) conducted two focus groups, using facilitators who were also service users, to explore people's perceptions of mental health services. Using IPA, it was identified that important themes impacting on the effectiveness and accessibility of services were surrounding; staff being genuinely interested, good communication, competence-promoting support, and making past-present-future links in therapy (Kroese et al., 2013).

1.8.2. Experiences of Being an Inpatient in Hospital

Brown and Beail (2009) used IPA to explore the experience and understanding of self-harm in people with ID living in secure accommodation. While this research did not necessarily focus on the experience of care, it is useful to note the interpersonal factors that participants felt contributed to self-harm– such feeling a sense of powerlessness in relation to others, and the influence of living in a controlled environment. Brown and Beail discussed the inherent frustration in the lack of power and control that participants felt in their life circumstances and interactions with others.

A paper which directly explored what people with ID value in an inpatient service and their staff is that of Clarkson, Murphy, Coldwell and Dawson (2009). Interviews with 11 adults with ID revealed that the participants valued a consistent and familiar staff team. Qualities such as honesty and trust, and having a caring manner, were also highly valued. On the other hand, staff who seemed young and inexperienced evoked suspicion in participants, and participants often found it harder to build a relationship with these staff. The relationship formed with staff was an important influence in participants' views, with those staff with better relationships with participants being perceived as being more consistent and in-tune with participants' needs. This study by Clarkson et al. (2009) echoes findings of previous research, such as that of Longo and Scior (2004), who found that participants in general inpatient services trust staff who are perceived as knowing more about their needs – and are therefore seen as caring and nurturing, and able to provide practical support.

1.8.3. Diagnosis and Disability

The theme of having and being given a diagnosis of something has been explored in a number of studies with individuals with ID using IPA. Dysch, Chung and Fox (2012) interviewed four adults with ID about their experience and perceptions of having diabetes. This study focused mainly on the physical, emotional and social consequences of having diabetes and the barriers that individuals faced, such as the impact on quality of life and living with multiple chronic medical conditions.

Kenyon, Beail and Jackson (2014) used IPA to find out more about what it was like for individuals to be told that they had a diagnosis of a learning disability. Eight participants with ID were interviewed about their experiences of this. One of the themes that emerged from the analysis was surrounding awareness of difference, particularly from a young age and at school. Participants described adolescence as a particularly difficult time and a time when the understanding of their disability developed. Results also highlighted people's responses of coping in the face of stigma, and also participants' views on the label of ID. The authors concluded that it is unclear to what extent a healthy identity of ID is possible, particularly as the definition is based upon what someone cannot do. They discuss that learning to manage a label of learning disability is a lengthy process which involves learning to manage how one is viewed by others as well as themselves.

While this research by Kenyon et al. (2014) provides interesting insight to the experience of diagnosis, even though the majority of the sample had been diagnosed with ID whilst they were still at school, the average age of participants was 47. This means that participants had had a number of years to reflect upon their experiences and to integrate their ideas about ID into their lives. It also means that participants may not have had a clear or accurate memory of the assessment process itself, or around being given a diagnosis, simply due to the number of years between diagnosis and the interview for this research.

Monteleone and Forrester-Jones (2017) further explored of how adults with ID experience and think about their disability, and looked at implications on self-esteem, stigma and social interactions. IPA revealed that participants experienced feelings of difference, despite sometimes not being able to articulate this. Many participants experienced stigmatisation and ‘otherness’. Participants often rejected the status of being disabled and expressed a need to want to feel normal. The authors suggested having a limited understanding and conceptualisation of disability status could negatively impact self-esteem and political movement (Monteleone & Forrester-Jones, 2016).

1.9. Discourse Analysis Research Involving People with ID

The literature search revealed that, to date, there have been no studies using discourse analysis with people with ID to explore perceptions, talk or positioning surrounding cognitive assessment. However, discourse analysis can be a vital tool in helping us to understand complex phenomena such as power relations, constructions of identity, and the positions that people place themselves and others in within their talk. Therefore, the following section outlines four key areas that have been investigated in ID using discourse analysis – identity, power and position, resistance, and choice.

1.9.1. Identity and ID

To date, very few discourse analysis studies involving participants with ID have been published. Instead, studies have largely focused on the talk surrounding ID of parents, carers, or professionals, but have rarely examined the talk used by individuals with ID to describe their experiences. However, Davies and Jenkins (1997) and Rapley, Kiernan and Antaki (1998) are exceptions to this, in that they have both explored how people with ID construct their identities in interactions with others, paying particular attention to the discursive devices used.

Davies and Jenkins (1997) examined self-identity in people with ID, particularly regarding how people position themselves in relation to the term ‘learning disability. This was a large-scale study conducted over three years, which involved interviews with sixty young adults who had been diagnosed with an ID. The researchers found that most participants (42%) did not appear to attach meaning to the words ‘learning disability’, with many respondents using words such as ‘don’t know’, ‘not sure’ or ‘you tell me’. Of the 30% of participants who did show some understanding of the term, around half did not attribute any qualities of this definition to themselves. However, Davies and Jenkins found that participants did appear to incorporate some aspects of the category identity ‘ID’ into their own self-identities. This was partly surrounding talk about medical problems or physical difficulties. Some of the talk also involved comparison with siblings, which highlighted what participants weren’t able to do, such as have a job, or take exams. Parents also took part in the interviews, and the research highlighted that generally parents avoided any discussions surrounding ID as they felt “it would be too cruel to do so or assuming that they could not possibly understand the explanation” (Davies & Jenkins, 1997, p. 107-108). The authors go on to explore the implications of having this ID category identity upon people’s relationships with others, and with the institutional structures in which people are reliant upon. Indeed, this label appears to have clear influences on the power afforded to people with ID and their reliance upon others.

Rapley, Kierman and Antaki (1998) investigated to what extent people with ID understand the idea of disability and its consequences. The researchers used interview data from existing studies and found a number of discursive devices used by individuals in their talk. In particular, Rapley and colleagues identified that participants held a dual notion of themselves – owning both a disabled identity but also rejecting others’ prejudices about what this may mean. For example, participants highlight frustration with others’ judgements and reactions towards ID. An extract of analysis which exemplifies this complex set of beliefs and identities, comes from Rapley and colleagues describing one particular participant, Sally:

> In acknowledging that her identity as a disabled person might account for the (negative) reactions of people out shopping who, by implication do not treat her as a `human being’ like the people at church (line 23), she is also

> careful to position herself as ‘knowing her own mind’ and ‘not giving a heck what they think’ (Rapley, Kierman, & Antaki, 1998, p. 814).

Here, Rapley, Kierman and Antaki suggest that Sally has positioned herself as understanding the possible negative consequences that might come from having a label of ID and about how people might act, yet Sally also shows strength and confidence in not letting that judgement from others get in the way of living her life. Rapley and colleagues use this evidence to argue against the idea that people with ID are ‘invisible to themselves’. This latter idea was first raised by Todd and Shearn (1997), who presented that people with ID are shielded, by parents and society, from the true nature of their disabilities, due to the toxic and stigmatised identity of disability. Todd and Shearn go on to suggest that, due to this shielding, people with ID are unaware of their label of ID and the limitations that go with this.

1.9.2. Power and Positioning

One advantage of discourse analysis, particularly in the field of ID, is that it has the power to highlight the way that individuals with ID position themselves within the talk, and to highlight how others also position them. Rapley (2004) observed this approach closely, by examining talk between Australian people with ID who live in supported housing and their support staff. The analysis of these conversations shows the contrast of responses between residents and staff, for example showing the position of power that staff have to decide the topic of conversation and to decide what is considered a relevant answer. Rapley also draws attention to the way that people with ID are infantilised within the talk, for example being spoken to like children, and discusses examples where the incompetence of residents is heavily suggested at by staff. Later in his book, Rapley discusses strategies within talk between residents and staff that can be used in order to flatten this power differential, such as “collaborative pedagogic talk” (Rapley, 2004, p. 177-179), which involves a staff member bringing up a problem, the individual with ID suggesting solutions and the staff member agreeing.

The analysis of interactions with people with those with ID can reveal a wealth of information about positions of power that speakers position themselves and others in, and that people are positioned in by others. Antaki, Finlay and Walton (2007) observed that staff routinely control the structure of the conversation in interaction with people with ID. Part of the way this is done is by highlighting the incompetence of people with ID. This idea is explained by Antaki:

> It might be argued that here we see the bald operation of power: it is the staff who control the interaction and its outcome, and judge whether an utterance is adequate or not, even though the agenda item they are following mandates them to find out the residents ’ views. The content of the discussion is almost irrelevant here – it is in the process that relationships and identities are enacted. (Antaki, Finlay and Walton, 2007, p. 12).

This idea of incompetence of people with ID has been further added to society’s rhetoric of people with ID through research such as that of Sigelman et al. (1980). This work sampled 151 adults and children with ID and asked interview questions that produced seemingly contradictory answers. For example, Sigelman observed that people would answer ‘yes’ to questions such as ‘are you usually happy?’ as well as ‘are you usually sad?’, and thus interpreted these responses as acquiescence, i.e. a form of compliance in producing an answer that is expected of them by the questioner. Sigelman later concluded through his work that “because mentally retarded persons asked yes or no questions tend to acquiesce, their answers are likely to be invalid” (Sigelman, Budd, Spanhel, & Shoenrock, 1981). This led subsequent researchers to conclude that it is not possible to validly gain access to the views of people with ID, and that it is instead more reliable to ask a carer or professional’s views (Dagnan, Look, Ruddick, & Jones, 1995). These findings, however, proved to be controversial. One researcher who published the most critique in response to Sigelman’s work was Dr Mark Rapley, a British Psychologist, who expressed strong scepticism about the reliability of the findings that people with ID acquiesce. Rapley argued that this apparent acquiescence bias observed by Sigelman was in fact a situation specific set of answers given by people with ID (Rapley & Antaki, 1996).

The authors used conversational analysis to investigate this further and found that the interviewers appeared to query the initial answer given by participants, as people's initial answers tended to look incompetent against the official vocabulary of the interview schedule. Further examination of the text revealed that interviewers tended to have pre-existing expectations of the right answer, which encouraged a specific line of questioning until that particular answer was given. Rapley and Antaki reasoned that in both these sets of circumstances that "the respondent's utterances may have looked contradictory and the final utterance 'acquiescent', but this is an artefact of the complex manoeuvres into which both interviewer and interviewee become enmeshed" (Rapley & Antaki, 1996, p. 224).

1.9.3. Resistance

Discourse analysis studies with participants with ID have revealed how, within speech, people with ID express personal competence as well as resistance to the social roles that they are placed in. For example, Rapley and Antaki (1996) in their analysis of acquiescence within speech, found that people with ID exhibit, what the authors call, anti-acquiescence. Rapley and Antaki described that participants did this as a form of resistance to change their answers, even when prompted to do so by the interviewer. This had the effect of showing the speaker as being competent and independent, despite the clear power differential that existed between interviewer and participant (Rapley and Antaki, 1996).

It has been observed that people with ID use resistance as a tool within speech with several possible motivations – one of these being to reject the social categories and status of reduced power that they are placed into (Goodley & Rapley, 2001). An excerpt from Goodley demonstrates this rejection of being labelled, and of a participant, Karen, assigning clear reason and choice to her situation:

> Karen had recently had a meeting with an educational psychologist because, she joked, "I'm dumb in the head." A supporter who works at the college suggested that this meeting be arranged because Karen "was not joining in in class". Karen disagreed— "No, I was bored" (Goodley, 2000, p. 191).

Karen here appears to reject the assumptions made by her about others, demonstrating dignity and autonomy. Again, even in the face of being placed in a position of reduced power, she is able to speak out and ask to be respected and heard. This is consistent with the notion that where there is power, there is also resistance (Foucoult, 1975).

1.9.4. Choice

Giving choice to individuals with ID is commonly talked about within learning disability policy in the UK. When it comes to analysing how readily choice is actually given within interaction to people with ID, however, a different picture is painted. Care workers have institutional responsibilities for those they care for, for example relating to keeping people safe. Discourse and conversation analyses can highlight the strategies used by staff, and with individuals with ID, that help to resolve the conflict between giving people choice versus feeling that there is no option to give people choice.

Jingree and Finlay (2013) used critical discourse analysis to examine how people with ID use talk to reflect the power and positioning that they are placed into when expressing dissatisfaction about their care. In particular, the authors were interested in how people talked about having choice and control within their care. Several discursive strategies were used by the speakers when talking about choice, such as referring to the rhetoric of having the right to free choice, and speakers presenting themselves as fair and reasonable when expressing a complaint. Speakers, either explicitly or implicitly, positioned themselves as competent, which served to add weight and reliability to their speech. Participants also drew upon the inherent power held by staff, e.g. using staff voices to corroborate their accounts – which also served to add the perception of competence to their talk.

In an earlier paper, Jingree and Finlay (2008) examined how power and choice manifest in subtle ways throughout speech, particularly through talk used by staff. For example, it was found that staff justify their actions to deny choices by drawing upon certain medical understandings, such as the individual model of disability (Oliver, 1996), which has the effect of positioning service users as "incapable, irresponsible, and vulnerable" (Jingree & Finlay, 2008, p. 20). Staff also used justifications, such as a lack of practicality, to position themselves as being advocators for choice for individuals with ID, but yet being stuck in an institutionalised position that cannot always safely, or morally, allow for choices to be given (Jingree & Finlay, 2008).

Research using discursive analysis has also revealed how, even with the intentions of giving choice within speech, staff sometimes achieve the opposite effect of this. For example, Antaki, Finlay, Walton and Pate (2008) analysed video footage of people with ID living in a residential home interacting with their support staff. The authors were interested in the ways that choices were offered to people with ID by their staff, and the conversational practices that are used in these interactions. Conversation analysis showed that while staff used strategies intended to empower the residents, these often backfired. For example, one technique used by staff in response to residents making a choice was to offer them a further choice. Antaki and colleagues discussed how this can have the effect of implying to a person that their original choice was wrong, forcing them to choose differently next time (Antaki et al., 2008).

1.10. Involvement of People with ID in Research

It has been well documented that historically people with ID have been excluded from research (Goodley, 1996; Atkinson, 1997). It is only within the last 60 years that people with ID have been involved in any type of research involving their opinions and care. One of the first studies to explore opinions of people with ID was conducted by Robert Edgerton, exploring stigma (Edgerton, 1967). There is no evidence that "anyone had tried to access or represent the voices of people with learning difficulties in research terms" (Walmsley, 2001, p. 188) before Edgerton. When views were obtained, they tended to be through family members or professionals (Ward & Simons, 1998). Several influences throughout the 1980s and 1990s led to more inclusivity in research for people with ID, including theories of normalisation and a move towards the social model of disability. It started to become acceptable for people with ID to express opinions and to start being seen as experts of their own lives and experiences (Stalker, 1998). Throughout the 1990s, self-advocacy groups, such as ‘People First’, began to highlight and challenge the issues surrounding exclusion of people with ID from research, campaigning for people with ID to be included in both the design and the execution of the research (Tuffrey-Wijne & Butler, 2010).

1.10.1. Barriers to Being Involved in Research

A power differential exists between clinicians and people with ID. This has a number of implications, as people with ID are often viewed as not being able to express themselves confidently or clearly, and of being unaware of the options available to them (Perkins, 2001). Therefore, clinicians’ ideas about what is important in assessment and treatment often get prioritised (Perkins, 2001).

For service user involvement and feedback to be successful, a positive culture is required that does not encourage dependence (Chaplin, Halls, Carlile, Hardy, & Joyce, 2009). Chaplin and colleagues identified a number of barriers that may prevent people with ID contributing to research about their care, one of these being clinicians’ fears of clinical practice being subject to scrutiny (Chaplin et al., 2009). These fears may be due to an organisation’s perspectives and philosophies being challenged, or around the possibility that changes proposed by service users may be impossible to implement.

1.10.2. Improvement of Services and Patient Centred Care

It is vitally important that the perceptions of having a cognitive assessment are understood for several reasons.

Firstly, having this type of assessment has the potential to be time intensive, tiring and frustrating for individuals undergoing the test, and may take several appointments to be able to complete the examination. Therefore, understanding what the experience is like can help services enhance their delivery of the assessment. This in turn may lead to more accurate results, if individual needs and anxieties can be understood and adjusted for by the assessor.

Secondly, it is possible that this type of understanding of the subjective experience of testing may highlight the benefits that individuals have experienced from having the assessment. This could be important in demonstrating to commissioners the value of cognitive assessment and therefore in gaining necessary funding for services offering this to their patients, which might contribute towards extra staffing and decreases in waiting list times.

Lastly, in terms of making the assessment results useful for the patient and their families, Westervelt and colleagues discuss the potential dilemma that often arises in services in that neuropsychologists often work as consultants (Westervelt, Brown, Tremont, Javorsky, & Stern, 2007). The consultant role means that neuropsychologists may not necessarily have the time or opportunity to understand in detail the patient and their family's understanding of the diagnosis that may arise from the assessment and to discuss their responses to recommendations for intervention. They go on to describe that this type of research and its' feedback to assessing clinicians may "help shape the delivery of results and recommendations to enhance the patient's understanding of the results and maximize compliance with recommendations by exploring barriers to compliance" (Westervelt et al., 2007, p. 264). While improving compliance to treatment recommendations is not the aim of this research, it is hoped that having this type of insight may make the assessment process and receiving the results a more transparent, accessible and humanely informed process for people and families going through it. Feeling more understood may have the inadvertent effect of 'improving treatment compliance' as Westervelt suggests, due to possibly feeling more listened to and that interventions have been carefully tailored to individual needs.

1.11. Summary and Rationale

In light of the research findings outlined above, it is clear that people with ID have historically been excluded from research and have experienced a wealth of stigma and things being done to them rather than with them. Multiple barriers have made it more difficult for people with ID to contribute both to research and to improvement in care, such as communication difficulties, power differentials, and clinicians' own fears and stigmas. Societal attitudes and stigmas towards ID have existed for centuries. Thankfully, theories and models in the 1980s and 1990s, such as normalisation and the social model of disability, have helped it become more acceptable and accessible for people with ID to express opinions and to start being seen as experts of their own lives and experiences.

Discourse analysis research in ID is an invaluable tool which has been used to capture and explore concepts such as the power and positioning within talk, and the amount of choice and autonomy that people with ID feel they have/do not have within conversations. Particularly in situations where a power differential exists, for example with a client with ID and someone assessing them, such as during cognitive assessment, discourse analysis can be utilised to explore topics more thoroughly. DA offers a lens through which to do this, by examining how subjects position themselves within talk, how they refer to and navigate power differentials, and exploring what linguistic or rhetorical devices are available and used, or avoided, within speech. This could shed light on how people given the label of ID understand and operate within contexts and dialogues surrounding ID and diagnosis. No current research, to my knowledge, exists which uses discourse analysis to explore the subject positions afforded to adults who have been given a diagnosis of ID in their talk about cognitive assessment.

The experience of cognitive assessment is not an area which has previously received much research attention, and, to my knowledge, has never been approached as a subject matter using discourse analysis. The one study that exists in this area, using interpretative phenomenological analysis, revealed that the purpose of having the assessment often feels unclear to people, and participants felt that decisions about their care are often made without them. Research in other populations has also shown that the experience of cognitive assessment is not neutral. For example, factors such as quality and quantity of feedback given, accessibility of the assessment report, approach of the clinician, and level of test anxiety can all affect the experience of the assessment.

There are several reasons why the experience of cognitive assessment is an important research area, particularly in ID. Having a clearer insight into a person’s subjective experience can help the assessor to limit negative experience for the client, such as test anxiety or frustration, and can lead to more clarity as to what the results of an assessment actually mean. Substituting the research with additional examination of positioning and talk, such as by using discourse analysis, can also help to reveal attitudes towards power differentials and about the subject positions people are placed in.

1.12. Study Aims

This study aims to explore the perspectives of people with ID of having a cognitive test.

It is predicted that, similar to previous research, there will be parts of the assessment that people had positive experiences of, and parts that they experienced more negatively. It is also predicted that issues of positioning and power will arise, and that this will have an impact upon the subjective experience of the assessment. However, as research of this kind with this population has not been done before, more specific predictions about results cannot be made at this stage.

1.13. Research Questions

The study will take a qualitative approach using interpretive phenomenological analysis and discourse analysis. Qualitative research aims to investigate meaning and the sense that people make of their lives and their experiences of the world (Atieno, 2009). It has the advantage of capturing and considering the perceptions of the participants themselves and can examine interview answers in in-depth detail. This approach will be particularly helpful in my research, as it allows space for people’s opinions and subjective experiences, alongside the discourses that accompany these, to be understood in a large amount of detail.

The research questions which will be explored in more detail as the purpose of this study are:

- What are the experiences of cognitive assessment of adults who have a diagnosis of ID?
- What are the subject positions afforded to adults who have been given a diagnosis of ID in their talk about cognitive assessment?

The interview will be conducted in a semi-structured way, which feels most appropriate in the particular setting of working with people with ID, because this allows me to elaborate on questions or explain them in a different way if needed. It also allows the freedom to explore participants' answers in an open way. To make the process accessible, easy-read written questions with accompanying pictures will be available during the interview as well, and visuals will be available that people can point to if they feel unable to speak, such as 'yes', 'no', 'I want a break' and 'stop'.

2. METHOD

2.1. Introduction

The following section outlines my epistemological position and reasons for choosing this. I then discuss how this links with my chosen qualitative methodology; combining discourse analysis (DA) and interpretative phenomenological analysis (IPA). Following this, I outline the experimental design and procedures, followed by a discussion of the recruitment of participants. Lastly, I outline my reasons and plans for data collection and analysis.

2.2. Epistemological Position

Throughout this research, I shall be taking the epistemological position of critical realism. Bhaskar (1975) first laid out his explanation of critical realism as a critique of existing epistemological positions at the time. Bhaskar criticised positivism and constructivism, arguing that these positions wrongly combine ontology and epistemology, creating epistemic fallacy (Bhaskar, 1975). Critical realism arose in the 1970s and 1980s out of these ‘paradigm wars’ (Denzin & Lincoln, 2011), and was further refined and described by Bhaskar over several texts (1975, 1993, 1998).

In contrast to both positivist and constructionist positions, critical realism states that ontology (i.e. what is real, the nature of reality) and epistemology (our knowledge of reality) are indeed distinct from each other (Fletcher, 2017). From this emerges the concept of ontological realism – the idea that there is a reality that exists outside of the realm of consciousness that can never be fully knowable, and this reality operates independently of our awareness or knowledge of it (Archer et al., 2016). Danermark, Ekström, Jakobsen and Karlsson (2002) described this as a strength of critical realism, in that it does not deny that there is a real social world and a lens through which we will all construct our own understandings of reality. The aim of critical realism is to integrate cause and effect, which makes it a helpful way of viewing research in terms of analysing social problems and suggesting solutions for social change (Fletcher, 2017). Critical realism does not align itself with, or translate to, any particular methodology and is compatible with both quantitative and qualitative approaches.

This research will be based on a critical realist epistemology. My rationale for this comes from previous research into disability studies, as well as research that has used multiple approaches. Bhaskar has discussed how disability studies are a key area to which critical realism can be applied. In his research with Danermark, he discusses how critical realism can be seen as ‘maximally inclusive’, due to allowing space for insights from other theoretical positions (Bhaskar & Danermark, 2006).

Adopting a critical realist stance has allowed me to approach the research from different angles, and indeed to use a version of methodological pluralism, in which I use both IPA and DA to interrogate the dataset. I further explore below my reasoning for choosing this approach, and its alignment with critical realism.

2.3. Choosing an Approach and Methodology

2.3.1. Qualitative Methodology

Aligning myself to a critical realist epistemology allowed me the freedom to choose from among the qualitative and quantitative methodologies. I was drawn towards qualitative analysis, which tends to be underpinned by critical realism, phenomenology, and constructivism, particularly for the population that I would be working with, for a number of reasons.

Firstly, qualitative research aims to bring knowledge about the unknown into the known (Morse & Field, 1995). In terms of views of people with ID, this is still an under-researched area, and so taking an exploratory approach fits well in this instance. The qualitative approach is well suited to address open research questions, for example exploring what someone’s experience has been like, or in what ways they choose, or are allowed to, express themselves.

Secondly, adopting this approach allows the research to explore and comment upon positions of power. Aspects of DA specifically consider how power relations emerge over time, moulded by our interactions and current ideologies present in society (Foucault, 1972).

Finally, it is generally accepted that in qualitative approaches the power in the research is more equally shared, as the individual is placed in the position of an informant (Del Busso, 2004). In working with people with ID, whose voices and opinions have historically and presently have been suppressed and ignored in society, using research which actively addresses this power differential is a positive and necessary step forward.

2.3.2. Choosing a Qualitative Approach

In terms of choosing a qualitative framework for data collection and analysis, I considered a number of potential options. Grounded theory (Glaser & Strauss, 1967) was deemed unsuitable as it tends to be more helpful for explaining social processes rather than seeking to understand people's subjective experience (Willig, 2008). Narrative methodology was also deemed unsuitable due to the abstract nature of data analysis and the risk of this being difficult to apply to specific research questions (Stephens & Breheny, 2012).

I was drawn towards a dual approach of analysis in this research, namely by using a combination of IPA and DA. This type of approach has been demonstrated successfully by Hood (2014), who used a combination of DA and IPA (see further information in 2.6.2. Using IPA and DA Together), I further explain my choice to combine these two methodologies under 'methodological pluralism'.

2.4. Interpretative Phenomenological Analysis (IPA)

2.4.1. Overview

Reflecting its critical realist foundations, one aim of this research was to understand more about the experience of being cognitively tested. IPA is theoretically rooted in critical realism and is accordingly one of the methods I have chosen for the analysis of data in this research. One reason I was drawn to IPA is that it can be carried out in a fairly structured approach, e.g. by using the guidelines described by Smith, Flowers and Larkin (2009). I found this to be complimentary to the more detached and less structured method of DA, in that it would allow me to engage with the interview scripts on a more personal, meaning-driven way (before taking a step back for in depth textual analysis).

IPA has its roots in health psychology. It has its phenomenological basis through its intention to gain an insider perspective, with focus on the lived experience of people (Willig, 2013). However, IPA acknowledges that, while we can get close to understanding another's experience, we can never fully or directly know what something is like for someone else (Smith, 1996). The 'interpretative' element refers to the acknowledgement of the researcher's personal beliefs and viewpoints, embracing the idea that understanding requires interpretation (Fade, 2004). Smith and Osborn (2003), therefore, explain that IPA takes into account the interaction between a participant's perspective and the interpretation by the researcher. This explores the otherwise hidden role of the researcher, allowing their interpretations and ideas to be more visible (Tomlinson & Hewitt, 2017). Explicit reflexivity is used by researchers in IPA to help them to formally acknowledge their interpretive role and bias (Fade, 2004).

This will be a small-scale study using interview data from a small number of participants. Both DA and IPA are particularly suited to this type of research. IPA aims to explore how people make sense of the world and their experiences, rather than claiming to find definitive truths (Pestana, 2011). IPA is also a systematic and practical approach using a particular set of guidelines for researchers to follow (Smith et al., 2009), which I felt fitted well with one of the research questions. Furthermore, having knowledge of the unstructured and more free-flowing nature of DA, I wanted to compliment this with a type of analysis that works in a more prescribed fashion, which IPA lends itself well to.

2.4.2. IPA in ID Research

Historically, people with ID have been excluded from research for a number of reasons, for example researchers' fears in relation to coercion and people being able to give fully informed consent, as well as the research format not being accessible enough for people with ID to engage with (National Disability Authority, 2009). This has particularly been the case in studies using IPA, as interviews tend to be shorter and use less complex language with participants with ID. This has historically led to researchers avoiding using IPA due to fears that they might not be able to provide rich enough data to reflect participants' true experiences (Corby, Taggart, & Cousins, 2015). Sadly, this has meant that people with ID have often been excluded from qualitative research, particularly prior to the 1990s, rather than researchers attempting to adapt their process to provide access for those with greater support needs (Niry, Duvdevani, & Doron, 2015). I believe that it is the researcher's role to adapt their approach, not to simply exclude populations from research because it is assumed they cannot perform the functions expected of them in a certain method or paradigm. Recently, the situation has improved. A recent systematic review looking at research analysis with interview data from adults with ID revealed that IPA is a popular choice in ID research and is increasing in popularity particularly in health psychology (Corby et al., 2015). The review highlights the unique strength of adopting IPA in ID research, in that it allows the voices of people with ID to be heard as well as creating space and discussion for issues of concern for people with ID.

There are a number of advantages of using IPA in research with adults with ID. Firstly, IPA is an appropriate methodology for a small number of participants, which I had expected within my own recruitment for this study. Secondly, the IPA approach allows for in-depth analysis of data and themes, which can be helpful when a study is exploratory in nature. Furthermore, the approach is both phenomenological and interpretive, so it can therefore represent the participants' views as well as acknowledging the researcher's stance (Shewan, McKenzie, Quayle, & Crawley, 2014).

2.5. Discourse Analysis (DA)

2.5.1. Overview

DA is an umbrella term which includes to a number of different approaches that study language use and its role in social life. Here I shall discuss both discursive psychology and Foucauldian DA, and my decision to use a form of DA adapted by Potter and Wetherell (1987).

Willig (2008) outlines two major forms of DA; discursive psychology and Foucauldian DA. Willig explains that, although both are concerned with the role of language in the construction of social reality, there are important differences between the two. Discursive psychology has been heavily influenced by conversation analysis, in that it "studies what people do with language and it emphasizes the performative qualities of discourse" (Willig, 2008, p. 344). Foucauldian DA, on the other hand, was influenced by post-structuralist writers and Michael Foucault, who focused upon how language, and the discursive resources available to people, constructs positions, with respect to issues such as such as identity and power (Potter, 2008).

There are clearly advantages to both approaches of DA. Foucauldian DA can be an invaluable tool used to examine the use of language in power relations, e.g. to explore how one party exerts dominance, or to learn how language can be used as a resistance to those in power. Conversely, discursive psychology has its advantages in seeking to understand the negotiation of social interactions in order to achieve a certain objective, for example to justify an action or to attribute blame (Willig, 2008).

In deciding upon which aspect of DA to use in this research, I was drawn toward the approach taken by Potter and Wetherell (1987); they argue that it is most beneficial to examine both the discourse practices (i.e. what people do with their talk and writing) alongside the discursive resources employed by people (i.e. what they draw upon during this process). Wetherell (1998) further advocates for adopting both approaches. Using both of these approaches:

> …allows the discourse analyst to produce a reading that pays attention to both the situated and shifting nature of discursive constructions as well as the wider social and institutional frameworks (of meaning, of practices, of social relations) within which they are produced (Willig, 2013, p. 375).

This allows space to focus on two strands of knowledge; discursive practice and discursive resources, which are complimentary. Firstly, it allows us to understand *how* speakers construct and negotiate meaning, by examining discursive practice through interpretative repertoires. Secondly, it allows us to also explore *why* people use certain repertoires and not others.

In using the definition of DA employed by Potter and Wetherell (1987), the analysis produced in this research aims to explore the mechanisms through which knowledge about people with ID's experience of cognitive assessment is formed. It aims to do this through micro-level analysis of talk, to explain the way that certain descriptions become fact and how these facts are then used to perform particular actions (Potter, 1996). Woofitt (2005) suggests that linguistic events that occur in interview data (for example descriptions, anecdotes and comments) are constructions which "not only depend upon the context in which they are produced, but will also reflect the functions they have been designed to perform" (Woofitt, 2005, p.18).

In summary, Potter and Wetherell's definition of DA is concerned with investigating meaning through the analysis of language and considers how this then impacts upon the social world. This approach fits within a critical realist framework, as it addresses prior assumptions about society and dominant knowledge, while acknowledging that we are constrained by the lens of our own language (Mason, 2006).

2.5.2. DA in ID Research

In this research, one of my aims is to explore the adopted subject positions by people with ID when describing cognitive assessment. In order to fully explore this, it is also helpful to think more widely about how power and the social frameworks which influence people's interactions have helped to shape these discourses. DA is an under-used methodology in ID research, but nevertheless has the potential to help shed light on the way that people with ID construct and understand their social worlds.

One of the most influential authors in using DA-like methodology with adults with ID was Rapley (2004). In particular, he advocated for conversational analysis being a successful way to investigate language in ID, as it moves away from impressionistic accounts and instead observes how meaning is produced through talk in a joint interaction (Rapley, 2004). Other authors have also used DA to examine how adults with ID and their parents give significance to their experiences (Scior, 2003). Fullana, Pallisera and Díaz-Garolera (2019) identified that very few studies have used DA to examine the positions adopted by people with ID; their research focused on understanding how adults with ID talk about professionals and organisations. Conversations from focus groups were analysed using DA, and it was determined that adults with ID tend to allow professionals and other organisations to have agency over the decision-making processes in their own lives (Fullana et al., 2019).

2.6. Methodological Pluralism: Combining IPA and DA

In order to fully address my research questions, I chose DA in addition to IPA to fully address them as they seemed appropriate methodologies. I also felt able to operate within a critical realist epistemology for both sets of analysis.

This section outlines some of the advantages of using methodological pluralism. I then go on to discuss how a critical realist epistemology can be applied to DA research, and explain how, particularly in ID research, this is beneficial. I then go on to explore how previous studies have used IPA in combination with DA to interrogate a single dataset. Lastly, I revisit my aims for this study and my hopes for outcomes in combining DA and IPA.

In order to address the research questions, which concern both the subjective experiences of participants as well as examining the ways that these are constructed, an in-depth form of analysis was required. Methodological pluralism (i.e. combining two compatible methods to interrogate data) has been advocated for by numerous researchers (Layder, 1993). For example, this has been discussed at length by Danermark and colleagues, in which they suggest that it is "profitable to combine methods in practical research work" (Danermark et el., 2002, p. 151). The authors further argue that the research question and topic should take precedent over the epistemology when setting out a research design.

2.6.1. Discourse Analysis within Critical Realism

Though DA has traditionally been considered to reflect a relativist epistemology (Edwards, 1997) there have been researchers and studies which have used a critical realist epistemology within this type of analysis (Sims-Schouten, Riley, & Willig, 2007). In critical realism (CR), language is used to construct our realities. CR also theorises that these constructions of reality are "constrained by the possibilities and limitations inherent in the material world" (Sims-Schouten et al., 2007, p. 102). This, therefore, constitutes that there are material structures which exist independently of our understanding of them. One difficulty that the CR epistemology therefore brings up for DA is that this particular lens of interpretation denotes that while meaning is made in interaction, non-discursive (i.e. material) elements within the world, also impact upon that meaning. Those that have taken up CR as a standpoint within DA research have explored the extra factors that may influence someone's talk on a particular issue, such as underlying structures – e.g. political, economical or social (Willig, 1999). These structures can be seen from a critical realist perspective as having extra-discursive ontology and as factors that produce a particular context in which certain discourses are more easily enabled or disenabled.

The use of DA research within CR epistemology appears to be gaining some traction. A more recent contribution to this field has even put forward a structured model in using a CR DA approach to examine social change (Newman, 2020). There are several advantages of using DA research within a CR lens, particularly when undertaking ID research. Firstly, using CR can allow the researcher to consider why an individual might draw upon certain discourses – because the non-discursive elements give a context which may permit or allow certain talk. Within ID research, therefore, I hoped that using DA with a CR epistemology would allow me to examine the structures surrounding the cognitive assessment and to be open to discourses hinting at power structures or certain societal constraints that impact upon participants. Secondly, CR also allows space for researchers to explore the impact of these societal structures and material constraints upon the discourse used. I hoped that I would be able, for example, to view my participants' talk about their cognitive assessments as a product of the social roles and expectations that had been put upon my participants – allowing me space to examine what impact that may have had upon their discourses. Lastly, Sims-Schouten et al. (2007) also explain that it gives researchers the opportunity to map the ways that subjects use discourse in order to construct a particular version of reality; but also allows researchers to situate this talk within a material reality that people have to negotiate. I felt this was particularly apt in the field of ID. I believed that to analyse my participants' discussion of their experiences in a vacuum (i.e. to ignore, or not take account, of the power structures and historical oppression that has taken place towards individuals with the ID label) would move away from my hopes for this research – one of which was to create a more informed process of testing and diagnosis and to bring people with ID's voices to the forefront of the cognitive assessment process. To ignore the social and political context surrounding their voices would be to ignore a significant element of my participants' voices. There are crucial influences upon participants' discourses and perceptions that need to be acknowledged and understood in order to fully explore the data.

2.6.2. Using IPA and DA together

Various scholars have discussed the potential compatibility between discursive and phenomenological approaches (Yardley, 1997; Smith, 1996). Johnson, Burrows and Williamson (2004), for example, discuss how pragmatic theory can explain, in part, why DA and IPA are well suited to combine in studies. They echo previous explanations (Capdevila & Buchanan, 2002) arguing that the choice of approach should be based on the goals of the research. The authors go on to explain how epistemological dichotomies between approaches can actually restrict researchers finding meaningful more connections within data.

Further support for the potential for IPA and DA approaches to be used together comes from Ashworth (1997), who argues that a number of epistemological and ontological connections can be made between these two methods. Ashworth evaluates how DA can be viewed as an extension of hermeneutic phenomenology, by explaining how data is “interpreted as expressing one or more culturally available discourses, for which the research participants are the channel through which the discourses flow, rather than the originators of personal constructions of the world” (Ashworth,1997, p. 223). In this sense, Ashworth is highlighting how subjective experience, discourses used, and the societal context which has influenced upon these discourses, can all be observed, analysed and integrated through research.

A number of recent studies have begun to use DA alongside IPA to fully interrogate a single dataset. For example, Hood (2014) used this approach in his exploration of complexity in the way that professionals describe their work in children’s services. Hood emphasised how using a dual approach had benefitted his findings, discussing that, when trying to understand a particular lived experience, that these findings can be “enriched by also addressing the discourses and social processes that help to shape it, and which individual understandings in turn help to reproduce, transform or subvert” (Hood, 2014, p.76). Johnson et al. (2004) also combined DA and IPA to explore meaning and implications of bodily changes for first time mothers. These authors noted when reflecting upon using a dual approach that by linking IPA and DA this had led to a deeper analysis and level of meaning accessed during this research. In particular, DA can reveal the background practices, processes and social structures present which shape the individual experience of a participant; the analyses being able to observe the data in different layers (Johnson et al., 2004).

2.6.3. Methodological Pluralism in this Study

This study utilises IPA to address the experiences of cognitive assessment of adults with ID, as well as using DA to examine the subject positions afforded to these participants within their talk. The IPA analysis can reveal subjective experiences of what the assessment was like for participants. DA will compliment these findings by examining the discursive resources used by participants to frame their histories, therefore giving insight into the way that these subject positions are afforded.

This is research that, to my knowledge, has never been conducted in this way before. Davidson, Smith and Burns (2013) have examined experiences of assessment within this population using IPA, but parallel evaluation of subject positions within this talk has not been incorporated into a study in this way before.

In approaching my research, I aimed to remain curious about my findings, therefore accepting that there is no single ‘truth’ about people’s experience of diagnosis of ID, nor is there a single ‘truth’ about the discourse that emerges from these discussions. Therefore, I adapted these two conceptual lenses so that I could map the subject positions that people place themselves, and are placed in, within the context of their talk about their assessments.

2.7. Study Design

2.7.1. Procedure

Semi-structured interviews were undertaken, which are the most common form of data collection in IPA (Larkin & Thompson, 2011). In DA, any form of text may be subject to analysis, including interview transcripts (Potter & Wetherell, 1987). Semi-structured interviews generally involve “prepared questioning guided by identified themes in a consistent and systematic manner, interposed with probes designed to elicit more elaborate responses” (Qu & Dumay, 2011, p. 246). This essentially means that the interview process is designed around specific areas of interest to the researcher with enough space to question around the topic to gain more detail.

Using semi-structured interviews with participants with ID is advantageous for a number of reasons. The approach allows the researcher to build a rapport with participants and to share experiences and reflections in a meaningful way (Rubel & Okech, 2017). This is particularly important in ID research, where participants may need to build rapport and trust with the researcher

Current research highlights that when conducting interviews with people with ID, it is common for interviews to last around 30 to 60 minutes (Elford, Beail, & Clark, 2010).

2.7.2. Interview Schedule

When conducting semi-structured interviews in IPA, it is advised by Smith and Osborn (2003) that the researcher should develop an interview schedule. The aim of this is to focus on certain areas of interest, consider difficulties that may arise, and to formulate appropriate prompts. It is not, however, intended to be prescriptive or a checklist of questions. I wanted to use questions which had the potential to explore both positive and negative aspects of the assessment process without being too leading. I also wanted them to be open enough to allow for discussion. The interview questions which I used emerged from the research questions. They were phrased in such a way informed by my own work with people with ID, so that the questions were accessibly enough to suit the communication needs of the participant. I discussed the questions with my supervisor and with clinician experts working in the field of ID. See Appendix B for the list of questions used during the interviews.

2.8. Participants

2.8.1. Number of Participants

For qualitative studies using interviews and IPA, small numbers of participants are recruited. Turpin et al. (1997) recommend recruiting a small handful of participants. This allows for enough opportunity to investigate similarities and differences between individuals, but also ensures that the amount of data generated is not overwhelming (Pietkiewicz & Smith, 2014). The aim of having small numbers of participants is to give insight to their experiences and to be able to consider connections between each participant's individual accounts (Smith, 2004). While there are varying recommendations for the optimal number of participants in IPA, Pietkiewicz and Smith (2014) outline clearly that "there is no rule regarding how many participants should be included" (Pietkiewicz and Smith, 2014, p. 364). Similarly, in DA analysis there is no recommended minimal sample size in interview data, instead it is recommended to keep texts small enough to be able to interrogate the data in sufficient detail as to answer the research questions (Malterud, Siersma, & Guassora, 2016). With this in mind, I set out to recruit between 3 and 5 individuals to interview. The aim of this was to give me enough data to be able to analyse emerging themes and structures, however to not have an overwhelming amount of data.

2.8.2. Inclusion Criteria

The main inclusion criteria for participants for the study were:

- To have been given a diagnosis of ID in the last 6 months following a cognitive test administered by a psychologist (qualified, trainee, or assistant);
- With a resulting given IQ of 69 or less (to meet the conventional criteria of ID).
- To have memory of this assessment to reflect upon.
- English speaking, and able to communicate language verbally.
- Aged 18 years or above.

Participants could choose whether to attend the interview alone, or with a parent or carer. This was to allow participants to feel relaxed, and to ask for support around answering some questions, if they wished.

2.8.3. Recruitment

Recruitment to research involving adults with ID has been described as a difficult process, due to complexities with informed consent, ethical approval and people's general understanding of research (Oliver et al., 2002).
Nicholson, Colyer, and Cooper (2013) investigated barriers to recruitment in interview research with adults with ID, and found that using a personal approach, appropriate advertising, and meeting potential participants prior to the study all increased participant numbers.

With the findings of this research, I aimed to use a person-centred approach in my recruitment strategies. I followed these stages when recruiting for participants:

1) My sample of participants came from inner London ID teams. I remained in close contact with service managers of the teams throughout this process to inform them of my steps and intentions.
2) To begin recruitment, I liaised with qualified or assistant psychologists employed by the service to identify potential participants. This method of contacting clients ensured that ethical protocols were followed that the first contact made with any NHS patient was made via an existing employee of the service they are under. Also, it meant that many potential participants already had an existing relationship with the assistant/qualified psychologist and might be more willing to hear more about the research.
3) Potential participants had to have undertaken a cognitive assessment within the last 6 months and have been given a diagnosis of ID, in addition to the other inclusion criteria (see section 2.8.2). The identity of these potential participants remained anonymous to me at this stage. Participants were initially assigned a code number to protect identity when discussing with the psychologist/assistant.
4) The psychologist/assistant then liaised with their colleagues at the ID team. This had two functions; firstly, to ensure that the potential participant was engaging well with the team and (in the care coordinators' opinion) had the capacity and ability to take part in a spoken interview about their experience of assessment. Secondly, this was to ensure that the participant was currently well enough within themselves (e.g. within their physical and mental health) to take part in an interview.
5) Potential participants identified by the team were then contacted by the assistant/psychologist to ask if they were interested in taking part in the study, and, if so, to give their consent to be contacted by me.
6) For those interested and consenting volunteers, their names and phone numbers were then passed to me.
7) I then contacted potential participants by phone, or spoke with a parent/carer on the phone if the participant so wished (instead of speaking directly with them). I explained the intention of the research and process of the interview and enquired if they wished to take part.
8) Participants who were interested were invited to an initial meeting with me, along with their parent/carer.

9) At this initial meeting, I explained the process and aims of the research. I accompanied my explanations with easy read materials for participants (see Appendix C), and longer more detailed materials for parents/carers (see Appendix D). I gave multiple opportunities for participants and parents/carers to ask any questions or express any concerns. I also made participants and parents/carers aware that I would liaise with their care coordinator to ensure that it was suitable for them to take part in the interview, and that we would not continue if there were any concerns about their safety, or if it might upset them.
10) For participants who wanted to take part, I then liaised directly with their care coordinators to inform them of this. For any participants where concerns were identified, the recruitment process would have been terminated here and parents/carers and the participant informed. There were no concerns raised by care coordinators about any participants at this stage.
11) I then waited two days to allow ample time for volunteers to think about taking part, to ensure that participants wanted to go ahead with the interview, before contacting them again via phonecall to book them for an interview with me.
12) Before the interviews took place, I went through the easy-read consent forms with participants (see Appendix E) and explained again how the interview would work. I emphasised that parents/carers could be in the room with participants during the interview if they preferred and that we could take a break or stop at any time if needed.

2.8.4. Demographic Information of Sample

The participants included in the study were recruited from inner London learning disability services. No participants were recruited via non-NHS sources. All participants who took part had obtained a diagnosis of ID following completion of a cognitive assessment with a psychologist. Ages ranged from 19 to 45, and the sample consisted of 1 female and 3 males. Two participants identified as white British, one as British Asian and one as Black African. Two participants chose to have a parent or carer with them for some of the interview. One of these wanted a parent to be present for the duration of the interview, while the other chose to have part of the interview alone. All participants have been given pseudonyms in what follows below to protect their identity and confidentiality. A summary of this information is given in Table 1.

Table 1. Participant Demographics.

Participant psueodonym	**Age**	**Gender**	**Ethnicity**	**Time since cognitive assessment completed**	**Attended with parent/carer?**
Zara	19	Female	British Asian	2 weeks	No
Michael	21	Male	Black African	3 weeks	Yes – only for second half with mum (April)
Richard	45	Male	White British	7 weeks	No
Marvin	26	Male	White British	4 weeks	Yes – attended with mum (Gloria)

2.9. Ethical issues

2.9.1. NHS Ethical Approval

Ethical approval was applied for and granted by one of the London NHS Research Ethics Committees relevant to the Trust where I had aimed to recruit participants. Some amendments and further information were requested during this process. One of these was to ensure that all information and consent sheets were formatted alike and that the pictures in them were in consistent places. Additionally, I was also requested to add clear information about who participants could complain to if they were unhappy, and to put contact details of the local Patient Advice Liaison Service. The ethics committee also recommended that the length of time of the study was increased, as they suggested that it may take longer than first estimated to recruit and interview participants. Following these amendments, the chair of the committee reviewed the application, and the project received ethical approval (see Appendix F).

2.9.2. UEL ethics

In addition to the NHS ethics process, UEL ethics was also applied for and granted. This was initially to widen recruitment options while waiting for NHS ethics, but also allowed me to advertise the study through charities and via social media. See Appendix G For a copy of the UEL ethics approval letter.

2.9.3. Informed Consent

I followed ethical guidelines on research with people with ID published by Dalton and McVilly (2004), and from these ensured to explain to participants:

- Why the research was being carried out and by who.
- How the research would be conducted.
- What the potential impact on the person taking part might be.
- How the person’s information would be stored and used.
- The right to withdraw from the study at any time, and without needing to give a reason.
- Withdrawal from the study would not affect the care being received at the ID service.

To supplement the conversation, I also produced illustrated easy-read materials, such as letters of invitation (Appendix H) and information sheets (Appendix C) which I read through with participants.

Guidelines recommend that adults with ID should be capable of providing informed consent unless formal assessment or a legal document has provided evidence contrary to this, however the person should be provided with every opportunity to understand the potential research, which can include involving a trusted adult (McVilly & Dalton, 2006). Therefore, I encouraged parents/carers to attend the initial meeting to discuss the research and I gave parents/carers an information sheet about the research (see Appendix D) so that they could support the potential participant in making a decision as to whether to participate. This information sheet was more detailed than that given to participants, for example documenting ethical approval and a longer description of the study. This was also so that the parent/carer could fully support the participant if they were unhappy or wanted to make a complaint.

To allow ample time for the participant to consider whether to take part, I initially met with them to introduce myself, explain about the research and about consent. I agreed to phone the participant after two days to ask if they would like to take part, and if they did I arranged an appointment to conduct the interview with them. At this point I asked participants to sign a consent sheet (see Appendix E).

2.9.4. Capacity

Guidelines around informed consent to participate in research for people with ID apply in the same way that it would for participants without ID (Wiles, Crow, Heath, & Charles, 2008). In approaching my research, I knew that many people with ID are capable of understanding information, either verbal or written, about research and can decide for themselves whether or not to take part. However, I was also careful to take into account potential issues of capacity when thinking about recruitment.

Capacity is defined by the Department of Health (2005) as being able to; understand relevant information; retain that information long enough to be able to make a decision; weigh up the information to make the decision; and communicate that decision. Under section 3 of the Mental Capacity Act (Department of Health, 2005), if a person cannot do one of these four things in respect of a specific question or issue, then they are classed as being unable to make that decision for themselves – and may thus be deemed as lacking relevant capacity. Furthermore, the first key principle of the Mental Capacity Act states that just because someone has a particular medical condition or disability, it cannot be assumed that the person does not have capacity. The 'presumption of capacity' must be followed – i.e. as clinicians and researchers, we must presume that every adult has the capacity to make their own decisions about a given issue unless proven otherwise.

With the Mental Capacity Act in mind, I was conscious that a capacity assessment would only ever be carried out if there were doubts over the ability of a participant to make an informed decision about taking part in the research. These doubts could be raised by either myself, a parent/carer, or a care coordinator. In the case of my research, if any doubts about capacity had been raised by any of the above parties, the research, at any stage, with that particular participant, would be stopped and the reasons why would be communicated to the participant, parent/carer and care coordinator.

In my individual informal assessments of my participants' capacity I checked that participants understood what was going on at every stage of the research. Potential warning signs of lacking, or fluctuating, capacity that I was careful to look out for included;

- Ambivalence about making a decision to take part
- Participants seemingly not understanding the purpose of the research or interview (e.g. asking why they were there, or why we were talking/asking about these things, after going through the study information and consent sheets).
- Not understanding questions asked if this was still the case after rephrasing/using more simple language.
- Being unable to communicate their thoughts or experiences

I was prepared, at any stage of the research, to stop the recruitment or interview, if I had any doubts about the capacity of a participant.

2.9.5. Confidentiality and Anonymity

The information sheet given to participants and to parents/carers explained about confidentiality and the limits of this. I was careful to discuss this with participants upon first meeting, particularly the meaning of confidentiality, which I found from my own experience of working in ID services, can be a difficult concept for some people with ID to understand. To aid this process, I gave participants easy-read information sheets, which had accessible language appropriate to the needs of participants with a ID. I also gave parents/carers information about confidentiality.

In terms of information and data storage, I informed participants that consent forms and any identifying information about participants were stored securely in a locked filing cabinet at the University of East London. I transcribed all interviews myself, and no external person, other than my research supervisor and examiners of the thesis, would have access to transcripts. I ensured that each transcript was password protected and anonymised

For the write up, participants names and identifying information were removed to protect confidentiality. Each participant was assigned a number, and I was the only researcher who knew which participant had which number.
Any audio recordings made and paper information concerning consent and personal details will be destroyed after examination of the thesis. Anonymised data will be kept for three years following submission of research and will be destroyed after this.

2.9.6. Minimising Potential Distress

Due to the nature of the interview questions, it was felt that potential distress caused would be minimal. However, I took a number of steps to ensure any potential distress caused was acknowledged and mitigated. Firstly, participants could attend with a parent or carer if they wanted. Secondly, opportunities for frequent breaks were provided, which can help reduce fatigue and distractibility (Cook & Gladhart, 2002).

I also closely monitored participants for any signs of distress and was prepared to stop the interview if at any time a participant became upset or distressed. Participants were also given a debrief session after the interview, where the purpose of the research was explained again, and details were given of who to contact should they have any questions or worries following the research.

2.10. Data Collection: Semi-Structured Interviews

For those that decided they would like to take part, I met them again, either alone or with a parent, at their local ID team to conduct the interview. The pace of interviews varied, as I adapted the speed and nature of questions dependent on the pace and communication level of each participant. Interviews lasted on average around 35 minutes and were recorded on a hand-held Dictaphone. As noted earlier, regular breaks were offered to participants. Following the interview, participants were given an opportunity to ask questions about the research or the interview process. I also gave a verbal debrief to participants. Following this meeting, interviews were transcribed and analysed, with any identifying information being omitted from transcripts.

2.11. Data Analysis

2.11.1. Memo Writing

After each interview that took place, I made a note of any thoughts, reflections and observations about the interview. These included my impressions of how the interview had gone, my style as an interviewer (e.g. which questions had seemed to open up/close down conversations), and my impressions of how participants had found, and responded to, the questions. I also made notes of any topics relevant to my research questions that I noticed.

2.11.2. Transcription

I recorded each interview using a Dictaphone. Following this, I transcribed each interview verbatim, including my own part in the dialogue. I took care to remove any identifying information and ensure that each transcript was anonymised.

After conducting the IPA analysis, I revisited the audio-recordings and transcriptions to prepare for DA. I added in information about emphasis, tone, interruption and laughter in line with the guidance provided by O’Connell and Kowal (1994). They advocate that there is no standard transcription system that can be applied to DA research, instead the type of transcription should be used that best fits the purpose of the research. As I was interested in participants’ use of language, I felt it important to capture emphasis, tone and interruptions within the text. The notation system used for the purposes of DA is detailed in Appendix I.

2.11.3. IPA analysis

I followed guidelines set out by Smith et al. (2009) to analyse the data using IPA.

2.11.3.1. Approach to transcription: To begin with, I read over my transcripts a number of times and listened to the audio recordings at least twice again, after the transcription had been written. This allowed me to immerse myself in the data and recall each interview with clarity. Each time I listened to an interview, or re-read the transcript, I noted down my initial thoughts and insights about the interview or any points of significance. As recommended by Pietkiweicz and Smith (2014), I paid attention in particular to three types of focus; content (i.e. what was being discussed), language use (linguistic features, for example symbols, metaphors, repetition, pauses) and context, and then I made my initial interpretative comments. At this stage I also began to make comments which related to personal reflexivity, e.g. how my personal characteristics (such as my age, or being white, female) and own personal experiences (such as having a family member with ID) might have affected the rapport or discussions with the participant. I also made notes on any phrases that were distinctive, and about the emotional tone at each stage of the conversation. An abstract from my note making stages is given in Appendix J.

2.11.3.2. Generation of emergent themes: For my research I followed the procedure recommended by Smith et al. (2009). After making initial comments and notes on the left hand of the transcripts, I next conducted an intensive line-by-line analysis, by capturing more psychological concepts which explained more succinctly the process and function of participants' speech. I then began to combine themes into headings, capturing these under subordinate and superordinate themes. See Appendix K for this process.

2.11.3.3. Reflexivity in IPA: Reflexivity requires researchers to acknowledge and consider the ways in which their own views and experiences influence their analysis and findings. It is a skill that is highly valued in qualitative research, as it relies on the ability to be assertively introspective and examine external forces upon the researcher, such as culture, religion, politics, history, and the social interactions between the researcher and participant (Sandelowski & Barroso, 2002). Reflexivity acknowledges that researchers are not neutral in the data collection and analysing process.

It has been argued that reflexivity is a vital aspect of qualitative research, particularly in studies involving IPA analysis (Shaw, 2010). Rather than the researcher being a neutral collector of data, reflexivity can help researchers understand their own impacts upon the research, which can help exposure and mitigate bias, therefore bringing a better contextualised version of participants' accounts to light (Underwood, Satterthwait, & Bartlett, 2010). The reflexive process brings bias to the forefront, allowing researchers to examine and take account of it.

It is important for researchers to pay attention to reflexivity throughout the research process (Larkin & Thompson, 2011). At each stage, i.e. after each interview, while listening to recordings, and while reading and writing transcripts, I reflected on how people's stories made me feel by taking notes. I also aimed to notice and document my preconceptions about people and their stories, which Larkin and Thompson (2011) recommend is helpful for researchers to do in an intentional and consistent manner. In an attempt to capture my thoughts and impressions in a strategic and constant way, I made notes after each interview about my initial impressions but also kept a reflective journal so that I could notice and analyse my own biases and potential influences on the study. This allowed me to capture both my emotional and intellectual reactions to people's experiences.

2.11.4. Discourse Analysis

In undertaking the DA, I was aware of Potter and Wetherell's caution; that outlining the researcher's approach to DA is “not a case of stating, first you do this and then you do that” (Potter & Wetherell, 1987, p.169), and that “there is no analytic method” (Potter & Wetherell, 1987, p. 169). Instead, I drew upon several sources to inform my analytic process. I was guided by the rough steps outlined by Potter and Wetherell (1987), who recommend initially conducting preliminary reading of the data (i.e. searching for action orientations), which is followed by generation of results, focusing on discursive devices and rhetorical/interactional strategies. I outline further the steps I have taken below.

2.11.4.1. Preliminary reading: Initially I read and re-read the texts. This is because it allows researchers to experience some of the discursive effects of the text (Willig, 2013). Next, I began to search for action orientations, i.e. what is being accomplished in the data (Goodman, 2017), particularly for those that are relevant to the research questions. I also kept note of any initial thoughts about the data and for any emerging discourses. (See Appendix L).

2.11.4.2. Generating results – discursive devices and positioning: After making note of the relevant action orientations occurring in the data, I began to generate appropriate outcomes. A number of different findings are suitable DA, which are often referred to as discursive devices but may also be called rhetorical or interactional strategies (Willig, 2008). Goodman says that these are “ways of making arguments which may achieve (or can be seen at least as attempting to achieve) some kind of action orientation, that accomplishes something in the interaction” (Goodman, 2017, p. 148). There are various potential discursive devices and strategies which are accessible within interactions. For example, participants may say things in a way to legitimise a viewpoint, or to discredit another perspective, or to present the speaker in a certain light, e.g. as honest, by using phrases such as ‘to be honest’ and ‘actually’ (Edwards & Fasulo, 2006). I put these action orientations into various groups which appeared to achieve something within the interaction. See Appendices M and N for a list of codes and resultant discourses.

3. RESULTS

In this chapter I present the results of both IPA and DA performed on transcribed interviews with 4 adults with ID, who completed a cognitive assessment which had led to their diagnosis of an intellectual disability. The results outlined here capture the experience and positions that the participants had about the processes and outcomes of being tested for, and diagnosed with, an ID. I first present the results from the IPA and then go on to present the results of the DA. Each participant has been given a pseudonym to protect anonymity, and to promote readability.

3.1. IPA

Here I outline three superordinate themes which I identified in the IPA. I will address each theme in turn, using quotes from participants to illustrate examples of the theme. A summary of the resultant themes is shown in table 2.

Table 2. IPA Superordinate and Subordinate Themes

Superordinate themes	**Subordinate themes**
Disconnected services	Multiple professionals Repetitive or further assessment Poor communication from services
Positive experience of assessment	Experience of the assessor Hope
Views surrounding test performance and outcomes	Wanting to do well in the assessment Shame of getting things wrong Unclear expectations and feedback

3.1.1. Disconnected Services

This theme highlighted the experiences that participants reported of undergoing multiple assessments across several services, and the impact that these experiences had upon their most recent assessment experience. In particular, participants talked about the difficulties seeing various types of professionals and what this is like with having to repeat their stories. Perceived problems in accessing services are also discussed, for example long waiting lists and inflexibility of appointments. The underpinning sub themes illustrate how participants described their experiences of disconnected services.

3.1.1.1. Multiple professionals: This theme addresses the impact that having appointments with multiple professionals had upon the participants. Participants said that these experiences led to difficulty in building rapport and trust with new professionals and made it harder for them to remember the names of the people involved in their care. Within this sub-theme, the powerlessness of people's position is highlighted in relation to the services they access and the power held by professionals.

Marvin discusses his experience of accessing a multitude of services and professionals. This is both within the service in which he had his cognitive assessment and others. Marvin's description of this reflects the great number of different professionals that Marvin says has seen. Words such as 'they' are used frequently, suggesting that professionals were, to him, an indistinct group. This is the case until Marvin begins to discuss one man he did not feel neutrally about:

> *114. Marvin: Yeah, but I didn't like (name) though*

Marvin then goes on to explain:

> *118. Marvin: Coz he just said he's going to put me in care*

Marvin's description here is linked with an experience of what may be a social worker, who Marvin described was 'going to put me in care'. This appeared to be a frightening experience for Marvin, and by explaining it that the man 'just said' – it implies that Marvin hadn't been given, or didn't remember, reasons why; but had experiences of being told that something was going to happen to him. This may reflect Marvin's powerlessness in the situation and his fears of things 'just' happening to him.

Marvin goes on to describe how hard he finds it meeting new professionals all the time, and what it was like in the context of meeting with the assessing psychologist:

531. Marvin: It's like sometimes when you go to tell someone, you meet
532. someone for an appointment, like 6 weeks or 6 months later it's
533. someone new

This reports an experience Marvin has had several times, as he goes on to explain:

566. Marvin: Coz it was like when I had a social worker innit I had like four
567. social workers in, like, the space of like three months
568. Int: Right, ok
569. Marvin: That was madness innit

By using the word 'madness' here, Marvin is describing his experience of these situations as senseless, or incomprehensible. Marvin seems to be talking about high staff turnover. Within this, his experiences link to a feeling that services seem depersonalised. This appears to be consistent with Michael's experience too, as, in reference to the psychologist who assessed Michael, he could not seem to remember their name:

114. Michael: I don't know

This experience is also echoed by Richard when I asked which psychologist in the team he saw:

203. Richard: Oh I can't, I couldn't tell ya
204. Richard: I, I saw him once
205. Int: Yeah
206. Richard: Saw him once and that was it

Richard goes on to tell me about how he had recalled that a different psychologist gave him the results of the assessment. It is apparent is that Richard does not remember seeing the same psychologist again.

The experience and frustration of seeing different psychologists within the assessment sessions, were also echoed when discussing other types of professionals:

573. Marvin: And it was all like well we're only here for a short time
574. Int: Ahh
575. Marvin: We're only, we're only here to cover someone
576. Int: Yeah
577. Marvin: And then a new person would come, oh we're only here to
578. cover someone.

The caveat that Marvin talks about of professionals saying they are 'only here to cover for someone' implies that they will again be someone temporary that Marvin interacts with, which understandably makes it more difficult to build a trusting relationship with new staff. This appears to have left Marvin feeling that he has been stuck in a cycle of constantly meeting new professionals, and possibly has left him expecting that anyone else he meets in the service will be replaced soon or will leave.

3.1.1.2. Repetitive or further assessment: Participants described experiences of having some type of assessment for an ID earlier in their lives. When I refer to assessments that have been conducted to assess ID for Michael, he questions which assessment I am referring to:

330. Michael: About which one?

Michael has, it seems, experienced having multiple assessments across his life. It emerges through this conversation that Michael reported that he had an assessment for ID when he was in school.

Similarly, Richard expresses recognition about a certain part of the assessment, which leads him to explain to me that he thinks he has had an assessment for ID before. Here, Richard recalled what may be a formal test being done with him at a younger age:

816. Richard: Them blocks right, I've done them, I've done before
817. Int : Ok, you've done them before? When was that?
818. Richard: In urm (4 second pause) when I was at school

Participants then go on to talk about their experience and memories of having one-to-one help at school and things that were academically difficult for them.

Marvin also recalled having an assessment for ID when younger, while talking about the length of time the assessment took:

321. Marvin: When I was younger though we dunnit and it was like three
322. hours or two hours long innit?

Participants described having memories of these assessments at some point in their early lives, which they experienced as not seeming to translate into a diagnosis, as far as the participants knew or a diagnosis that could be documented in their view.

Later Marvin also recalls being asked similar questions as part of his assessment when new staff members start at the service:

578. Marvin: ….And then they're asking the same questions
579. that the other person asked
580. Int: Yeah
581. Marvin: So it's just on repeat, I'm just doing the same, first, the first, the
582. meeting. That was mad.

Marvin here experiences frustration and disbelief, as exemplified by the use of his word 'mad'. Marvin's speech here emphasises his experience of having to repeat the same session over and over again.

In Zara's discussion, she expressed frustration at having to go through the process again.

221. Zara: They lost it then I had to go back and eventually and do the, the
222. test all over again

She later goes on to describe:

233. Zara: It was… they just said that, we don't have, we don't actually
234. know what the test was
235. Int: Right
236. Zara: We don't have the results

This apparent lack of communication from Zara's point of view between services across her lifetime meant that she had felt she had had to have at least two cognitive assessment over the period of her life.

During our discussion, I asked Zara a question about health appointments that she goes to, and about why she had come to her specific appointment with the learning disability service. Zara replies:

144. Zara: Yeah. And I get it, yeah, that there's these all the times I have to
145. do something. But I didn't know why I was there

Zara seems to refer to her appointments, both in a health context and regarding the cognitive assessment, as a frequent occurrence. This implies that these appointments are so frequent and necessary, that Zara has become used to this as part of her life. This may be evidence of a degree of resignation and powerlessness that Zara now feels in response to attending multiple appointments.

3.1.1.3. Poor communication from services: Participants described experiencing difficulties in communication between themselves and their learning disability service. These experiences particularly concern reports being sent, or professionals saying that they would be in touch.
Richard demonstrates this in talking about the results of his cognitive assessment:

673. Richard: They said they was gonna send me a letter
674. Int: Right, ok
675. Richard: Which I never got

Richard told me that he remembered meeting a psychologist in person to go through the results of the assessment, but he said that he had not received the full report. Richard did not appear to express dissatisfaction with this event, however seemed to wonder aloud about what had happened. Richard's comment about not receiving this correspondence is not followed by any subjective statements of feeling let down or disappointment. This raises questions about if this is something that has possibly happened to Richard before and seems normal.

In Zara's position, having had an assessment already lost, she seemed to express a loss of faith in the service:

757. Zara: I don't think it will come
758. Int: You don't think it will come?
759. Zara: I know they will lose it again

When I had asked Zara about how it felt that the service was unclear what her lost test results were, Zara used the words:

287. Zara: Err, just devastating

This is a strong word and suggests that Zara felt demoralised and let down by her experience. Zara was the only participant who expressed overtly negative overall experiences of the assessment, and it seems that the service losing a report had impacted how she felt about the assessment overall.

3.1.2. Positive Experiences of Assessment

Despite experiencing the disconnect between services, as elaborated upon above, the participants said that some of their experience of the assessment was positive. Participants said that this was due to their experience of their assessor personally, e.g. being kind or empathic, and of the feelings that the assessment left them with, namely hope.

3.1.2.1. Experience of the assessor: Participants commented upon what it was like to work with their assessor and build a trusting relationship. This was related to their expectations of the assessment, and as a result, participants said that they had tried hard during the assessment, i.e. they expressed wanting to do well. In relation to Zara's assessor, she said:

39. Zara: She was nice, like, she did say to me, like, if you, erm, need a
40. break then you, you can take a break

It seemed that Zara experienced her assessor as being compassionate towards her, thinking about Zara's welfare. Zara went on to say:

101. Zara: Like, it was.It kind of felt ok coz she said that
102. if I didn't know the answer it was alright

This implied that Zara experienced her assessor as reassuring, and that Zara felt she had let Zara know what it was ok not to know.

Marvin described his psychologist too:

153. Marvin: She was a doctor, nice doctor

Upon exploring this further with Marvin, he told me:

166. Marvin: Mmm… she was just, she was just polite. No not polite, but she
167. was.. she listened as well
168. Int: Mm
169. Marvin: But sometimes, not gonna lie, you can have some debates like
170. this and they don't give a shit

Establishing a personal connection seemed important for the participants, with qualities such as being nice, listening, and genuinely caring standing out as memorable parts of the interaction. It seemed that Marvin had had experiences of professionals not ‘giving a shit’, possibly that Marvin had perceived them as not caring or being rude to him in the past. The positive connection with the assessor seemed to influence how participants perceived the help they were getting:

180. Marvin: You could tell she cared

This kindness that was perceived by Marvin towards him seemed to have a significant effect upon his experience of the assessment. These answers were given by Marvin after I had asked what was good about the assessment, so this connection seems to have had an impact upon Marvin’s perception of the experience as a whole.

3.1.2.2. Hope: When discussing the outcome of the assessment, it was referred to as fulfilling a certain purpose. For Michael, he described to me about what had changed for him since having the assessment, he told me:

76. Michael: It, it, it’s gone better
77. Int: Can you tell me a bit more
78. Michael: I, erm, uh g got, um interview

Michael described that he saw having the cognitive assessment as a way into services which would help him to get a job. Michael had described that he finds things such as tests and interviews really difficult, and that his hope for doing the assessment was to access help to get a job. It seemed that Michael felt he was on his way to getting closer to his goal, which he felt was aided by the service he had the assessment with.

For Marvin, he seemed to have a less specific outcome in mind, but overall was hopeful about it happening. For example, when talking about what happens next, he refers to what he remembers his assessing psychologist had told him:

395. Marvin: And then, we’ll talk and then we’ll go on from there, and then
396. that’s when she said about
…
399: Marvin: (carries on) .. about if this service doesn’t can’t help you, she’d
400: find something that another service or whatever I need to help
401. me

Marvin appears to be describing here that whatever the outcome of the assessment, there will be help available for him. By using the words ‘whatever I need to help me’ suggests that he maybe does not know what this help involves, but perhaps feels that it will fit with his own particular needs.

3.1.3. Views Surrounding Test Performance and Outcomes

Participants talked about feelings towards their expectations of how they wanted to do in the assessment, as well as feelings such as embarrassment and shame in relation to not knowing certain answers or understanding how to answer.

3.1.3.1. Wanting to do well in the assessment: Participants expressed that they wanted to do well during their cognitive assessments. An example of this is shown during Richard’s explanation of trying hard during the assessment with his psychologist:

910. Richard: No it’s just uh, sit there and do the blocks and bits and pieces right
911. Interviewer: Yeah
912. Richard: I just sat there, and er.. done the best I can

Richard here shows an investment in wanting to do well in the assessment, in trying his best. It appears that this is something Richard cares about and wanted to perform to the best of his abilities.

Marvin describes how he was able to ask for help during the assessment if something felt confusing for him:

716. Marvin: Some things, nah it was all alright, there were some things I
717. didn’t understand, but then if before I’d even got to say to her I
718. don’t understand, she’d already said to me, if there’s anything
719. you don’t understand
720. Int: Mm
721. Marvin: Ask me
722. Int: Ok
723. Marvin: And I told her

Marvin here shows motivation to engage with the assessment; to try as hard as he could to answer the questions correctly, asking for help if he didn’t know what to do.

Marvin contrasts this to his memories of school, where it did not feel safe to express that he didn’t know, and this therefore had the opposite effect of trying hard on tests:

792. Marvin: Sometimes in school, if you don’t know it yeah
793. and…
….
795. Marvin: In school when you done that yeah, one of the teachers were
796. like proper horrible like innit
…
800. Marvin: So I just like, not even answer anything like that, just…
801. Int: Yeah
802. Marvin: Keep myself to myself and just
803. Int: Sure
804. Marvin: Not have to say if I can’t do it, do it. Or how do kn know I’ve got
805. it right

It seems here as though Marvin is contrasting his experience of not knowing answers on the cognitive assessment with what it was like not knowing things at school. Marvin is explaining that in school he would disengage if he didn’t know an answer, as the teachers were ‘proper horrible’. In contrast, during the assessment, he talked about feeling reassured about his performance:

775. Marvin: And then she said. She was just alright. But then she didn’t,
776. she didn’t say, n’ I go oh I think I got that one wrong, and she
777. was like nah nah nah nah nah it’s alright
778. Int: She did
779. Marvin: So even then she reassured me , even though she probably,
780. she probably like, it (1 second pause) I was probably wrong

The reassurance he received from his assessor seemed to play a role in keeping his confidence up, even though he expressed doubts about his own performance.

3.1.3.2. Shame of getting things wrong: In addition to wanting to get things right on the assessment, participants expressed feelings of shame surrounding getting answers wrong.

Zara describes things poignantly here:

101. Zara: It kind of felt ok coz she said that
102. if I didn't know the answer it was alright, but, I, like. I knew I
103. didn't get it right. And that wasn't nice
104. Int: Mm, so that wasn't nice for you?
105. Zara: No (5 second pause). I don't get things right and I couldn't get
106. any of the questions right

Zara's use of the words that it 'wasn't nice' shows that it felt painful not knowing the answers. Her description of 'I don't get things right' implies that the assessment experience evoked feelings that Zara has of herself, perhaps of being 'stupid' or 'inadequate'. The second part of this quote (that Zara 'couldn't get any of the questions right') suggests a motivation that Zara wanted to do well in the assessment and that it held some importance to know things. The lack of this confidence in her own knowledge, and the fact she perceived that she couldn't get 'any' questions right, seems of great importance to Zara.

This shame at not knowing, and not being able to 'perform' what is being asked, continued for Zara when describing other experiences. For example, Zara told me that she had been asked to draw one of the pictures again. When I asked how that experience was, Zara used the words:

172. Zara: It's terrible because I couldn't draw. I couldn't draw at all

The word 'terrible' here suggests that this was an awful experience for Zara, and that she perhaps felt embarrassment and humiliation. Zara seems to set high standards for herself, and again by using the words 'at all' she suggests that she should be able to draw a little bit, but that by failing to be able to do this, it proved a total failure.

Michael also expresses his feelings towards not getting some answers right:

769. Marvin: But I didn't think, I I didn't think it was gonna be that one
770. that I thought it was. It sounded stupid so I thought it can't
771. be that

Feelings of shame appear to be evoked for participants at difficult questions during the assessment.

Richard was able to express other emotions, such as surprise and possibly frustration, when trying to comprehend why he couldn't do one of the tasks:

Richard: (coughs) the last two, and then it started getting a bit, bit
hard, I tell you I'm looking at it right and, thought
Int: Yeah
Richard: Wait a min, what's am I doing, a and I thought, f f fuck me
he did it, but h how come I can't do it

There is a clear comparison Richard makes of the assessor's ability to copy the block pattern and his own. Richard almost expresses disbelief at the difficulty he found in completing this task. The words he chooses; 'fuck me', and the fact he hesitates in this sentence, maybe reflect the frustration and surprise that he experienced during this task.

3.1.3.3. Unclear expectations and feedback: Participants talked about not knowing the reason for, nor outcome, of the assessment. The below extract was taken from my conversations with Marvin:

Interviewer: Ok.. I wonder what you remember about… what she told
you about what the service could offer you
Do you remember what she said of why it could help?
Marvin: I can't remember

Here I was asking Marvin about his hopes for what he might get out of the ID service which he was now under. Marvin's words 'I can't remember' suggest a number of things. It may be that Marvin has been told about what the learning disability service could offer him, but as he says – he can't remember what this is. Another possibility is that Marvin was told about what the service offers, but that maybe he did not understand what this meant or was not able to take on board what was told to him. Or it may have been that Marvin was not told about what the learning disability service offers. Marvin's statement here implies that he is unsure about why he is having the assessment, as he is unclear about the services or support that may follow afterwards.

A second extract which demonstrates participants' confusion about the purpose of the assessment is shown below in my interview with Zara:

122. Zara: Coz no one told me why I was there, like it was confused
123. Interviewer: Confused?
124. Zara: Like I think yeah there was testing for a disability and which
125. kind I have but I don't know why I needed to do all of those
126. things
127. Interviewer: So it felt unclear why you were there?
128. Zara: Yeah

Interestingly it seemed that Zara had an idea that the purpose of the assessment was to contribute towards diagnosis of a learning disability. However, as she used the word confused, I asked further about what Zara thought:

132. Interviewer: Why did you think you were there?
133. Zara: My parents, we say, they saying to me that I need to have
134. this assessment but I dunno why, but I did it anyway

Zara says that she believed she was there because her parents wanted her to do the assessment. This raises systemic questions such as 'who wants what for who' (Brown, 1997), and in this case it appears that Zara perceives her parents as being the people who want the assessment to happen. Zara's saying of 'but I did it anyway' suggests that, despite not being aware of the function of the assessment, she continued regardless. This raises ideas surrounding who holds the power in this situation (Zara's parents) and this influencing Zara to do an assessment. I was left feeling that Zara was not sure if she wanted to do the assessment. I also wondered whether Zara felt she had a choice in deciding not to do the assessment. Her words ('I did it anyway') suggests that Zara was reluctant to do the cognitive assessment, but possibly felt powerless to challenge or question the systems around her which seemed to require her to go through this process. Although the function of the assessment concerns further support from the learning disability service, it became apparent that Zara did not appear to have an understanding of this:

469. Zara: If they could, if they could give a small detail of
470. understanding like why I'm actually doing the assessment,
471. of what it's for.

Interviewer: Yeah, what it's for. Yeah that's really, that makes sense to me, I think that's very fair. Um, and I, I'm curious as to what happens next for you

Zara: Yeah

Interviewer: Have you got any hopes or any plans for what you would like to happen?

Zara: No

Zara's words in the first part of this extract that she felt that she has not been given an explanation about why she is doing the assessment. The use of the words 'a small detail of understanding' implies that Zara might not have even basic knowledge about what happened in her situation. Whether this is the case from the service's point of view, or her parents' points of view, we do not know – however, it seems that Zara's perception is that no one has told her why this process is happening. This may link to similar questions to those discussed in Marvin's extract above as to how much Zara has been told and by who, about what her understanding and memory of this explanation was, and the quality/clarity of what has been told to her.

The second part of our interaction here, in terms of Zara having hopes or plans about what happens next, appears to show that Zara doesn't know what happens next with the learning disability team, and doesn't have particular hopes surrounding the outcome. However, this answer may have been linked to an unclear or not specific enough question being asked by myself. While Zara, however, could have answered 'I don't know' (which has been the case when asking about outcomes for some of the participants), Zara instead chooses to use the word 'No'. This potentially indicates that Zara does not have an outcome in mind after the assessment or knowledge about the next steps in terms of support for her that may be provided by the learning disability team.

3.2. Discourse Analysis

Four discourses are presented within this chapter. These are

- The System Holds the Power
- Fear of Abandonment
- I am Resilient – Don't Feel Sorry for me
- Having to do Something versus Choosing to do it

3.2.1. The System Holds the Power

This discourse captures the way that participants discuss the power that is held by the professionals who are providing the cognitive assessment.

It was evident in all the interviews that all the participants have been expected to complete the assessment, though participants were not always clear about the rationale for this. Upon asking participants about the results of the assessment, or the reason that they had completed it, many of the answers involved words and phrases such as 'um' and 'I don't know' and 'I'm not too sure'. It did not seem massively important to participants about what the cognitive assessment had shown about them. However, all the participants reported feeling that the assessment was something they "had to do".

The following extract is from my interview with Marvin. Marvin recalls being first invited for the assessment and what this was like for him

127. Int: Yeah(.) gosh. And I wonder what it was like for you to first
128. ↑come here and ↑talk to someone(.) what that felt like?
*129. Marvin: *I didn't wanna (.) I didn't wanna**
130. Int: You didn't want to (.) Ok
131. Marvin: I didn't wanna come to the appointment (.) I kept putting it
↑off (2)
132. [didn't I]

Here Marvin repeats himself three times, using the words "I didn't wanna". Initially when speaking, Marvin is quiet, as though what he saying is taboo. Possibly Marvin is building himself up to elaborate upon the reasons, possibly testing the water of the reaction that he got initially when saying this. After hearing my response in that I paraphrased what Marvin had said, without particular emotion or surprise, Marvin then uses this phrase “I didn’t wanna” again for the third time. This time, Marvin’s volume of speech increases, as though to emphasise his point and to show confidence in what he is saying. At line 131 Marvin tells me that he “kept putting it off”. These particular words suggest that there wasn’t an option to cancel, or to tell his mum that he wasn’t going, even though he didn’t want to. It implies that this was an appointment that Marvin did not have a choice in going to and that it was going to need to happen eventually. At line 132, Marvin turns to his mum to back up his point, almost as if I may not have believed him. Credibility is added to his explanation by his mum’s voice being involved, as Marvin’s mother is positioned here as having greater power and knowledge. By doing this, Marvin positions himself as having less power. Interestingly, Marvin is interrupted a lot during our conversations, mainly by his mother but sometimes also by me, which reinforces the idea that Marvin’s voice is less dominant, perhaps less important, during these conversations.

The power of the doctor-patient differential is also evident throughout all of the interviews. Many of the participants refer to visiting a ‘doctor’ or having multiple tests. In Zara’s interview, when I asked her why she had to go for the assessment, she refers to health profession appointments:

148. Zara: No (.) like there’s always all of the ↑appointments
149. Int: Ok (.) all of the appointments?
150. Zara: Yeah (.) my ↑physio and to pick up my tablets and then I (.)
151. we (.) for the (.) the ↑doctor and that
152. Int: So you’ve got lots of other ↑health ↓appointments that (.) you
153. (.) well er (.) that you go ↓to
154. Zara: Yeah (.) ↑And I ↑get it (.) ↓yeah (.) that there’s these all the
155. times I have to do something (.)

The way Zara describes this, using the words ‘physio’, and ‘doctor’ and with an emphasis on the word ‘tablets’ is to tell me that these are important things, that Zara cannot miss. The alignment of power that Zara gives the learning disability service as compared to a physical health appointment, suggests that it carries equivalent weighting and power – i.e. that this a crucial appointment, with potential detriment to health upon missing it. Zara seems to accept the power carried by these services as well, by using the words on line 154 ‘I ↑get it’ –

suggesting that Zara understands and does not question the power held by these services. The upwards inflection at ‘get’ does suggest a tone of frustration upon Zara’s part, as though she is powerless to resist these appointments and the situation.

During the interviews, hesitation and stuttering occurs at times, which, at points, conveys an anxiety and uncertainty in using certain words or phrases. For example, at one point during our conversation Marvin uses a swear word (expletive) and afterward apologises:

169. Marvin: But sometimes (.) not ↓gonna lie (.) you can ↑have some
170. debates like this and they don’t give a ↓shit
171. Int: Mm
172. Marvin: Sorry (.) s sorry
173. Int: ↑No no
174. Marvin: [d d don’t]

Marvin’s stuttering here reflects uncertainty in choosing his next words and is perhaps an expression of embarrassment. Marvin does not often raise his voice or emphasize any words during our interview. However, the emphasis on ‘sorry’ at line 172, and the quickness with which Marvin said this, suggests immediate regret in the interaction. The power inequality becomes apparent through this interaction, with Marvin feeling the need to repair his perceived rupture in the conversation. Marvin’s words and reaction also reflects the formality of the situation and the expected social norms that Marvin perceives he must abide by in a certain type of context. Marvin’s next words of ‘d d don’t’, which were spoken over by his mother, indicate his reluctance at me putting these words in my report, as though Marvin will get into trouble for expressing these views or using this language. In this above interaction, Marvin has not only has sworn but has expressed a strong opinion about how badly he has been treated by people in the system. Though it is possible that Marvin is perhaps regretful for swearing, it may be that Marvin is instead regretful of expressing such a strong opinion about receiving poor care, as I am a person within the system that he is describing.

Examining the subject pronouns used by participants, the word ‘we’ is commonly used by participants during the interviews rather than ‘I’. This has the effect of lending credibility and generalisability to what is being said by the individual with an ID. Marvin's mum does the opposite when talking about him – she switches into 'I' to convey his point of view, as if she is speaking 'as' Marvin, not 'for' him. This again reflects the power, not only that participants give to their parents, but the power that is perceived by parents over and above their son or daughter with an ID. By mixing these personal pronouns – it has the effect of giving weight and trustworthiness to the voice and opinions of the person with ID.

3.2.2. Reliance on Others

During their discussion of the assessment process, participants said that they had usually completed the assessment for a specific reason. In Michael's case, when I asked if he knew why he had done the assessment, he replied:

Michael: (2) erm(.) yes(.) erm(.) Because (1) they will
help me find a job(.) at in(.) interview placements(.) and put
me in a placement

The word used in relation to services here is that they will 'help' Michael. Here, Michael positions the service has having power and authority to make some tangible changes in his life, and potentially reflects the faith that Michael places within the system. Instead of using words such as they might, or could, help Michael, he tells me that the service 'will' help him. This reflects a certainty that Michael has about these actions. The second part of Michael's sentence describes that he thinks the service will 'put me in a placement'. Here, it is the ID service who is doing the 'putting' – Michael refers to himself as an object, as something to be positioned somewhere at the discretion of others. Michael seems to negate himself of autonomy in this interaction, positioning the service as having the power and authority to make decisions for, and about, Michael for him.

A couple of sentences later, Michael appears to adjust his positioning to something that has a more equal distribution of power:

Michael: They can, they can help me meet the people and do
stuff

By instead using the words 'they can', Michael is now implying that the service has the power to do these things, but that it does not necessarily mean they will.

Again, this implies that Michael is depending upon the service deciding for him. The second part, however, of that ‘they can help me meet people and do stuff’ positions Michael himself as being more capable and competent – someone who is able to, and wants to, do these things, but needs some assistance. Michael is positioning himself as prepared and able to act.

Later during our conversation, in relation to the support Michael expects to receive following the assessment, he likens this to his thoughts about other services that Michael has accessed:

295. Michael: I had ↑support(.) but it wasn’t (.) it wasn’t ↓enough
296. Int: (3) it wasn’t enough(.) yeah(3) I wonder (2) what else you
297. would have ↑liked(.) what would have made it ↑enough?
*298. Michael: (3) *I don’t know**

This three second pause from Michael at line 298 appears significant, implying that he is thinking hard about his answer. His reply is quiet too, which has the effect of Michael positioning himself as smaller or less significant within our interaction. Michael’s response places him in a position of holding less power and knowledge than I. Upon further examination of my question to Michael, it suggests that Michael’s wishes and opinions would clearly have been significant upon receiving ‘enough’ support, and that possibly by Michael knowing or talking about what he wants that these events may occur. Michael’s quiet response is possibly coming from a position of not being able to express what he wanted, or thought would be enough. In that sense, both Michael and I have positioned him as responsible for what happens to him in his care.

Following the discourse of reliance on others, the next extract focuses on Marvin’s recollection of the psychologist who did his assessment. He describes her explaining that if she isn’t his allocated worker, then she will at least try to come to his first appointment:

656. Marvin: [to the first appointment so I’m alright]
657. Gloria: Right person, so yeah
658. Int: [That’s nice]
*659. Marvin: [*So I’m not forgotten about*]*

Both Marvin's mother and I talk over Marvin in this interaction, and Marvin's last phrase is extremely quiet. Marvin had to interrupt both his mother and me in order to be heard. Not only in Marvin's words does he imply that he could be forgotten about, but in the nature of the interaction – in the fact that his mother and I both talk over him, perhaps seeing our own voices as being dominant or important. Marvin is suggesting here that he needs continuity of care otherwise the people involved in his care will forget about him. It conveys a neglect rhetoric, as though Marvin is vulnerable and dependent upon others otherwise he will be lost or, in his words, forgotten about.

Marvin also conveys what appear to be fears about being taken away, or lost within the system, and at the mercyof a powerful system beyond his control. A significant sentence that Marvin uses in our interaction is when he is discussing a negative experience with a social worker, and says he didn't like that man "coz he was going to put me in care" (line 118). By using that word 'put' it conveys that this would just be something that is done to Marvin, without his choice or consent. In this sense, it has the effect of Marvin conveying worries about being acted upon. Marvin is highlighting his sense of vulnerability here, and a fear that this will be abused by others in power. It is an interesting contrast to the position that Marvin adopts later (see 3.3. 'I am Resilient – Don't Feel Sorry for Me').

In the next extract, Richards talks about what it was like to have to do reading and writing as part of the assessment, and the memories that were linked to this. Richard states that he realised he had struggled with these aspects, and discusses his experiences of others helping him. Here Richard describes a previous work colleague:

430. Richard: I had a(.) I had a bloke who I come friends with right
431. Int: Mm
432. Richard: He was sitting down with me helping me to (2) you ↓know(.)
433. um(.) ↓bread(.) ↓cheese(.) and and w w w write it ↓down and all
434. that ↑right
*435. Int: Yeah *mm**
436. Richard: And ↑he (2) and then there's these ↑other ↓blokes and they
437. used to sit there take the ↑piss and ↓all ↓that right(.) and he

438. used to get up and have a ↑go at them
439. Int: *↓Ohh* (.) oh ↑good so he was ↑stickin' up for you ↓then
440. Richard: Yeah(.) he'd get up and have a go at them and things like that
441. ↑right and he said (2) he said 'well I haven't seen you read the
442. newspaper'

Here, Richard seems to be recalling an experience of feeling different. He remembers his friend and colleague 'helping' him to write down words, and then having the power to defend him. By having a different level of knowledge of reading and writing, Richard describes being positioned by others as stupid, or less than.

3.2.3. I am Resilient – Don't Feel Sorry for me

There are several examples of individuals portraying themselves as being resilient and strong, able to cope with challenges within the assessment context that are given to them. There are also times when participants resist the pity shown to them by others, protesting that they do not need to be protected or felt sorry for.

In Richard's talk, he conveys several positions of strength and resilience. When discussing having to do the assessment on his own, Richard compares this to feeling on his own at other points during his life. I convey sympathy, which you can observe through the use of the words 'oh' and 'gosh', and by my volume of speech lowering:

162. Richard: Coz I was(.) coz ↑since my mum and ↑dad died right(.) I
163. was(.) put(.) bringing myself ↓down
164. Int: *Oh gosh(.) yeah*
165. Richard: ↑Right(.) coz I live(.) I live on me own(.) right
166. Int: Mm
167. Richard: (2) live on me own(.) and er just sit(.) sit there and talk to the
168. f(.) the four walls(.) just like ↑this bloody room ↑here
169. Int: Just like this ↑room(.) yeah(.) *oh gosh*
170. Richard: Yeah (3) and like me(.) me daughter comes round now
171. and again

Though it is conveyed through Richard's speech here that he is lonely, he is not trying to elicit sympathy. In fact, when I showed this reaction Richard then goes on to talk about successfully living on his own, having a daughter and having a job. Clearly Richard wants to communicate that no-one needs to feel sorry for him, even though I have suggested this in my tone with the words ‘oh’ and ‘gosh’. Richard here positions himself as resilient and responsible, capable of looking after himself.

Richard uses several discursive devices to support his account. He uses story telling, in order to draw me into his experience and help me see his point of view. Richard also uses humour, and sometimes expletives, to emphasise his point and the importance of what he is saying. For example, when comparing the assessment to feeling like he is being recruited to join the army, Richard uses the description:

881. Richard: ↑We ↑need ↑you! You ↓know(.) <u>feck it you’re not getting</u>
882. <u>↑me though</u>!

This is an example of Richard protesting what other people expect of him - a demonstration of Richard’s determination to not conform to expectations, and indeed to live his own life.

In Richard’s speech, there is also lots of use of the word ‘right’ with an upward inflection, at the end of Richard’s sentences. This could be viewed as Richard using that point in the story to ask ‘are you listening to me?’ or ‘do you understand me?’, which suggests that he feels it is important to be heard and to be understood. It may also reflect his experiences of not feeling heard or understood by other people at times, and the frustration that this has caused him.

During a discussion with Marvin, we were talking at one point about what had led Marvin to first access the service in which he taken the cognitive assessment. His mother has described prior to this that things were difficult at home and that she felt sorry for Marvin, spending time alone.

23. Marvin: [I wouldn’t put it like that].
24. I’m on my own then ↑innit
25. Int: Ok, so you prefer it then being that [way?]
26. Marvin: [↓Yeah]

By interrupting his mother, and by disagreeing – “I wouldn’t put it like that”, Marvin is communicating several things. Firstly, by interrupting his mother he is communicating supervening on her account, in that Marvin doesn’t want her to continue describing him in this way. He does not think that people should feel sad, or sorry, for him. Rather, Marvin is happy with his choices and prefers some time by himself. Secondly, by interrupting, Marvin is demanding that his mother and I listen to him. This may be perhaps linked to experiences that Marvin has of people not listening to him, and by talking over Gloria, Marvin’s speech has the function of telling us ‘listen to me’.

In a similar example, Zara also shares frustration at others assuming that she is vulnerable, or is unable to cope with the truth. Zara tells me about a certain way that professionals explained to her about the test:

Zara: They kind of like said that ‘there’s no right or wrong answer’ so
I’m just thinking in my head like (.) I don’t even know what I’m
doing because if it’s an [assessment]
Int: [↓mm]
Zara: …then I’m meant to like supposed to see what I’m doing wrong
or right myself

Zara goes on to say:

Zara: It was just ↓difficult (.) it’s just ↓like (.) how can there not be a
right or wrong [↑answer?]

Zara expresses that the explanation given to her doesn’t make sense, and that she wants the truth, not to be shielded from it. It implies that Zara has been told this to spare her feelings. This, however, appears to have frustrated Zara. She wishes to be taken seriously and given autonomy, through the words then “I’m meant to like supposed to see what I’m doing wrong or right myself” – these words imply that Zara wants to understand the function of the test and to make the choice within her own ability and capacity about whether she is doing something right or wrong. Her question at the end: “how can there not be a right or wrong [↑answer?]” echoes this frustration. For Zara, it seems that the assessment was a meaningless experience.

Richard frames something similarly when getting the results of his assessment; after being told he did well, he asks his assessor:

781. Richard: And then I turned round then and said right(.) how did
782. I ↑really ↓do

The emphasis on ‘how’ is Richard communicating that he wants an honest interaction, and the emphasis on ‘really’ suggests that he viewed his assessor as lying to him beforehand, or trying to spare his feelings. Richard clearly seems to have no interest in having his feelings spared, or in having people treat him with pity or unnecessary kindness.

3.2.4. Having to do Something Versus Choosing to do it

When recalling the assessment, participants linked this to memories of school. It became apparent through participants’ speech, that they had been expected to follow instructions and do what people had asked of them, not only in the assessment, but at various times in their lives. Richard describes to me about a previous time he had seen the blocks (part of the test kit) from the cognitive assessment before:

867. Richard: And he used to ↑take you out the ↓classroom and ↑take you in
868. a little ↓room
869. Int: Mm
870. Richard: And you’d have to do these ↓blocks
*871. Int: Ok(.) right(.) *↑mm**
872. Richard: ↑Right
873. Int: And was that to help you at ↑school? Or(.) what was that ↑for?
874. Richard: It was just to(.) ↓um(.) to educate you

Richard suggests here that he was in need of educating, and that he was positioned as a pupil or school child in the assessment relationship. It does not sound like Richard felt he had a choice in what had happened to him – it was something normal that he had to accept. It is as though the choice had been made for him. This is exemplified in Richard’s use of the words ‘have to’ – there was no alternative choice.

Later in our discussion, Richard goes on to tell me about a time during the cognitive assessment where a choice was seemingly made for him by the assessors, but in response Richard makes a clear choice, positioning himself as independent and capable. Richard tells me that he wanted to finish the block design task, even though the time had run out.

982. Richard: Right? And they're looking at me like that right and said ↑don't
983. ↑worry about it they said(.) I said ↑nah(.) I wanted to

Richard goes on to say:

990. Richard: Yeah I was ↑determined(.) I was ↑determined to ↑do ↓it
991. Int: Yeahh(.) you ↑wanted to get it done(.) Did they ↑let you(.) or did
992. you have to ↓stop?
993. Richard: I didn't ↑give(.) I didn't give them ↓no ↑option

Here, Richard positions himself as being autonomous in making the decision to carry on the task – he lays claim the the power in the situation. and his decision, about his performance in the assessment. By saying that he 'didn't give them no option' Richard is taking control over his own decisions in the assessment, positioning himself as knowledgeable and with power in the interaction.

Conversely, all of the participants, when describing the process of doing the assessment, use the words 'had to' or 'have to' when recounting their experience. Early on in Zara's interview, she begins to use these words when recalling the assessment.

13. Zara: I remember there was this (.) ↑like (.) book where you
14. had to like see animals and then you just had to build stuff

The use of these words 'had to' implies that this was something imperative, and that there was no choice. Zara's choice of language here suggests that taking part in the test was an obligation. Later during our discussions, Zara also describes that '*they'* (i.e. her assessors at the learning disability service) '*did an assessment'* (line 170), implying that this was something that was done to, Zara rather than with her.

In interview with Zara, I wondered aloud whether Zara had felt like she had had to do the test, regardless of what she thought, or that maybe she felt neutrally towards it – or that because the system had told her she had to do it, that she would not question or fight this. Zara tells me about a different reason that she chose to stay and complete the assessment:

*Zara: I (.) *I dunno* I just did it (.) I had to finish it (.) It just took*
long (.) I had to finish first ↑before I could ↑go.
*Int: *Mm* (.) Did you feel like you couldn't ↑leave?*
Zara: I (.) er (.) yeah (.) ↑sort of ↑like (.) in a ↑way (.) I knew (.) I
thought I could leave (2) But I knew (.) for (.) like my
↑parents wanted me to stay to get it done

Zara's response to my question positions herself as having multiple options available to her. Zara is describing making a conscious, and informed, choice. She has decided to do the test because it is something that she thinks her parents would like and knew they would be disappointed if she doesn't continue. Zara seems aware that she could have not done the assessment. Zara positions herself here as a daughter, aligning her own views with those of her family. Therefore, through doing this, Zara positions her family's views as carrying the most weight and power, rather than the service or individuals assessing her. Zara uses the guidance of her family when making the decision to continue assessment. However, while Zara seems to know that she can leave at any time, there are forces bearing down on her – her parents and the ID service. So although Zara 'knows' she can leave, she appears not to feel able to.

4. DISCUSSION

4.1. Overview

This chapter will firstly summarise the main findings of this study, discussing these further and situating them within the context of current literature. Following this, I provide a reflective review of the study, and finally highlight potential future research and clinical implications.

4.2. Research Question 1 – What are the Experiences of Cognitive Assessment of Adults with ID?

To answer this research question, IPA was utilised to assess the experiences captured by the participants in the interviews. Participants described a variety of experiences, with each of these being captured under a number of themes. Below I evaluate some of these themes in more detail.

4.2.1. Disconnected Services

A common theme amongst participants was the experience of having to repeat their story across various services. One aspect of this was related to seeing multiple professionals across their experience of the cognitive assessment, as well in other services in the lead up to the assessment. This had the effect of making it difficult to build rapport and trust between participants and the professionals involved in their care. The ability to build this rapport is essential in helping to facilitate the assessment, particularly as people rely on trust being established in order to then follow advice from professionals (Robinson & Thomson, 2001).

The number of different professionals that participants had contact with appeared to have different types of effects upon participants. One of these is that, to participants, professionals seemed to become indistinct, with participants referring to their assessors and others as ‘they’. This can have the effect of people with ID feeling disenfranchised, leading to poorer engagement, and to people needing additional assessment or treatment (Cambridge & McCarthy, 2001). It may also lead to people disengaging from services, particularly if barriers such as high staff turnover are present.

This raises questions about what professionals can do to make the experience of assessment more personalised. One potential option could be for psychologists to ensure that their name and picture, and a description of what a psychologist is, to be sent out with the appointment letter for the assessment. However, as shown by Davidson et al. (2013), participants with ID sometimes feel excluded from decisions made about them if communication is mainly done via letter. Therefore, another possible difference could be some handover occurring between professionals, e.g. with the referrer possibly attending the first appointment with the service user, to ensure a smoother and less anxiety provoking transition.

Participants all expressed recognition of the cognitive assessment that they had undertaken, particularly linking this experience to having done formal tests previously in their lives. Some participants appeared to feel neutrally about this, almost as if this was just something normal that they had to go through. Others, however, felt aggrieved by this process, and about having to repeat themselves in terms of answering certain questions or doing aspects of the assessment over again. Due to the number of health appointments that participants had to attend throughout their lifetimes, the cognitive assessment was placed by participants among the medical assessments.

It became apparent throughout our conversations that every participant was describing memories of, what they perceived to be, a previous formal cognitive assessment in the past for suspected ID. It was striking that many of these memories were in relation to education settings. It seems perplexing, not only that participants' networks had previously suspected ID and this had not translated to diagnosis or to the perceived required support that participants felt they needed, but also that participants appeared to feel mainly neutral towards the experience of multiple assessment.

One explanation for this may be the perception from people with ID that they do not have control over the circumstances surrounding their assessment. This view, a lack of control leading to the possible development of learned helplessness, was supported by Bukowski, Asanowicz, Marzcova and Lupianez (2014). However, these findings may be more in line with previous authors' explanations of the social treatment of people with ID. Rapley (2004), for example, highlights how the option of choice is often not given to people with ID, and that staff and parents often make decisions for people with ID. This may be the case for the participants in this study as well, and may explain why they feel mainly neutrally about repetitive assessments – maybe it has not been their choice in the first place to conduct these, and that it was never seen as an alternative to object.

4.2.2. Positive Experiences of Assessment

The few positive experiences of assessment reported by participants, were in relation to two distinct aspects; the experience of the assessor personally, and a feeling of hope. Though the overall experience of assessment was not viewed as positive, the human qualities of the assessor appeared to help participants feel listened to and cared for. Specific personable qualities about the assessor of most importance to participants included being nice, empathetic, and listening. Things such as reassuring participants when they needed a break, and encouraging people if they didn't know the answer, seemed extremely important to participants.

These findings echo previous research surrounding the relationship of the assessor, such as those presented by Owen (2012), in that participants responded well to particular reassuring styles of the assessor, and that it appeared to help participants to know their assessor prior to the test. Similarly, this mirrors findings from Davidson et al. (2013), who used found that a positive experience of the assessor is associated with feeling comfortable and trusting that the clinician was acting in their best interests. This theme of trust is important for participants. It can make the difference between having faith in a service, versus feeling pessimistic about outcomes.

The feelings of hope that participants were left with were mainly in relation to the practical elements that a diagnosis of ID might bring, e.g. what input services could offer them. While this appears to reflect the gatekeeping function that ID services can be perceived as having (Hare, 2016), it also appeared, to participants, to represent the potential for change and additional, tailored support. This is encouraging to hear, as it fits with the recommended legislation regarding care for people with ID, which should be individualised to fit with a person's unique needs (Department of Health, 2009).

4.2.3. Views Surrounding Test Performance and Outcomes

This theme covered participants' motivations to do well in the assessment, as well as the feelings of shame that came with getting things wrong.
Participants expressed wanting to do their best and get answers right. This would cause distress for participants when they felt this wasn't possible.

Participants felt it was important to try their best, work hard and to know whether they had gotten their answers right. This reflects attitudes that people may have towards the word 'test' and societal views towards trying your best. The shame surrounding getting answers wrong may reflect feelings of fear and embarrassment, possibly towards being seen as stupid, as suggested by Puente and Ardila (2013), but may also have been linked to anxiety surrounding the assessment. as Gass and Curiel (2011) suggest that test anxiety may lead to intrusive thoughts about one's own performance.

It also appeared that participants did not have clear hopes or expectations about the outcome of the assessment, or about why some of them were having it. There was confusion about the purpose of the assessment amongst participants, even though they knew it might contribute to a diagnosis of an ID. Even then, participants did not know why getting this diagnosis was important. Participants would defer to parents' wants and wishes when discussing the motivations for the assessment. Participants did not express any specific knowledge about what may happen next after the assessment, other than referencing some support that they may then be given – but didn't know what this support would involve. These findings are consistent with the findings of Davidson et al. (2013), in that participants expressed confusion about the purpose of assessment. Similarities also arose between the current study and Davidson et al. (2013) in that participants didn't know how the results of the assessment would be used. Interestingly, in Davidson's study, interviewees reported feeling excluded about decisions being made about them after the assessment had happened. This was not a theme that explicitly came up for participants in this study.

4.3. Research Question 2 – What are the Subject Positions Afforded to People with ID in their Talk about Cognitive Assessment?

4.3.1. The System Holds the Power

Participants' speech revealed the way that the power held by the assessing clinicians and related systems, influenced them. Participants were under pressure to come to their appointment for the cognitive assessment. The assessment was situated in relation to medical appointments, reflecting the 'active doctor' versus 'passive patient' discourse. The dominance of the power of the medical model became evident in how power differentials also arose during our conversations, as participants appeared to view me within the system of power that they were discussing. Participants positioned me as part of this powerful system, and as part of this they viewed me as having dominance and influence. Merriman and Beail (2009) found that participants were reluctant to criticise the services they were in, for fear that they may be withdrawn, and this is an important consideration to bear in mind while interpreting these results. Therefore, it may have been more difficult for participants to express honest and negative views about the service to me.

4.3.2. Reliance on Others

This theme revealed the trust in, and dependence upon, others, that participants spoke about within the context of cognitive assessment. The outcome of the assessment was situated as having vital importance for a positive outcome for participants. The word 'help' is used frequently by participants to describe expectations and hopes, which positions the system as powerful and with the potential to make influential changes within people's lives. Participants contrasted what it would be like to not have this help, and notions of abandonment and vulnerability arose. When considered in the context of the previous theme (‘the system holds the power’) it is clear that participants are reliant upon others within the system, as they themselves have been positioned without power or influence over their own outcomes. This theme echoes previous findings of Rapley (2004); that people with ID can be denied access to choices due to the power residing in individuals and systems around them. This is often from a place of wanting to protect people with ID, and this is linked with society’s views of people with ID as childlike and vulnerable (Rapley, 2004).

4.3.3. I am Resilient – Don’t Feel Sorry for me

This theme drew attention to participants exercising their power within their experiences about cognitive assessment, positioning themselves as capable and resilient. Several examples pointed towards participants’ resilience, such as Zara’s questioning and frustration at the technique of the assessor in not giving her a right or wrong answer (lines 585-589), and Marvin’s challenging of his mother not to feel sorry for him (lines 23-26). These self-positionings are examples of participants pushing against the ‘pity’ that people with ID are often labelled with, i.e. society’s view that these are people we should feel sorry for (Ryan & Thomas, 1987). Though participants appear to have had experiences of not being listened to, in our interviews they state their specific wishes and hopes for the assessment, and how they are able to convey these despite a system which potentially does not always create space for this speech. Participants have sometimes had to do this in forceful ways. Discursive devices such as repetition and storytelling are used to add reliability to their position here, and using confirmatory words/phrases to ensure that I understood and was following their argument. These techniques position participants as competent, which Jingree and Finlay (2013) observed is a strategy used by people with ID to add reliability and credibility to their stories.

This resilience discourse may serve the function of helping to reject the labelling and expectations placed upon participants, and resist positions of reduced power that they are placed into (Goodley and Rapley, 2001).

4.3.4. Having to do Something Versus Choosing to do it

Here, participants deal in their experience of to having to do something versus having a choice about it. Participants make reference to things ‘happening to them’, and the word ‘had’ is used to express a position of having to do something that was either required or expected of them in the assessment. However, there are also times where participants talk about wanting to do things differently, or giving justifications for why they did things, which adds another layer, of choice, to their descriptions.

Though this study did not specifically explore whose choice it was for participants to carry out the cognitive assessment, this would have been interesting information to ascertain further, possibly even substituting with views from parents or carers. Though participants were asked about this, many said that they either did not know or that the suggestion had come from someone else. Having choice over the type of care and treatment for people with ID is presented as a right within current law (Department of Health, 2009). Therefore, this tension between participants feeling that they have choice, as well as sometimes being denied choices, surrounding assessment, carries important significance for clinicians’ considerations of cognitive assessment for people with ID.

4.4. Limitations of the Study

The results of this study should be viewed in light of the limitations surrounding the research.

Firstly, the participants who I interviewed were all currently patients under various ID services throughout London, and had all received a recent diagnosis of an ID. Overall, the experience of assessment was not experienced as neutral – in fact, certain aspects of the experience seemed to evoke confusion, such as questions surrounding the purpose and function of the assessment. Other elements, such as a lack of clear communication from services, and little continuity between which clinicians people saw, appeared to frustrate and disappoint participants, which may have contributed to negative views about the assessment process. While these results have highlighted problematic experiences, did not explicitly offer negative experiences, and were instead quick to reference the ‘good’ aspects of their care – such as personal qualities of clinicians. There may be a number of reasons for participants not feeling they could easily express dissatisfaction or poor care, which are discussed below.

It is important to bear in mind that the participants all had connections to the teams which were supporting them. This will have made it more difficult to speak openly and honestly about negative opinions they may have had. Participants may have feared that by expressing dissatisfaction or frustration, that the potential care and support may have been taken away from them. The inherent power held by the ID services in terms of helping the participants to access certain vital resources, such as social workers, advice about benefits and finance etc., might have played a role in influencing some of the participants’ answers. Means of expressing their subjugated positions were not available to them.

It is also possible that the subjective experience of the assessment itself influenced which participants wanted to take part in the study. For example, it may be the case that those who declined to take part in the study had a different or distressing experience of the neuropsychological assessment and did not wish to talk about, or think about, it again. The interview itself may have been viewed as an implicit but material extension of a participants’ service provision, so those who have a poor experience of services may have felt more disinclined to take part. As the participants who declined to take part were not asked about their reasoning for this, it is difficult to establish whether this self-selection bias affected the current study.

When considering limitations, it is also important to consider the small number of participants who took part in the interviews – four in total. There are advantages to a small sample size from a methodological point of view, for example it can allow for the researcher to more easily reach saturation in qualitative research (Vasileiou, Barnett, Thorpe, & Young, 2018). However, there are also difficulties brought about by it, for example, the small sample size makes it more difficult to extend findings beyond the study participants. Additionally, the sample who took part could not be described as homogenous, particularly as participants were of different ages, genders and ethnicities. While there are some advantages of having a larger sample, the small number of participants interviewed for this research did allow for in-depth individualistic analysis.

In reflecting further upon the sample used to obtain the research data, it is worth evaluating the impact that recruiting from an NHS sample may have had upon the final dataset. As all participants were recruited from NHS services, they may have had quite a different experience to, for example, participants who may have had the same assessment privately. Similarly, if participants had been successfully recruited via non-NHS routes (which was attempted but unsuccessful), this might have led participants to feel more open about giving negative feedback about their assessment experiences in services they were currently under. As it was only an NHS recruited sample, this may have skewed the results in a certain direction, though we cannot know how the results might have been different had other recruitment strategies been successful.

Lastly, in terms of the research design chosen, the data gathering was conducted through verbal conversations with individuals. This limited the sample of potential participants to those who could communicate their needs and views verbally, thus inevitably excluding a significant proportion of adults recently diagnosed with ID. In order to include a larger, and more representative, sample, an alternative method of interviewing would need to be used. For example, in future studies this could involve using alternative formats of communication, such as picture communication systems, or with the addition of analysing video footage in order to incorporate non-verbal communication.

4.5. Methodological Considerations – A Reflective Review

This section provides a critical review of methodological issues. I have followed specific guidelines for the evaluation of qualitative research as outlined by Yardley (2000). I will focus on each of these in turn:

- Sensitivity to context
- Commitment to rigour

- Transparency and coherence
- Impact and importance

4.5.1. Sensitivity to Context

In order to remain sensitive to the context of this research, I began the research process by engaging with the related literature in this particular area. This helped me to understand the existing views towards cognitive assessment from different client groups, and to spot potential gaps in the existing literature. This aided me in formulating research questions which were unique and attempted to address the topic in a distinctive way. My literature search also helped me understand more closely the relevant issues surrounding discourse and power that emerge throughout ID research, which helped me to examine my data with sensitivity towards these issues.

So that I could remain sensitive to the context of my chosen methodologies, I ensured that my interviews remained semi-structured. This had the advantage of being able to guide the conversation towards relevant topics, but also allowing participants to express their views and related themes in a natural, free-flowing way. This allowed the interview to follow in an exploratory conversational manner, which not only had the effect of helping participants to relax but allowed for more freedom and depth questioning of related themes.

Lastly, so that I could keep my results as relevant as possible, I followed guidance by Elliott, Fischer, and Rennie (1999) and grounded my findings in examples. I did this by using exact quotes from participants to help to illustrate particular themes and patterns.

4.5.2. Commitment and Rigour

I adhered to commitment and rigour throughout this research from the beginning. I did this initially by reading thoroughly about the research methods I would be using and by making a plan for how to approach my research.

I have shown commitment by taking a personal approach to the research, in terms of ensuring that I met with potential services and participants prior to them deciding to assist or take part in the research. I have also followed research guidelines and recommendations for conducting interviews with adults with ID, so through this process I attended to various recommendations. For example, I ensured to speak with participants prior to them conducting the interview to allow for people to make a fully informed decision about whether or not to take part. Furthermore, I thought carefully about issues in relation to capacity, and ensured that only people who had fully capacity to decide and consent to taking part were included within the research sample. Participants were also given a choice of attending the interview with a parent or carer if that helped them to feel more comfortable and relaxed. Lastly, I attempted to make my research materials as user friendly as I could, by providing easy-read information and consent sheets. I provided parents/carers with additional, more detailed, documents in case they needed to support the participant about making an informed decision, and to let them know about how they could make a complaint if they wanted.

I have also attended to rigour through my research in a number of ways. For example, I kept notes on my thoughts and reflections after each interview so that I could fully capture the process of how various themes emerged. I have also taken care to obtain credibility checks of my analysis and emerging themes. This has been through asking a qualified psychologist to share their thoughts and opinions about the possible emergent themes early in the research process, so that I could that the developing topics fitted with the style and design of both IPA and DA.

4.5.3. Transparency and Coherence

With regard to Yardley's (2000) recommendations regarding transparency and coherence, I have taken a number of steps to adhere to these.

In terms of transparency, I have written in detail about my research process and have provided evidence and reasoning for particular decisions that I made. I have provided example copies of the materials and forms utilised in this process by attaching copies of these in the appendices.

I have also taken steps to situate the sample of participants, for example by outlining basic details about demographic information and the time since they completed the assessment. This latter information was vital to note, as this research relied on people’s accounts of their recent experience. It would have been difficult if people had had the assessment either a significant number of months/years before the research interviews, or if they could not remember anything about the assessment.

In terms of situating my views, I have outlined my epistemological position and my reasoning for choosing a critical realist approach to this research. I felt that this fitted best with the research aims and questions, and with the analytic procedures that followed. When approaching this research, I was acutely aware of my own views about families’ experiences of ID services and good practice. I aimed to be transparent about this in my research, by acknowledging that I acknowledged that my views surrounding ID and assessment were largely driven by my own personal experience of having a family member with ID. This had contributed to the formation of my own views about what constitutes good versus poor care from services. I had witnessed examples of people with ID being treated as though they were incapable of making choices and of things being ‘done to’ rather than ‘for or with’ people with ID. Therefore, I was sensitive to particular discourses surrounding choice and power, and my own assumptions and experiences impacted upon the way that the themes within the analysis emerged. I have also experienced, through my work in ID and mental health services, the conflicted position that service users and professionals find themselves in with regard to diagnosis – the benefits and access to services that come with this, but also barriers and stigma. In this sense, I was attuned to the particular ways that people described their feelings about diagnosis, but was aware of my own opinions in this area, which I tried to be aware of during the analysis process in order to be as impartial as possible.

4.5.4. Impact and Importance

This research has the potential to have an impact upon services and care for people with ID who may receive a cognitive assessment. For example, the findings may help to inform psychologists about the potential frustrations that their clients may have experienced in cognitive assessments, or of the stress and confusion surrounding seeing many different professionals. It may support clinicians to explain boundaries and expectations about who a client will be seeing, in what capacity, and how long for. These findings have also supported previous research, in that they tell a story of how people with ID notice and address power differentials within our conversations. This is important for clinical practice to help psychologists think about ways to help share that power with clients undergoing cognitive assessment. This may be in the form of, for example, giving people frequent and varied opportunities to give feedback about the care they are receiving, and about what they would like services to be doing differently.

This study's findings will be disseminated back to the services whose service users took part in the interviews. This will be via presentations and discussions within team meetings remotely due to the current circumstances surrounding the recent Covid-19 pandemic. Other forms of dissemination include publication of the findings in a relevant journal, such as the British Journal for Learning Disabilities, or the Journal of Policy and Practice in Intellectual Disabilities. There may also be scope for the findings to be presented at conferences for wider discussion and debate.

In addition, I have created leaflets which summarises the research and the outcomes of the study. I have created a detailed version for clinicians and parents/carers (see Appendix O) and an easy-read version for service users (see Appendix P). These will be disseminated to the services which took part in the research.

4.6. Reflexivity

When I first began this research process, and throughout my literature review, and the gathering and analysis of data, I was acutely aware of my own views about cognitive assessment regarding people with ID. These views had come partly from working in ID services and conducting the assessments, but also from having a close family member who has significant cognitive difficulties. My views from these two experiences were somewhat conflicting. From personal experiences, my close family member had experienced stigma, lack of choice, and an overall loss of confidence after having an assessment for ID and had found the label challenging throughout his life. I therefore, early in my training, approached the idea of cognitive assessment for people with ID with scepticism and care, even initially resisting conducting the assessments myself.

Inevitably, however, this was something that I had to do within my clinical training. I found it interesting to observe a very different response to the assessment process from the clients I worked with. Many described finding it liberating to finally get an assessment of this kind, and reported positive experiences of their assessors and of the ID service as a whole. Through discussion with people after they had had assessments, clients did not seem to share the experience of my family of feeling that they were under scrutiny and being ‘medicalised’ by going for an assessment. I therefore view cognitive assessment as a double-edged sword – having potential to help people, and open doors to services and support, but also having the potential to stigmatise and induce shame. In holding these two opposing viewpoints, I approached this research with interest and curiosity as to what I would find. While this made it harder to narrow down my research question into something specific, this led me to choose a very open-ended research question, with the potential to uncover both positive and negative experiences.

I was aware that my own characteristics and experiences will have shaped not only how I have approached and conducted this research, but also how certain services and potential participants will have responded to me.

As a white clinician, I am aware of the perceived, and actual, positions of power that the colour of my skin has afforded me. The majority of the psychologists I have worked with have been white, as will, likely, the assessing psychologists with whom my participants met. I wondered about whether my participants saw me in a similar position of power as a white clinician, and whether this may have impacted either upon their decisions to take part, or upon the particular words and discussions that arose throughout the interview. Two of my participants were white, one was Asian, and one was black. I met the majority of my participants' parents/carers, either during, before or after the interviews. I noticed in particular that both my black and Asian participants' parents thanked me for my time and services after the interview, which perplexed me and made me feel uncomfortable, and I rushed to thank them back graciously, telling them that it was indeed their time they were giving me. This did not happen with white parents/carers. This highlighted to me the inherent power imbalance which still exists starkly between white clinicians and their BAME clients, even in seemingly more 'neutral' spaces.

I have found that a larger proportion of clients using ID services are male (for various reasons, which I will not elaborate upon here). This was reflected in the demographics of my final sample. I was unsure initially if being female, and older than most of my participants, what impact that would have had upon the interviews. I might have shared many of the outward characteristics of the psychologists who had conducted the assessments with participants.

Throughout the interviews, it was only afterward when reflecting upon the conversations, that I noticed any particular impact that gender or age had had on the discussions. For example, the only time I had felt slightly uncomfortable with a participants' answers had been at one point during an interview with a male participant, where he described an 'embarrassing medical procedure' prior to undertaking his cognitive assessment. I had wanted to end this line of talk, and had to do this by interrupting him, which caused a rupture in our conversation. Questioning my own experience of this afterwards, I felt that I would not have reacted in this way if I had been talking to a younger, female participant.

I experienced that I felt protective towards many of my clients, and through that I noticed that at times I myself perceived them as being, or having the potential to be, vulnerable. Undoubtedly, this will have had an impact upon the way that I undertook my analysis. I was, however, aware of this effect upon myself, and was careful to keep notes in my reflective journal of particular clients, or parts within interviews, that elicited this feeling.

4.6.1. Reflections Upon Being Part of the System

It was apparent to me that I likely would have, understandably, been perceived as being part of the system that I was asking participants about. Throughout this process, I had a dual role and identity of being both a trainee psychologist and a researcher. As I had been on clinical placement at one service I was conducting interviews in, and had a professional relationship with other staff members at that service, I could not consider myself as neutral in the assessment process, and neither would participants have perceived me as such. This is an important reflection, especially when holding in mind the discourses surrounding 'the system holding the power'. It is likely that participants will have positioned me as being part of the system I was asking them about, and therefore they perceived me as having dominance and influence. This may have made it more difficult for participants to express negative opinions and experiences about their assessment. Another important factor is that participants were still current service users of the ID teams. To express a negative view or dissatisfaction might have caused anxiety about the possibility of services being withdrawn, which will have skewed the answers that participants gave in their interviews.

People's feelings and choice of words within my interviews were also likely linked with their experience of the ID service as a whole. As discussed above, it is possible that participants who chose to take part had had a better experience overall of the ID service. This again could be linked to not wanting to give negative feedback about their experience for fear of a service being withdrawn or could be to do with not wanting to relive memories of a difficult, or upsetting, assessment experience. As the results suggested, the experience is not emotionally neutral for participants, so it is not out of the question that some people would not wish to think about the cognitive assessment again. As participants who did not want to take part did not give reasons for this, and were not asked, it is difficult to know whether this was the case.

4.7. Clinical Implications and Recommendations

The findings of this research have a number of important clinical implications for practitioners conducting cognitive assessments for people with a suspected ID.

4.7.1. Improving Communication and Personalisation of Services

The results highlighted that the participants had had at least one previous assessment prior to undertaking their cognitive tests as an adult. Participants' talk reflected the impersonal manner these interactions can take. A potential solution to this could be to provide pictures of, and names of, the professionals who will be working with someone, with a short outline of what they do. Meeting the person one or more times before the assessment might also help to build rapport and manage anxiety.

Participants discussed experiencing poor communication from services. During the rapport building sessions, it may be useful to explore previous experiences of services, both good and bad, and to outline clear expectations about communication methods and frequency between the individual/family and the service. This could be in addition to written information about this, and with information about how to contact a local patient advice and liaison service (PALS) if a service-user is unhappy with the care they are receiving.

It emerged through the analysis that people's experiences of the assessor were significant in influencing how they felt overall about the assessment. Empathy showed by clinicians, not only before and after, but during the assessment, helped people to feel calm. Giving reassurance or saying things such as 'it's ok' or 'don't worry' or 'take your time' have a big, and positive, impact on the experience. This has implications for clinicians conducting assessments on some widely used instruments. There are only a set number of specific phrases that clinicians are permitted to say during cognitive assessment. However, these results highlight that clinicians may want to use their own discretion in what they say so that they can help clients to feel at ease and perform to the best of their abilities.

4.7.2. Improving Clarity Surrounding Consent and Expectations

This research has also highlighted strategies that clinicians can use in terms of minimising shame that clients may feel, and about setting clear expectations for communication. For example, calling the assessment ‘doing some work’, rather than being a ‘test’, as this helped participants to relax. It is important to bear in mind issues such as consent given by clients when undertaking cognitive assessments and attending to potential ethical issues and pressures that may be put upon clients to do an assessment. Using a systemic approach and an exploratory line of questioning may help address these issues, such as asking who wants the assessment to be done, what do they expect from it, and how does this fit for the individual with suspected ID.

This research has added to the body of research which draws awareness to the power of the professional model that psychologists have within their interactions. It may be something for psychologists to consider when working with disadvantaged groups – i.e. considering how useful the ‘doctor’ title can be to build rapport, versus what barriers it may put in place, when it comes to assessment.

4.7.3. Alternative Methods of Obtaining Consent

When considering how to widen the pool of potential participants who may be able to take part in this type of research in future, and also making services accessible and useful, using video recording may be a particularly useful tool. There are several reasons, and potential functions, of this.

Firstly, when giving participants information about research studies, video recordings could be used to ascertain and document about when someone gives their informed consent. In ID services this could be particularly useful for working with potential participants who are possibly nonverbal or cannot read or write. These would usually be exclusionary criteria (for example, being nonverbal was an exclusion criterion in this study) for research. Therefore, using video as a way to document informed consent could widen the range of people who could take part in research, and as a result, have a direct impact upon giving feedback about their care. Analysis of video recordings could also be an alternative way to investigate service users' opinions and experiences having a cognitive assessment.

As capacity can fluctuate depending on when this is assessed, video recording of informed consent or assent would need to be done at different timepoints within the research process – such as when going through the study information, as well as prior to conducting the actual procedure to gather date for the research.

Another potential could also be for participants to be given the study information in the form of watching a video. This could also be something that they take away with them, so that they can watch it multiple times if they need further time to process and decide whether to take part.

4.8. Future Research

There are a number of key avenues of research which would be useful to explore following the research project described here.

4.8.1. Re-Examining the Role Played by Cognitive Assessments

Due to the difficult experiences that participants reported in going through the cognitive assessment, the question is raised concerning what place cognitive assessments may have in ID services. There is no doubt that identifying people who have difficulties in, for example, their educational, developmental and social progress, can help them to access support services and can improve long term outcomes (O'Brien, 2001). However, it is not clear whether cognitive assessment needs to be part of this process, particularly due to some of the themes that have arisen in this research, such as shame, a lack of power, and some participants feeling they did not have a choice but to do the assessment. This therefore raises potential for some of the money and resources that focus on cognitive assessment to instead be put into improving interventions and the available resources for treatment.

The idea of stopping, or reducing, the use of cognitive assessments is, however, made more difficult by service constraints such as having a maximum capacity available for accepting new patients, and therefore needing some kind of assessment of need, so that services can still identify who would benefit most from the service. A significant barrier in this process, is that the definition of ID itself includes an element involving intelligence; the World Health Organisation definition takes into account IQ, social functioning, and age of onset (World Health Organisation, 2018). Until this definition changes, or is revised, it is difficult for services at ground level to change how they themselves assess eligibility for service users to access ID services. Therefore, a key component in services being able to rely less on cognitive assessment, surrounds the definition of ID being revised. This could be influenced in a number of ways. For example, bottom up research could be conducted involving focus groups of people who have got a diagnosis of ID, asking them what they think the definition of ID should entail and how it should be assessed for. Surveys of clinicians could also be conducted to ask about their experience of the most ethical and useful ways of diagnosing ID. Once the definition of ID is then influenced and revised to not have to include IQ, cognitive assessments can then be allowed to take a back seat in the assessment process.

4.8.2. Exploring Views of Parents, Carers and Professionals

Going forward from this study, it may be interesting to conduct a larger study involving parents/carers, and to address their views of the assessment process along with to the views of those people with a diagnosis of ID. This would allow for differences in perspectives to be highlighted and explored, and the reasons for these differences elaborated upon. It would be interesting to observe what, if any, similarities appeared across speech and interpretative repertoires, and to explore why this is the case.

A further area of research would be to explore professionals' ideas and beliefs, i.e. psychologists' views, of conducting cognitive assessment, particularly with clients with ID. This could highlight some of the benefits, pitfalls and challenges involved in assessment from a professional point of view. It may also be interesting to explore whether an assessor senses whether their client has had a positive or a negative experience of the assessment, and to explore what factors they think may have influenced this. These findings could then be used in comparison to the results of individuals with ID to help us understand the discrepancies in viewpoints between people involved in this process.

4.8.3. Expanding the Potential Research Sample

In addition to the above, a further research question that has not yet (to my knowledge) been explored, is regarding how the experience of cognitive assessment of ID would differ in individuals who had not then gone on to be given a diagnosis of ID. Due to the specific aims of my study, individuals who did not receive an ID diagnosis were deliberately excluded from the research sample. These results could possibly reveal whether being given a diagnosis seems to have an impact upon the subjective experience of having an assessment.

4.8.4. Emancipatory Research

To truly explore viewpoints of people with ID in a meaningful way, emancipatory or participation action research (PAR) has shown to help individuals feel meaningfully included, and in control, at multiple points during the research process (Kiernan, 1999). This could be an interesting and meaningful approach in designing future research by helping to ensure that the priorities of people who actually undergo such assessments are being fully addressed.

4.9. Conclusion

This research has centred around the subjective experience of cognitive assessment in adults with ID and the associating discourses and subject positions which emerge as part of this talk. The DA results have shown that various issues of power, choice and control have arisen, and are navigated by people with ID in accessing services. In addition, IPA has revealed that the subjective experience of assessment is often far from positive – themes such as unclear communication from services, having multiple different clinicians, and having unclear expectations about the assessment, have contributed to problematic experiences and frustration of participants throughout the assessment process.

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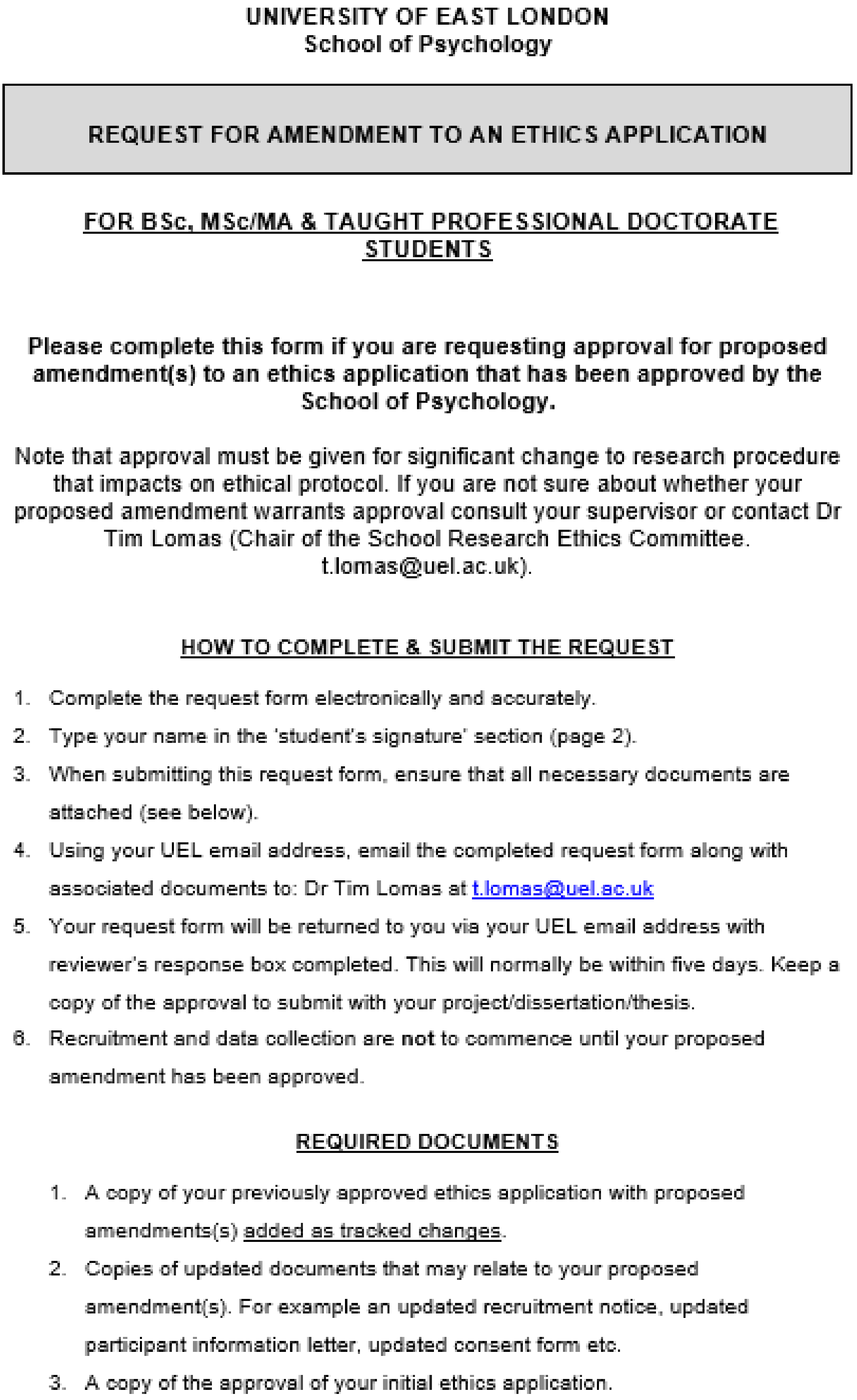
Appendix A – Title change confirmation



UNIVERSITY OF EAST LONDON
School of Psychology

REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION

FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS

Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Tim Lomas (Chair of the School Research Ethics Committee. t.lomas@uel.ac.uk).

HOW TO COMPLETE & SUBMIT THE REQUEST

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Tim Lomas at t.lomas@uel.ac.uk
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

REQUIRED DOCUMENTS

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.
3. A copy of the approval of your initial ethics application.

Name of applicant:	Genevieve Martin
Programme of study:	Doctorate in Clinical Psychology
Title of research:	The experience of neuropsychological assessment, views of clients with a learning disability
Name of supervisor:	Dr Matthew Jones Chesters

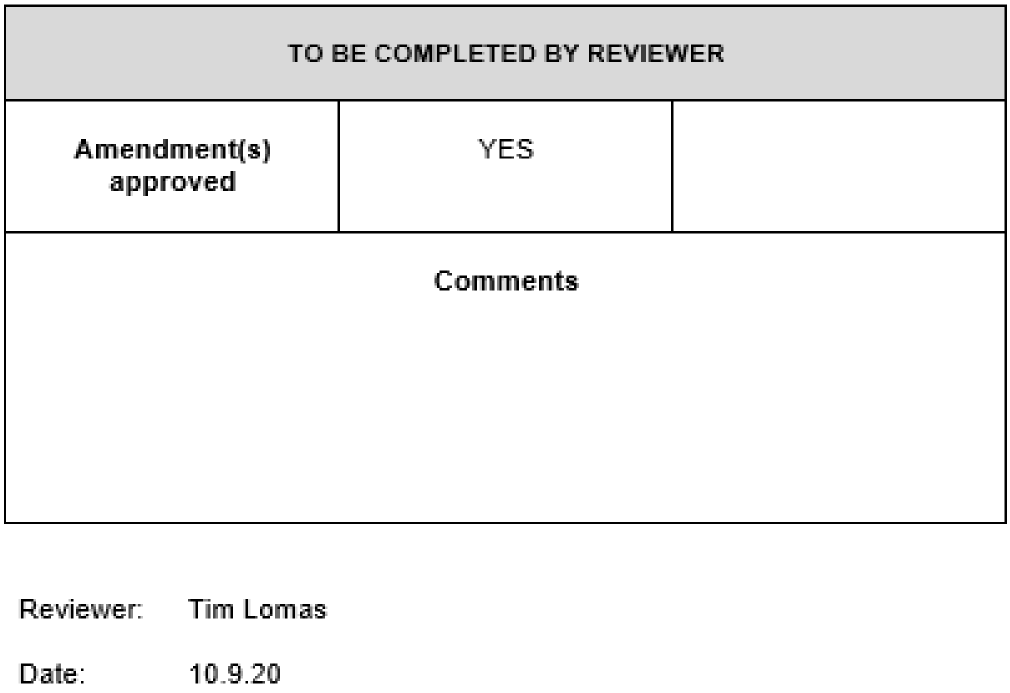
Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	**Rationale**
Title change To change to: Cognitive assessment: Perspectives from adults with intellectual disability	This new title would better reflect the design and research questions (these have not changed, and the title change does not affect the implementation or analysis of the research). Participant forms have not been amended, as they were in accessible format. Furthermore, as the only change is to the title this was not deemed necessary.

Please tick	**YES**	**NO**
Is your supervisor aware of your proposed amendment(s) and agree to them?	✓	

Student's signature (please type your name):
Genevieve Martin

Date:
10th September 2020



TO BE COMPLETED BY REVIEWER		
Amendment(s) approved	YES	
Comments		

Reviewer: Tim Lomas

Date: 10.9.20

Appendix B – Interview Schedule

The questions I asked participants were:

1. What would you like to say about the experience of having the assessment?

I chose to open with this question because it allows space for the participant to think about and reflect on their own experiences of the assessment. There might have been a specific element of it that felt important to them, and these conversations might have been shut down or sidelined by the following questions, which are more structured.

2. What was it like to have the test?

Similarly to the first question, this invites participants to talk about what it was like to have the assessment. It also allows space to talk about positive and negative aspects of the process.

3. What is your understanding of why you were assessed?

I was interested in what people were told in relation to why they were having the cognitive assessment. I wondered whether there was similarity in the experience of the explanations of the tests, and whether these explanations had made sense to, and were memorable to, people.

4. What was the experience of having the results given to you like?

This question was to explore the way that the outcome of the assessment was delivered and what that was like for people.

5. How useful did you feel the experience was?

I was curious as to whether people used the term 'ID' and whether they felt this term fitted for them. I also wanted to explore whether the assessment helped people learn anything about their learning needs or areas of strength/weakness, or whether its function was simple to lead to the ID diagnosis and potentially access to services.

6. Is there anything you would want to change about the assessment process?

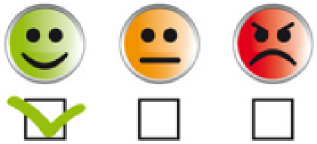
This question's main function is to explicitly ask about ways to improve care with the assessment process. It allows space to explore whether this is in relation to the test itself, or to the actions/manner of their assessor.

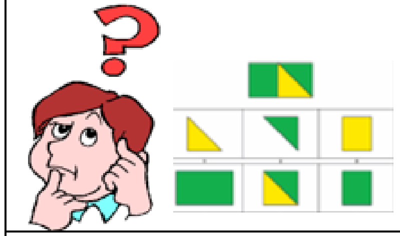
Appendix C – Participant information sheets (easy read)

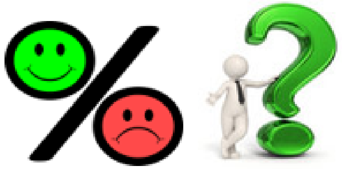
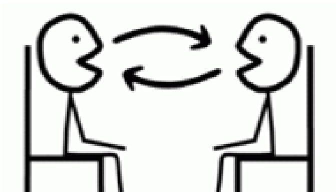
Experience of neuropsychological assessment: Clients with a LD
IRAS project ID: 252323
Participant Info Sheet v2 5/05/2019

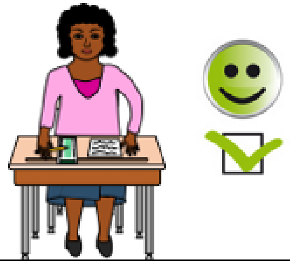
Research on Learning Disability Tests Information Sheet

	My name is Genny
	At university I am doing some research

	This letter is to give you some information about this research
	After reading this letter, you will be able to decide whether you would like to take part in the research
	I am interested in making people’s experience of learning disability services better.

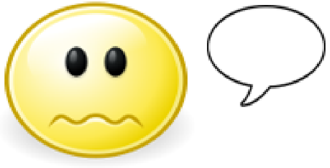
	One thing which a lot of people using learning disability services do is a special test with a psychologist
	You did one of these tests, where you had to answer some questions, do some puzzles, and look at some pictures
☑ ☒	These tests help us find out if someone has a learning disability

	My research involves finding out more about what it is like to have one of these tests
	Not much is known about how people feel about having these tests, and which parts are ok or not ok.
	So for my research, I am speaking to people who have had these tests.

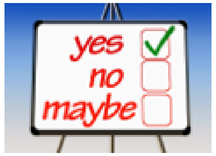
	I am asking people what it was like, and what things they would like to improve
	The hope is to make learning disability tests better, and for them to be nicer for people who have them
	If you would like to help with the research, I would set a date and time to meet with you

	We would meet once, for between 45 minutes and an hour
	When we meet, I would ask you some questions about what having the test was like
	If you need a break while we are talking that is ok

	All of your answers will be confidential, which means that only me and my university teachers will know what you have said to me
	When I am writing up the results of this research, I won't include any personal information from people who have spoken to me This means that no one who reads about the research will have any private information about you, like your name or address or your birthday.
	Talking to me won't change the people who are working with you or the care you are receiving

	When you talk to me it is ok to say whatever you like about the test
	If you change your mind about talking to me that is ok and nothing bad will happen
	If you feel sad or worried after talking to me, you can talk to ……………………………………………… (insert carer/parent name)

	You can ask me any questions you have about the research
😟 ✉	If you are unhappy with anything that happens during the research, you can email my supervisor, or ask someone to help you do this. His name is Dr Matthew Jones Chesters. His email address is m.h.jones-chesters@uel.ac.uk
😟 ☎	If you are unhappy about the research, you can also contact the Patient Advice Liaison Service. They are confidential and will be able to give you advice. Their number is (*insert number of local PALS)*

	If you would like to take part in this research please let me know
	Thanks for reading this letter about my research

Appendix D – Information sheets for parents/carers

Experience of neuropsychological assessment: Clients with a LD
IRAS project ID: 252323
Parent/Carer Info Sheet v2 06/05/19

PARENT/CARER INFORMATION SHEET

University of East London
Stratford Campus, Water Lane, London, E15 4LZ

NHS Research Ethics Committee

This research has been approved by an NHS Research Ethics Committee. If you have any queries regarding the conduct of the programme in which the adult you support is being asked to participate, please contact:

Health Research Authority, Skipton House, 80 London Road, London, SE1 6LH
Tel: 020 797 22567

The Principal Investigator(s)

Genevieve Martin, Third Year Trainee Clinical Psychologist
University of East London
Contact:
Supervised by:
Dr Matthew Jones Chesters, Consultant Neuropsychologist
Contact: m.h.jones-chesters@uel.ac.uk

Purpose of this Letter

The purpose of this letter is to provide you with information about the research study that the adult with learning disabilities you support might choose to take part in.

Project Title

Experience of neuropsychological assessment, views of clients with a learning disability

Project Description

This research aims to explore the views of adults with a diagnosis of a learning disability, of the experience of having a neuropsychological test to get this diagnosis. Its aim is to improve the experience of this assessment, and to find out from people which parts felt helpful and unhelpful, and to find out about what is most useful when receiving the learning disability diagnosis.

The results of this study will be fed back to learning disability teams to improve practice.

Participants who wish to take part in this study will be asked to meet with the lead researcher, Genevieve Martin, for one meeting of between 45 minutes and an hour. During this time, the researcher will conduct an interview, asking the person about their experience of being tested and being diagnosed.

Appendix E – Participant consent sheets (easy read)

Experience of neuropsychological assessment: Clients with a LD
IRAS project ID: 252323
Consent Sheet v2 06/05/2019

Research on Learning Disability Tests

Consent Sheet

Read each sentence and tick 'yes' or 'no'

	I have read the information sheet given to me by Genny about this research	Yes ☐	No ☐
	I have a copy of the information sheet to keep	Yes ☐	No ☐
	The research has been explained to me	Yes ☐	No ☐
	I have been able to ask questions about the research	Yes ☐	No ☐

	I understand what the research will involve	👍 Yes ☐	👎 No ☐
	I understand that my answers will be confidential	👍 Yes ☐	👎 No ☐
	I would like to take part in this research	👍 Yes ☐	👎 No ☐
	I know that I can change my mind at any time about taking part in the research and nothing bad will happen	👍 Yes ☐	👎 No ☐

It is helpful to let people's GP know if they are helping with this research

Would it be ok for Genny to let your GP know you are helping with this study?

Yes ☐ No ☐

Please write your name here:

....

And sign here:

....

Researcher's Name:

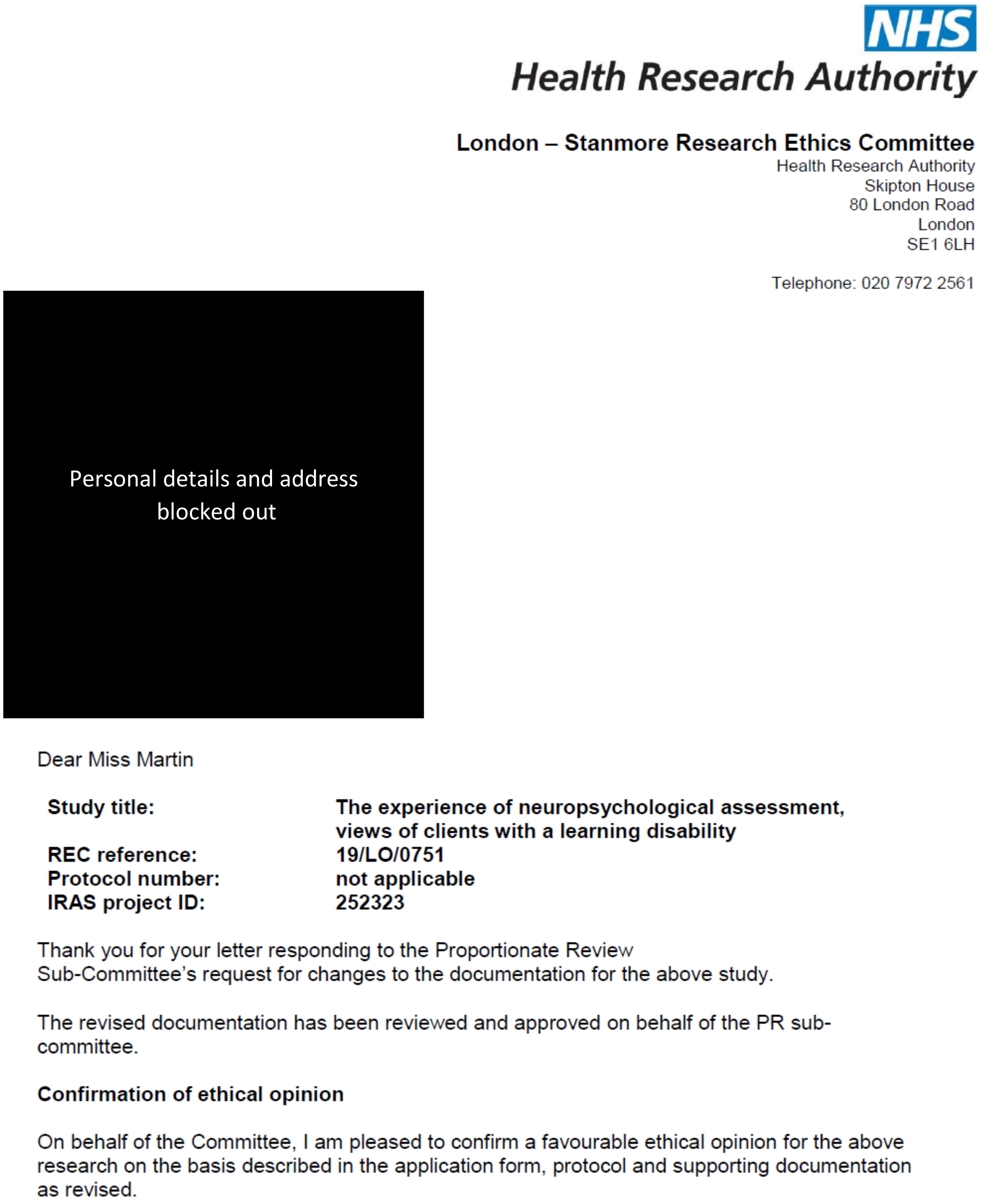
………………………………………………………………………

Researcher's Signature:

………………………………………………………………………

Date: ……………………………………………

Appendix F – NHS ethics approval



NHS
Health Research Authority

London – Stanmore Research Ethics Committee
Health Research Authority
Skipton House
80 London Road
London
SE1 6LH

Telephone: 020 7972 2561

Personal details and address
blocked out

Dear Miss Martin

Study title:	**The experience of neuropsychological assessment, views of clients with a learning disability**
REC reference:	**19/LO/0751**
Protocol number:	**not applicable**
IRAS project ID:	**252323**

Thank you for your letter responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

It is a condition of the REC favourable opinion that all clinical trials are registered on a publicly accessible database. For this purpose, clinical trials are defined as the first four project categories in IRAS project filter question 2. For clinical trials of investigational medicinal products (CTIMPs), other than adult phase I trials, registration is a legal requirement.

Registration should take place as early as possible and within six weeks of recruiting the first research participant at the latest. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/

As set out in the UK Policy Framework, research sponsors are responsible for making information about research publicly available before it starts e.g. by registering the research project on a publicly accessible register. Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improving-research/research-planning/transparency-responsibilities/

You should notify the REC of the registration details. We routinely audit applications for compliance with these conditions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Ethical review of research sites

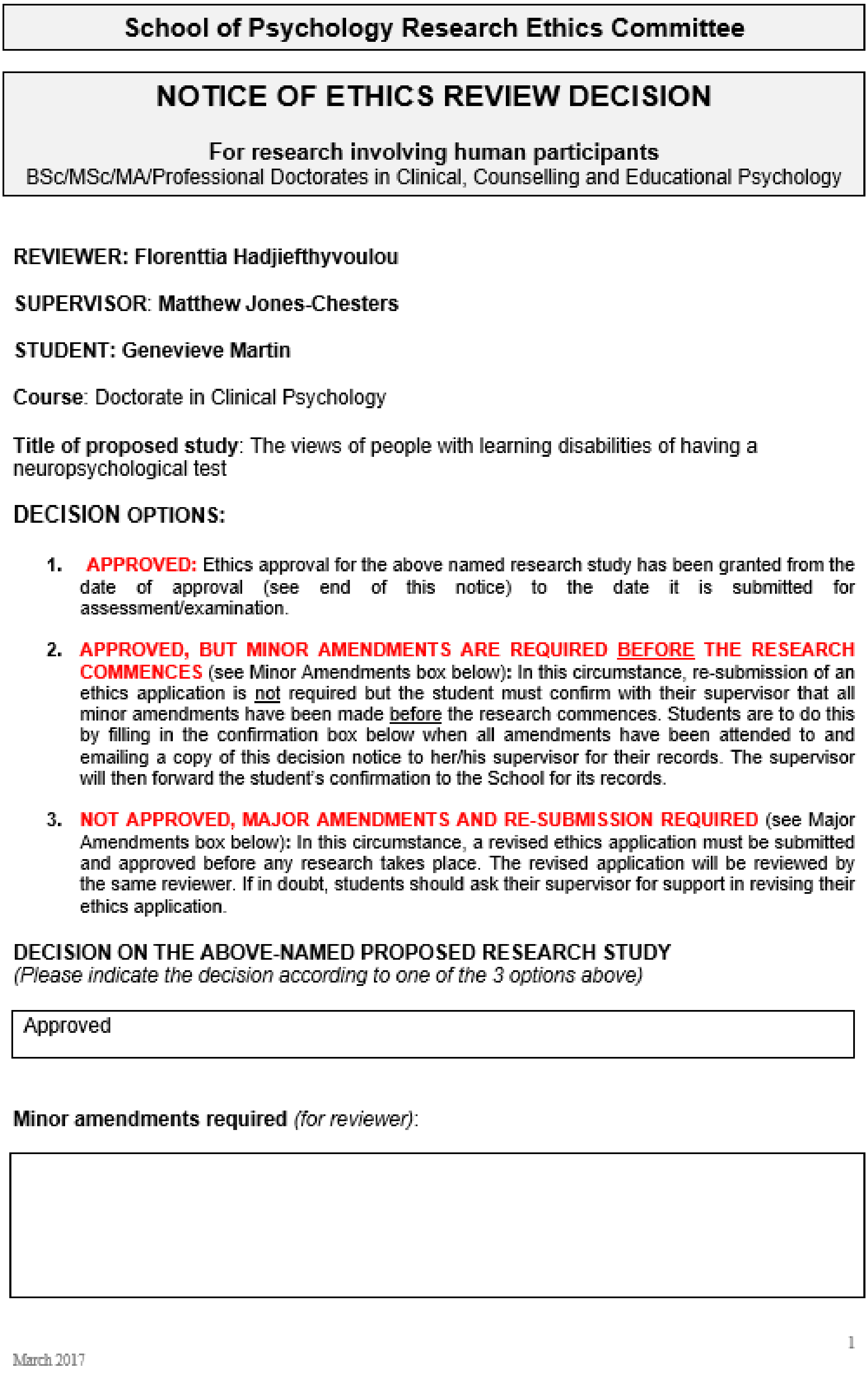
The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Combined TWMIC Certificate Insurance 18th July 2018]	v1	18 July 2018
GP/consultant information sheets or letters [GP notification letter v1]	1	05 May 2019
Interview schedules or topic guides for participants [Interview Schedule v1]	1	04 January 2019
IRAS Application Form [IRAS_Form_05042019]		05 April 2019
Letters of invitation to participant [Letter of invitation for participants v2]	2	05 May 2019
Letters of invitation to participant [Letter of invitation to participant v2 tracked changes]	2	27 May 2019
Other [Supporting interview materials]	v1	20 March 2019
Other [Ethical review - further information required]	1	27 May 2019
Participant consent form [Participant Consent Sheet v2]	2	06 May 2019
Participant consent form [Participant consent form v2 tracked changes]	2	06 May 2019
Participant information sheet (PIS) [Participant Information Sheet V2]	2	05 May 2019
Participant information sheet (PIS) [Parents and Carers Information Sheet v2]	2	05 May 2019
Participant information sheet (PIS) [Participant Information Sheet v2 tracked changes]	2	05 May 2019
Participant information sheet (PIS) [Parent and Carers information sheet v2 tracked changes]	2	06 May 2019
Research protocol or project proposal [Research Proposal v2]	2	27 May 2019
Research protocol or project proposal [Research Proposal v2]	2	27 May 2019
Summary CV for Chief Investigator (CI) [Chief Investigator CV]	v1	10 April 2019
Summary CV for student [Student CV]	v1	10 April 2019
Summary CV for supervisor (student research) [Summary CV for supervisor]	v1	08 April 2019

Appendix G – UEL ethics approval



School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

REVIEWER: Florenttia Hadjiefthyvoulou

SUPERVISOR: Matthew Jones-Chesters

STUDENT: Genevieve Martin

Course: Doctorate in Clinical Psychology

Title of proposed study: The views of people with learning disabilities of having a neuropsychological test

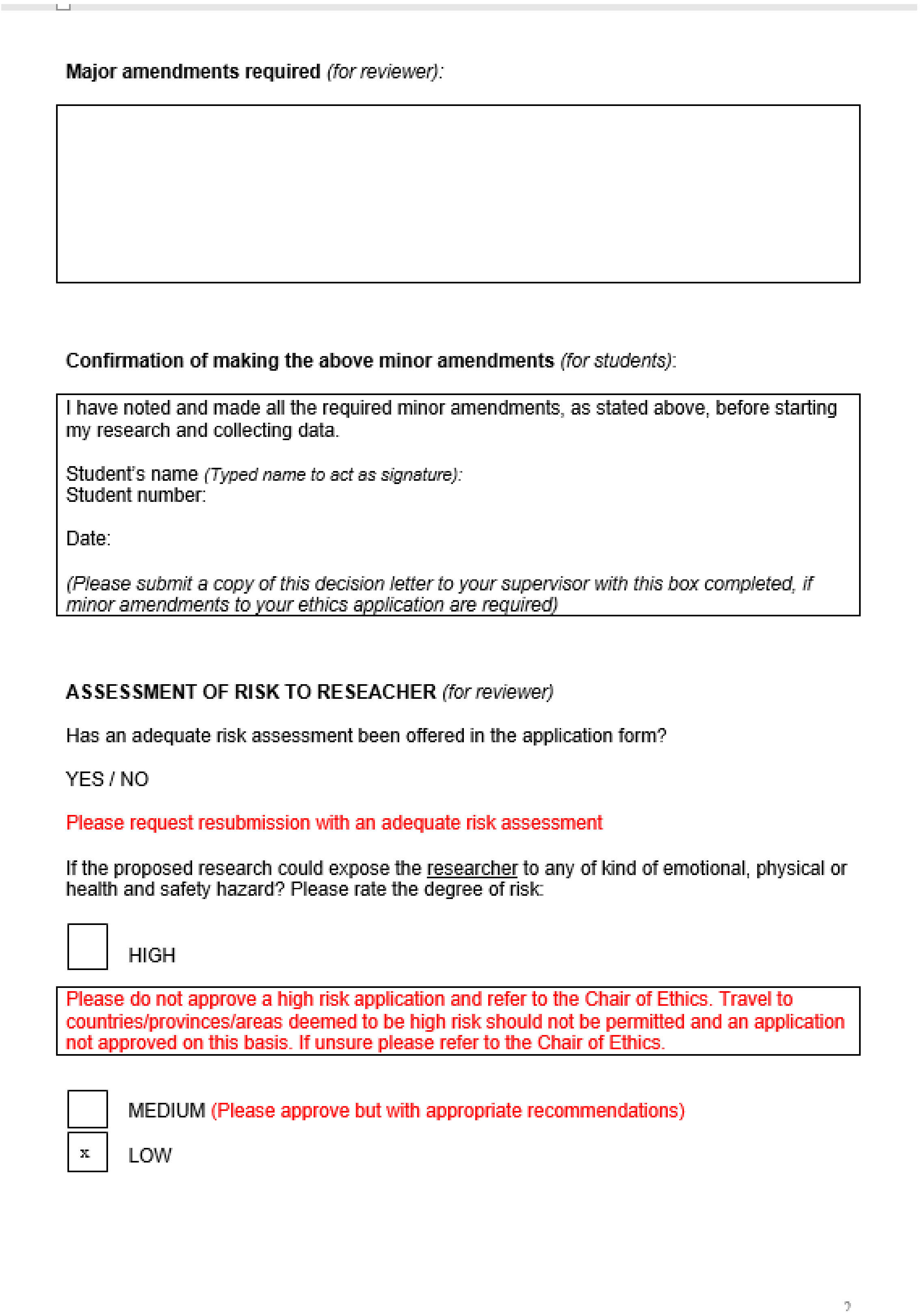
DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below)**:** In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below)**:** In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY
(Please indicate the decision according to one of the 3 options above)

Approved

Minor amendments required *(for reviewer)*:



Major amendments required *(for reviewer):*

Confirmation of making the above minor amendments *(for students):*

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature):*
Student number:

Date:

(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)

ASSESSMENT OF RISK TO RESEACHER *(for reviewer)*

Has an adequate risk assessment been offered in the application form?

YES / NO

Please request resubmission with an adequate risk assessment

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐ HIGH

Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.

☐ MEDIUM (Please approve but with appropriate recommendations)

☒ LOW

Reviewer comments in relation to researcher risk (if any).

Reviewer *(Typed name to act as signature)*: *Florentia Hadjiefthyvoulou*

Date: 5/7/19

This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee

RESEARCHER PLEASE NOTE:

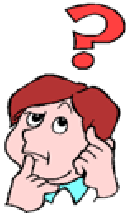
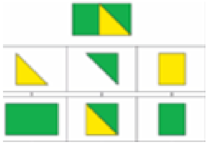
For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

Appendix H – Participant letter of invitation (easy read)

Invitation to take part in Research on Learning Disability Tests

	This is a letter to tell you about some research that is happening
	You did a test with someone called a psychologist

 	You answered some questions, did some puzzles, and looked at some pictures
 	We are interested in finding out more about what it is like to have one of these tests
	The hope is to make it as nice as possible to have one of these tests

	The research is with someone called Genny
?	She would like to ask you some questions about how you found the test
👍 👎 Yes ☐ No ☐	Would you like to find out some more about the research and how to take part?

☎	If you tick yes, Genny will phone you to give you some more information
	What number is best to call you on? ……………………………………………………………

Appendix I – Notation system used for DA transcription

Notation of transcripts for DA analysis

Notation	Meaning
(.) (1) [ ] <u>Underlined</u> ↑ ↓ CAPITALS *stars* Hum(h)our	Micro pause, a notable pause but of no significant length A number inside brackets denotes a timed pause, e.g. 1 or 2 seconds A point where overlapping speech occurs A raise in volume or emphasis A rise in intonation A drop in intonation When something was said loudly or even shouted Asterisks around a word, or set of words, indicates it is spoken very softly When a bracketed ‘h’ appears it means that there was laughter within the talk

Appendix J - IPA worked example of a transcript

	95.	Zara:	Yeah	
	96.	Interviewer:	Yeah (1 second pause). And that can make people feel (1	
	97.		second pause) different things sometimes.	
	98.		Sometimes people feel ok if they don't know the answer, but	
	99.		other times people feel a bit uncomfortable. What was it like	
	100.		for you when you didn't know the answer?	
Felt normal, ok to ask	101.	Zara:	Like, it was (1 second pause). It kind of felt ok coz she said that	Not knowing
	102.		if I didn't know the answer it was alright, but, I, like. I knew I	Reassured Felt ashamed
Knowledge that she didn't know, Felt different/ stupid?	103.		didn't get it right. And that wasn't nice	
	104.	Interviewer:	Mm, so that wasn't nice for you?	
	105.	Zara:	No (5 second pause). I don't get things right and I couldn't get	Failure
I am wrong/ dumb, always happens Failure	106.		any of the questions right	
	107.	Interview:	That must have felt tough for you. So you felt like you didn't get	
	108.		any of them right?	
Ok, not well	109.	Zara:	I thought I did ok at, in the start. But after that I didn't like it as	Feeling that she had to
Not good at anything	110.		much and I, kind of, like. I just wanted it over.	
To achieve = to have worth	111.	Interviewer:	How did you cope with that?	
	112.	Zara:	I, I dunno. I just did it. I had to finish it. It just took long. I had to	
Conforming Not being able to speak out when unhappy/ wants it to stop	113.		finish first before I could go.	Expectations
	114.	Interviewer:	Mm. Did you feel like you couldn't leave?	
	115.	Zara:	I, er, yeah, sort of. Like, in a way, I knew, I thought I could leave.	
	116.		But I knew, for, like my parents wanted me to stay to get it	Parent's agenda
Parent's agenda	117.		done.	
	118.	Interviewer:	So you stayed mostly, er, because your parents wanted you to	
	119.		(1 second pause) to stay and have, have the test?	Expectations
	120.	Zara:	Yeah	
	121.	Interviewer:	Ok	
Bewildered, lack of communication	122.	Zara:	Coz no one told me why I was there, like it was confused	
	123.	Interviewer:	Confused?	Unsure
Unsure of own understanding	124.	Zara:	Like I think yeah there was testing for a disability and which	
	125.		kind I have but I don't know why I needed to do all of those	
	126.		things	
Annoyance	127.	Interviewer:	So it felt unclear why you were there?	

Appendix K - IPA analysis: Audit trail of themes

Initial stage

Emerging themes	**Elements of the themes**
More than one psychologist	Not being able to remember their names Different professional giving feedback about assessment than did the assessment Unclear who will be meeting Gender – usually female assessor Felt impersonal
Multiple professional involvement	Staff leaving Frustration Confusion High staff turnover Lots of appointments Cost/inconvenience of getting to appointments Lots of different services Multiple medical appointments Just the way that things are
Lots of initial appointments	Appointments end up feeling the same Cost/inconvenience of getting to appointments Having to repeat self Anxiety Avoidance Resistance
Previous ID assessment	Comparison with school Other people helping them Length of the assessment Used to being assessed

	Assessment from a young age Memory of previous assessments Dislike of school
Poor communication from services	Haven’t received report Unsure who to contact Communication is via letters Inconsistent text reminders Lack of consistency and continuity
Feeling let down	Not knowing Lack of continuity Support isn’t enough Questioning what happens next Frustration When is my appointment?
Feeling positive/good	Continual support Potential for change Happy with the service
Rapport with assessor	Felt listened to Liked the assessor Remembered their name Appropriate adaptations made Reassured Listened to Trusted them Empathy/trust
Outcome of the assessment	Hopeful Felt useful Caring about the outcome

	Unclear of function of assessment Doing it anyway Other people caring about outcome
Wanting to do well in the assessment	Trying my best Wanting to prove self Parents expectations
Feeling stupid	Fear of failure Stress Questioning self Not wanting to get answers wrong
Shame of getting things wrong	Parents expectations Awkward/uncomfortable Uncertainty

Middle stage

Superordinate themes	**Subordinate themes**	**Elements of themes**
Disconnected services	Multiple professionals	High staff turnover Not remembering professionals' names Lots of different services Depersonalised Lots of appointments Frustration Gender of the assessor It's just 'how things are'
	Repetitive or further assessment	Have had ID assessment previously Appointments all feel the same Being asked personal questions Having to repeat self Assessment from a young age Avoidance of appointments Anxiety Difficulty getting to appointments Lots of medical appointments Length of the assessment Resistance Having to do the assessment Boredom Comparison with school
	Poor communication from services	Not receiving letters Unclear when appointments are Communication via letters Frustration Long waiting lists Feeling let down

		Lack of continuity Not knowing what happens next
Positive experience of assessment	Experience of the assessor	Good rapport with the assessor Liked the assessor Appropriate adaptations being made Empathy, caring Reassurance Being listened to Trust Explained things clearly Appropriate pace Breaks offered
	Hope	Positive outcome of assessment Potential for change Assessment felt useful Continual support
Views surrounding test performance and outcomes	Wanting to do well in the assessment	Parents expectations Proving to self/others Expectations of self Trying my best Not wanting to leave the assessment Invested in outcome Pressure to do well Difficulty in assessment
	Shame of getting things wrong	Feeling stupid when got answers wrong Awkward/uncomfortable Negative feelings/shame Uncertainty Needing reassurance Questioning self

	Unclear expectations and feedback	Unclear of function of assessment Doing it anyway Other people caring about outcome

Final stage

Superordinate themes	**Subordinate themes**
Disconnected services	Multiple professionals Repetitive or further assessment Poor communication from services
Positive experience of assessment	Experience of the assessor Hope
Views surrounding test performance and outcomes	Wanting to do well in the assessment Shame of getting things wrong Unclear expectations and feedback

Appendix L – DA worked example of a transcript

Speaker	Transcript	Comments
Richard:	And(.) and they're ↑watching ↓me to see how(.) how quick I do it right	Feeling judged? Watched? use of word 'right' – checking that I understand
Interviewer:	Yeah(.) timing you	
Richard:	And then as you was going along I was getting ↓slower and ↓slower	Use of 'you' instead of I – subject pronouns mixed Story telling, repeating
Interviewer:	*Yeah* that's quite normal(.) so	
Richard:	Getting slower and ↑slower(.) and on the last two ↑blocks ↓like or	
Interviewer:	*Mm(.) mm*	
Richard:	Right? And they're looking at me like that right and said ↑don't ↑worry about it they said(.) I said ↑nah(.) I wanted to	Reassurance. Pity? Autonomy, choice Taking control, making a choice about the assessment
Interviewer:	You wanted to do it	
Richard:	I wanted to do it	Capable, confidence Cares. Wanted to do it vs "I can do it" – capable.
Interviewer:	*↑Ahh*(.) Coz some of the the tests are timed	
Richard:	Yeah	
Interviewer:	So I think once the time ↑stops(.) sometimes you're meant to ↑stop(.) Oh but you wanted to carry on and ↑finish it	
Richard:	Yeah I was ↑determined(.) I was ↑determined to ↑do ↓it	Determination Assertiveness Repeating

Appendix M - List of initial codes for DA analysis

- Abandonment
- Assertiveness
- Autonomy
- Being pitied
- Being protected
- Being ‘put’
- Capability, competence
- Certainty
- Choice
- Comparison to health appointments
- Continuity of care
- Credibility within speech
- Dominance of the medical model
- Feeling different
- Frustration
- Function of assessment
- ‘Having to’ do something
- Help/assistance
- Hesitation
- Humour
- Justification
- Knowledge = power
- Listen to me
- Needing assistance
- No choice
- Parents have power/knowledge
- Reassurance
- Regret
- Reliance
- Repeating
- Resistance

- Results are not that important
- The system is powerful
- Story telling
- Strength
- Struggling with reading/writing
- Stuttering and anxiety
- Subject pronouns: I/we/they
- Uncertainty
- Unclear expectations of assessment
- Using more powerful voices to reinforce
- Vulnerability
- Who’s agenda?

Appendix N - Clustering of DA codes into themes

The System Holds the Power

- The system is powerful
- Dominance of the medical model
- Unclear expectations of assessment
- Parents have power/knowledge
- Using more powerful voices to reinforce own voice
- Help/assistance
- Comparison to health appointments
- Subject pronouns: I/we/they

Fear of Abandonment

- Uncertainty
- Stuttering and anxiety
- Hesitation
- Needing assistance
- Reassurance
- Abandonment
- Vulnerability
- Continuity of care
- Feeling different
- Struggling with reading/writing
- Being pitied
- Being protected

I am Resilient – Don't Feel Sorry for me

- Credibility within speech
- Listen to me
- Resistance
- Repeating

- Justification
- Autonomy

Having to do Something Vs Choosing to do it

- Story telling
- Humour
- Assertiveness
- Strength
- Choice
- No choice
- Being ‘put’
- ‘Having to’ do something

Appendix O – Leaflet summarising the research outcomes

COGNITIVE ASSESSMENT: PERSPECTIVES FROM ADULTS WITH INTELLECTUAL DISABILITY

A summary of thesis research
conducted by Genevieve Martin

Submitted in partial fulfilment of the requirements of the University of East London for the Degree of Doctor of Clinical Psychology

December 2021

<u>Purpose of this leaflet</u>

This leaflet aims to outline and summarise some research which was conducted between 2018 and 2021, which looked at the experiences of adults who had undergone a cognitive assessment at their learning disability service.

<u>The Principal Investigator(s)</u>

Genevieve Martin, Trainee Clinical Psychologist
University of East London, Stratford Campus, Water Lane, London, E15 4LZ
Contact:
Supervised by:
Dr Matthew Jones Chesters, Consultant Neuropsychologist
Contact: m.h.jones-chesters@uel.ac.uk

<u>Research Aims</u>

This research aimed to explore the views of adults with a diagnosis of a learning disability, of the experience of having a neuropsychological test to get this diagnosis. Its aim was to improve the experience of this assessment, and to find out from people which parts felt helpful and unhelpful, and to find out about what is most useful when receiving the learning disability diagnosis.

<u>Method</u>

Information was gathered using semi-structured interviews with four clients with a recently diagnosed intellectual disability.

<u>Analysis</u>

Results were explored using two types of analyses: Interpretative Phenomenological Analysis (IPA) and Discourse Analysis (DA). These aimed to look at various aspects of discourse alongside the phenomenological experience.

Results

The results showed a variety of different things. The IPA analysis revealed that participants often felt that services were disconnected – for example, communication between services and service users was not always clear. Participants also felt that letters were used a lot in the communication, which was not always a readily accessible means for them. Participants also highlighted that they had seen multiple different clinicians across the assessment process, and they sometimes had to repeat assessments. Positive aspects were also discussed, such as feeling that their psychologist was friendly and listened, and that they had hope that they would get some sort of help from the learning disability service.

The DA analysis revealed discourses within participants' speech. This revealed the power imbalance that participants noticed, as well as participants feeling that they need to rely on other people to get their needs met. Discourses around resilience and choice were also revealed.

Implications

The services where the research took place have been informed about the results. The following recommendations were also made to services:

- For there to be more continuity in services in terms of the clinicians that service users meet
- For communication to be clearer – e.g. to clearly outline expectations and to be clear about who the service user will meet and when
- For clinicians to be aware of their role in helping people feel at ease and confident in assessment situations – being friendly, listening, and giving reassurance were important to people
- For further clarity to be given around giving consent for assessments to happen, and alternative methods of giving consent to be considered – such as using video footage

NHS Research Ethics Committee

This research has been approved by an NHS Research Ethics Committee. If you have any queries regarding the conduct of this research or the results, please contact:

Health Research Authority, Skipton House, 80 London Road,
London, SE1 6LH
Tel: 020 797 22567

Confidentiality of Data

All interviews and transcripts have been stored securely and will be securely destroyed upon completion of the researcher's clinical programme.

No personal information or identifying information of any participants or services have been included in the write up.

Some of the information written up from interviews may contribute towards a publication of the data in a scientific journal.

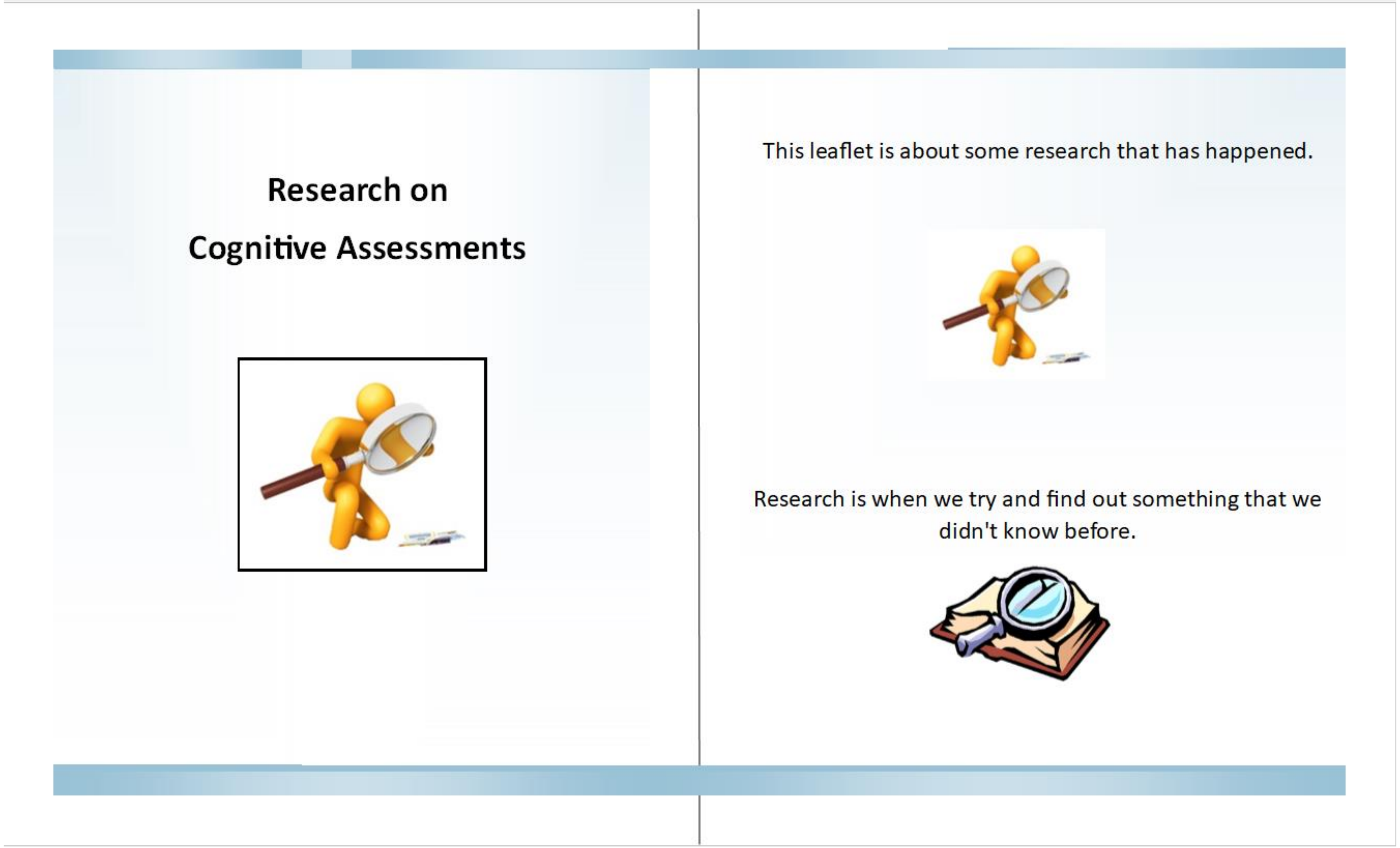
Seeking help or making a complaint

If you have concerns about any aspects of this research process, you are free to contact either:

Dr Matthew Jones Chesters, Consultant Neuropsychologist,
At: m.h.jones-chesters@uel.ac.uk

Or seek help from your local Patient Advice Liaison Service (PALS). Your local learning disability service will be able to advise of their contact details.

Appendix P – Easy-read leaflet summarising the research outcomes

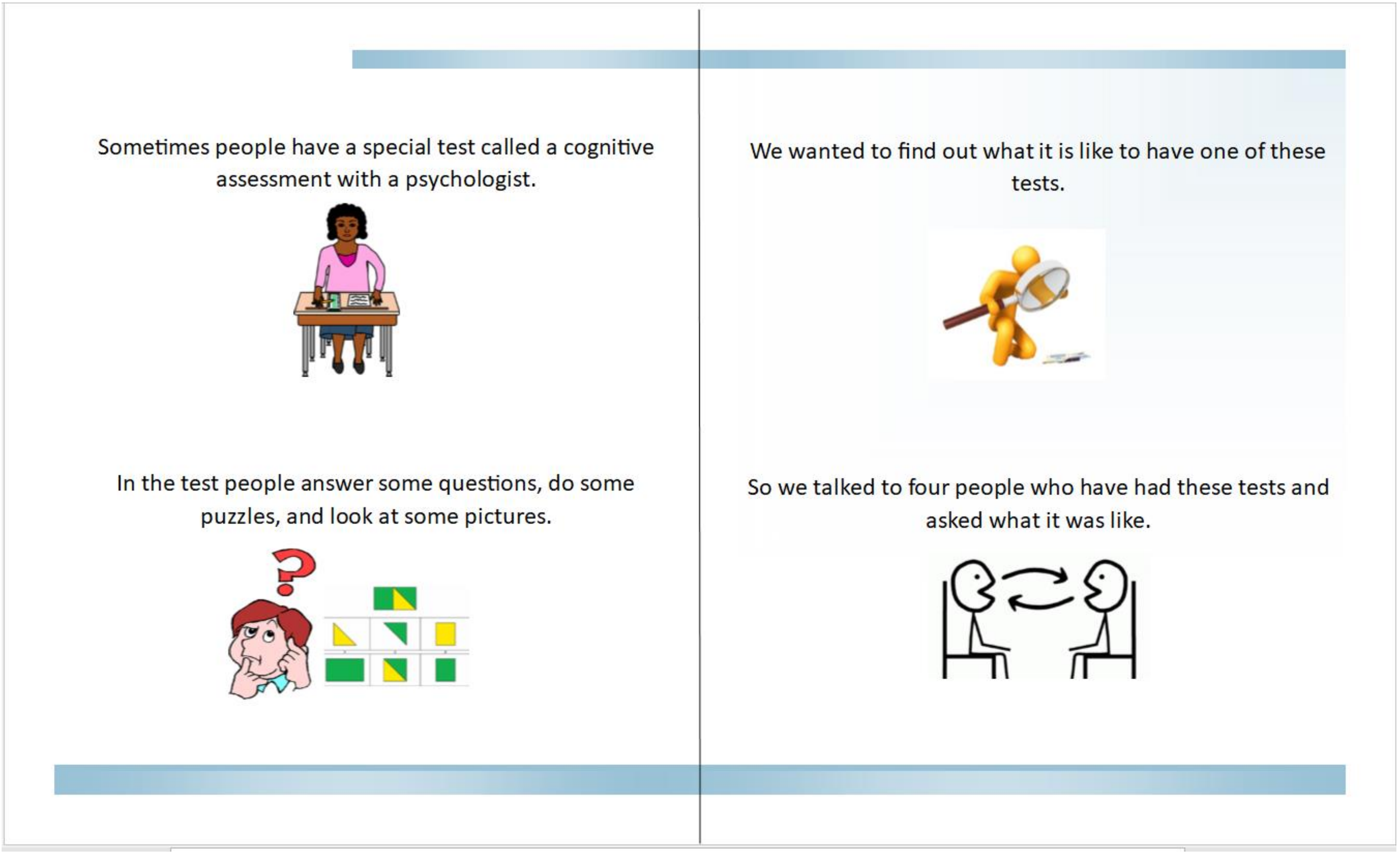


Research on

Cognitive Assessments

This leaflet is about some research that has happened.

Research is when we try and find out something that we didn't know before.



Sometimes people have a special test called a cognitive assessment with a psychologist.

In the test people answer some questions, do some puzzles, and look at some pictures.

We wanted to find out what it is like to have one of these tests.

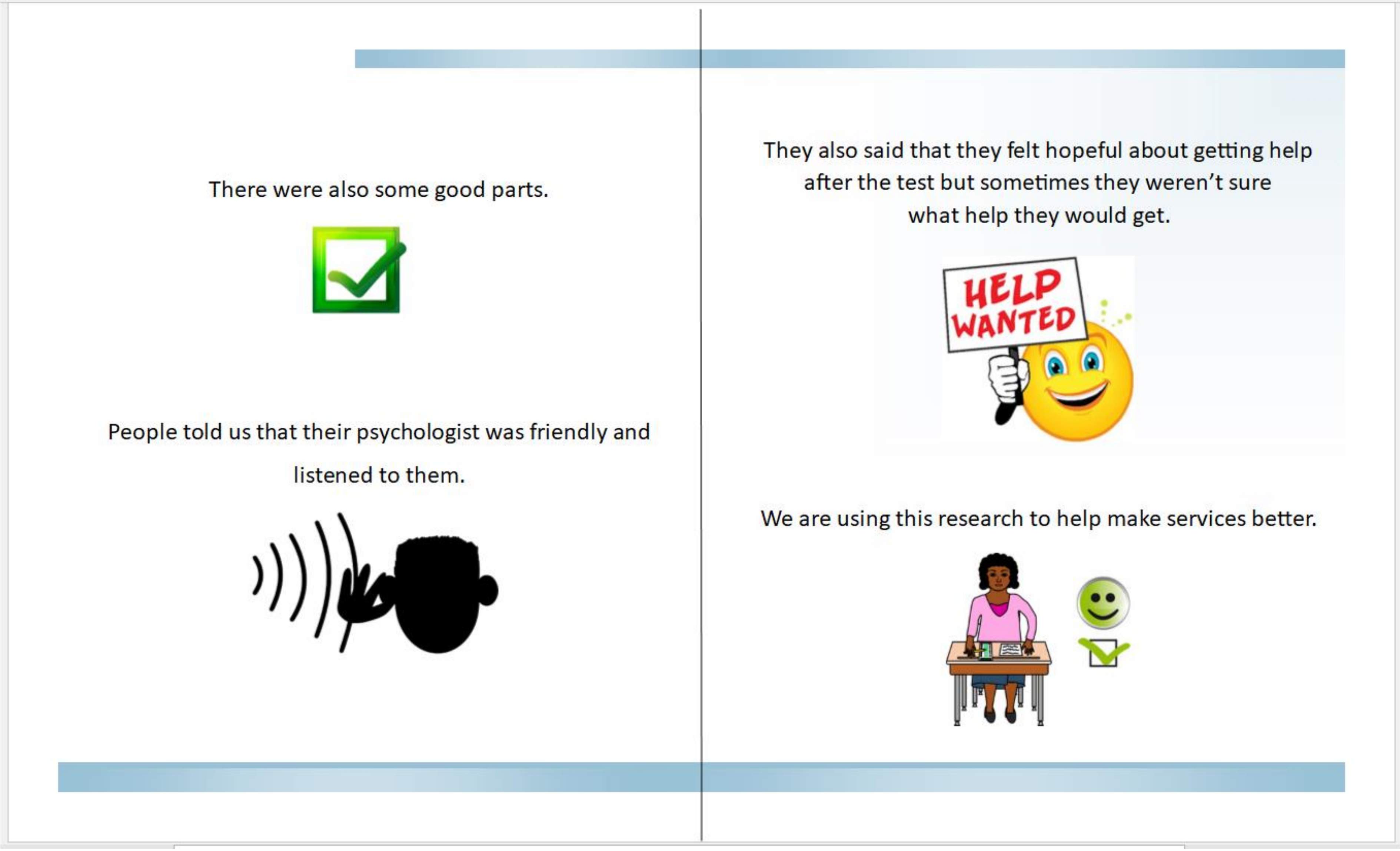
So we talked to four people who have had these tests and asked what it was like.

These four people told us that they sometimes had lots of different workers at the service.

This was sometimes confusing and frustrating for them.

Sometimes people also had to have more than one test.

They also told us that it can be hard or confusing when the services talk with them. Sometimes services send a lot of letters.



There were also some good parts.

People told us that their psychologist was friendly and listened to them.

They also said that they felt hopeful about getting help after the test but sometimes they weren’t sure what help they would get.

We are using this research to help make services better.

If you have any questions you can speak to your worker to find out more.

Thankyou for reading this leaflet